

Involving people with early-stage dementia in qualitative research about their lifeworld perspectives

Development of a participatory research model

Schack Thoft, Diana

Publication date:
2017

Document Version
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

Citation for published version (APA):
Schack Thoft, D. (2017). *Involving people with early-stage dementia in qualitative research about their lifeworld perspectives: Development of a participatory research model*. Aalborg Universitetsforlag.

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal -

Take down policy

If you believe that this document breaches copyright please contact us at vbn@aub.aau.dk providing details, and we will remove access to the work immediately and investigate your claim.

INVOLVING PEOPLE WITH EARLYSTAGE DEMENTIA IN QUALITATIVE RESEARCH ABOUT THEIR LIFEWORLD PERSPECTIVES

DEVELOPMENT OF A PARTICIPATORY RESEARCH MODEL

**BY
DIANA SCHACK THOFT**

DISSERTATION SUBMITTED 2017



AALBORG UNIVERSITY
DENMARK

INVOLVING PEOPLE WITH EARLY- STAGE DEMENTIA IN QUALITATIVE RESEARCH ABOUT THEIR LIFEWORLD PERSPECTIVES: DEVELOPMENT OF A PARTICIPATORY RESEARCH MODEL

by

Diana Schack Thoft



Submitted for the Degree of

Doctor of Philosophy

At The University of Northampton, United Kingdom

and Aalborg University, Denmark

2017

Dissertation submitted: 8th February 2017

PhD supervisors: Associate Prof. Anders Horsbøl
Aalborg University
Prof. Jacqueline Parkes
University of Northampton

Assistant PhD supervisor: Dr. Michelle Pyer
University of Northampton

PhD committee: Prof. Srikant Sarangi (chairman)
Aalborg University
Director, Christine E. Swane
Fonden Ensomme Gamles Værn
Prof. Helen Lomax
University of Northampton

PhD Series: Faculty of Social Sciences, Aalborg University

ISSN (online): 2246-1256

ISBN (online): 978-87-7112-813-0

Published by:
Aalborg University Press
Skjernvej 4A, 2nd floor
DK – 9220 Aalborg Ø
Phone: +45 99407140
aauf@forlag.aau.dk
forlag.aau.dk

© Copyright: Diana Schack Thoft

Printed in Denmark by Rosendahls, 2017



CV

Diana Schack Thoft was originally educated as a nurse in Sygepleje- og Radiografskole i Aalborg i 1999. After working as a nurse she completed the Supplementary Programme in Nursing and a Masters in Nursing Science (MNSc) from 2001-2004 at Aarhus University. Her Master's thesis was titled *"Hope, seen from the point of view of the dying and their relatives"*.

Since 2004 she has worked as an adjunct and senior lecturer at the Department of Nursing at University of Northern Denmark. In 2013 she started her joint PhD degree at Aalborg University in Denmark and University of Northampton in United Kingdom.

She is interested in giving vulnerable groups a voice in research, for example, hospitalised children, patients in palliative care and people with dementia with the purpose of involving them as equal partners and co-producers in participatory research. Ethics is also one of her great interests.

This thesis *"Involving people with early-stage dementia in qualitative research about their lifeworld perspectives: Development of a participatory research model"* engages people with early-stage dementia as active research participants with the aim of developing a qualitative participatory research model with the purpose of allowing more people with early-stage dementia a voice in research and in society as a whole.

ENGLISH SUMMARY

The aim of the study was to develop a participatory research model drawing from qualitative research about the lifeworld perspectives of people with early-stage dementia. Twelve participants with early-stage dementia were recruited from a compensatory adult school VUK (Voksenskolen for Undervisning og Kommunikation) in Denmark. They were trained in research skills to enable them to conduct a participatory research project in collaboration with the researcher. During the study, the participants informed the research project and the participatory research model.

A combination of participant observations, interviews and focus groups were used with observations and interviews being conducted before the research skills' training to enable the researcher to plan the training and the participatory research project in accordance with the participants' competencies and challenges. Data were analysed from a hermeneutic phenomenological perspective inspired from the work of Max Van Manen. The focus groups were used both during the training and the participatory research project and video data from these were analysed by a thematic analysis inspired by Braun and Clarke.

The participatory research model illustrates the importance of recruiting and gaining consent from people with early-stage dementia in a way which takes into consideration the needs of the participants. It can be necessary to both adjust the recruitment strategy and the consent form. In order to allow them to be involved as active research participants, it is essential to plan and establish a research project which reflects the participants' individual cognitive challenges. To simplify the project and establish small project groups can be supportive. Also role agreements are vital. It is essential to train and support them in different ways throughout the research process and, among other strategies; it is useful to have an errorless inspired learning environment with a structure that is repeated. Furthermore, it is important to evaluate continually to ensure the most constructive process throughout and focus groups can prompt more in-depth answers by the participants. The participants also need support and structure provided by the researcher in any dissemination phase.

Furthermore, the researcher needs to invest in the interaction with the participants to establish trusting committed constructive research collaboration from the beginning. It is also important that the researcher balances the roles of being a researcher and a supporter together with being a teacher and a learner when collaborating with people with early-stage dementia. It is about balancing the power in the relationship. Furthermore, the researcher has to support the participants own peer-learning and -support together with creating a relaxed atmosphere. The participatory research model "*Balanced Participation*" takes these considerations into account, with the

result that more people with early-stage dementia will be able to be involved in future qualitative participatory research.

DANSK RESUME

Formålet med studiet har været at udvikle en participatorisk forskningsmodel baseret på kvalitativ forskning om livsverden perspektiverne hos mennesker med en tidlig fase af demens. Tolv deltagere med en tidlig fase af demens blev rekrutteret fra en kompenserende voksenskole VUK (Voksenskolen for Undervisning og demens) i Danmark. De blev trænet i forskningsfærdigheder med henblik på at sætte dem i stand til at foretage et participatorisk forskningsprojekt i samarbejde med forskeren. I løbet af studiet bidrog deltagerne til forskningsprojektet og den participatoriske forskningsmodel.

En kombination af deltagende observationer, interviews og fokus grupper blev benyttet med brug af observationer og interviews før træning i forskningsfærdigheder med henblik på at sætte forskeren i stand til at planlægge træningen og det participatoriske forskningsprojekt i overensstemmelse med deltagernes kompetencer og udfordringer. Data blev analyseret ud fra et hermeneutisk fænomenologisk perspektiv inspireret af arbejdet af Max Van manen. Fokus grupperne blev benyttet både i træningen og i det participatoriske forskningsprojekt og video data fra disse blev analyseret via en tematisk analyse inspireret af Braun og Clarke.

Den participatoriske forskningsmodel illustrerer vigtigheden i, at når der rekrutteres og indhentes samtykke fra mennesker med en tidlig fase af demens bør det gøres på en måde, som tager hensyn til deltagernes behov. Her kan det være nødvendigt at både justere rekrutteringsstrategien og samtykket. I forhold til at tillade dem at blive involveret som aktive forskningsdeltagere er det essentielt at planlægge og etablere et forskningsprojekt, som reflekterer deltagernes individuelle kognitive udfordringer. At simplificere projektet og etablere små projektgrupper kan støtte. Også rolle aftaler er vitalt. Det er essentielt at træne og støtte dem på forskellige måder gennem forskningsprocessen. At have et fejlfrit inspireret læringsmiljø med en bestemt struktur, som bliver gentaget kan være brugbart blandt andre strategier. Yderligere er det vigtigt at evaluere kontinuerligt for at muliggøre den mest gennemgående konstruktive proces. Her kan fokus grupper prompte mere dybdegående svar af deltagerne. Deltagerne har også brug for støtte og struktur skabt af forskeren i enhver formidlingsfase.

Yderligere bør forskeren investere i interaktionen med deltagerne for at etablere et tillidsfuldt engageret konstruktivt forskningssamarbejde allerede fra starten af. Det er også vigtigt, at forskeren balancerer rollerne mellem at være forsker og supporter sammen med det at være underviser og lærerende, når der samarbejdes med mennesker med en tidlig fase af demens. Det handler om at balancere magten i relationen. Yderligere bør forskeren værne om deltagernes egen læring og egen støtte mellem ligestillede samt skabe en afslappet atmosfære. Den participatoriske

forskningsmodel “*Balanced Participation*” tager disse overvejelser i betragtning, med det resultat, at flere mennesker med en tidlig fase af demens vil være i stand til at blive inddraget i fremtidig kvalitativ partcipatorisk forskning.

ACKNOWLEDGEMENTS

To Professor Jacqueline Parkes, Dr. Michelle Pyer and Associate Professor Anders Horsbøl for always believing in the PhD project. For their always constructive criticism and unimaginable interpersonal skills across universities and national boundaries. They have contributed significantly to this joint degree PhD more than was possible to realise at the start.

To my family for their support and understanding throughout the period. For never questioning whenever I had to travel because of my joint degree.

To VUK and the students and teachers for welcoming, collaborating and supporting me throughout the data collection process. To meet such open and warm people has been a gift.

“Live every day and enjoy every moment because you cannot control tomorrow”

Thank you for teaching me that



TABLE OF CONTENTS

Chapter 1. Introduction.....	17
1.1. Introduction.....	17
1.2. Background.....	18
1.2.1 Introducing dementia	18
1.2.2 Dementia and research	19
1.2.3 Dementia and participatory research	21
1.3. The study.....	24
1.3.1 The aim and objectives.....	24
1.3.2 The context and design.....	25
1.3.3 Outline of the thesis	27
Chapter 2. Literature review	29
2.1. Introduction.....	29
2.2. Dementia and its challenges.....	29
2.2.1 Dementia	29
2.2.2 Dementia has become a national and global challenge	32
2.2.3 A marginalised and stigmatised group	34
2.2.4 The move towards a person-centred approach	36
2.3. Research and training in dementia	37
2.3.1 Participatory research.....	37
2.3.2 Patient and public involvement	42
2.3.3 Training people with dementia.....	46
2.3.4 Preparation for participatory research	49
2.4. Conclusion	51
Chapter 3. Methodology	53
3.1. Introduction.....	53
3.2. Methodology	53
3.2.1 The participatory methodological framework	53
3.2.2 Participatory research models	54
3.2.3 Participatory training and support models.....	58

3.2.4 Participatory research phases	62
3.3. The methodical approach	63
3.3.1 Human science and qualitative research	63
3.3.2 Phenomenology and hermeneutic phenomenology	65
3.3.3 Hermeneutics	68
3.3.4 Max Van Manen's hermeneutic phenomenology and lifeworld inspired analysis.....	69
3.4. Conclusion	75
Chapter 4. Methods.....	77
4.1. Introduction.....	77
4.2. Context.....	77
4.2.1 Current study.....	77
4.2.2 Research phases	79
4.2.3 Phase 1: Recruiting and establishing relationship and trust	80
4.2.4 Phase 2: Planning the training and the participatory research project	80
4.2.5 Phase 3: Introduction to project and establishment of project groups	81
4.2.6 Phase 3.1: The research question	81
4.2.7 Phase 3.2: The data collection methods	82
4.2.8 Phase 3.3: The data collection.....	82
4.2.9 Phase 3.4: The participatory data analysis	83
4.2.10 Phase 3.5: Plan the dissemination	84
4.2.11 Phase 4: Evaluation	84
4.2.12 Phase 5: Dissemination	85
4.3. Recruitment strategy	85
4.3.1 Research setting and participant recruitment	85
4.4. Ethical process	91
4.5. Data collection process	91
4.5.1 Participatory methods.....	91
4.5.2 Participant observation.....	91
4.5.3 Semi-structured interviews.....	92
4.5.4 Focus groups	93
4.5.5 Video recording and transcription.....	94

4.6. Analysis.....	95
4.6.1 The lifeworld inspired analysis	96
4.6.2 Thematic analysis.....	101
4.7. Conclusion	107
Chapter 5. Ethics.....	109
5.1. Introduction.....	109
5.2. Ethics and dementia research	109
5.2.1 Establishing the research project.....	109
5.3. Ethics and consent.....	113
5.3.1 Informing participants	113
5.3.2 Gaining consent.....	116
5.3.3 Consent as an ongoing process and a one-time situation	125
5.4. Ethics and the research process	128
5.4.1 Moral sensitivity in the research process	128
5.5. Conclusion	130
Chapter 6. The lifeworld perspectives of the student participants prior to the participatory research project	133
6.1. Introduction.....	133
6.2. Analyses of interviews	133
6.2.1 “We live a social and active life regardless of difficulties”	133
6.2.2 “We try to look at the bright side of life with dementia”	136
6.2.3 “It takes time to adapt, at the same time we are losing time”	137
6.2.4 “We can still learn but it is challenging”	140
6.2.5 “We try to remember but keep forgetting”	142
6.3. Conclusion	145
6.3.1 Knowledge gained for the training and participatory research project..	146
Chapter 7. The participatory research process in collaboration with the student participants.....	147
7.1. Introduction.....	147
7.2. Analysis of the focus groups	147
7.2.1 Introduction and establishment of the project groups	147
7.2.2 “Others don’t have a clue, let’s change it”	149

7.2.3 Preparation for data collection	152
7.2.4 “You may be our conductor”	158
7.2.5 Data collection and analysis	162
7.2.6 “We are still the same even though we are not the same”	167
7.2.7 “To be with the likeminded is liberating”	172
7.2.8 Prepare dissemination	176
7.2.9 “Why does it have to be so negative?”	177
7.2.10 The evaluation	181
7.2.11 “It is nice that some will collaborate with us”	182
7.2.12 Dissemination	184
7.3. Conclusion	185
Chapter 8. Discussion	187
8.1. Introduction	187
8.2. How to plan and establish participatory research with people with early-stage dementia?	187
8.2.1 The recruitment process	187
8.2.2 The consent	189
8.2.3 The planning	190
8.2.4 The establishment of the participatory research project	194
8.3. How to train and support people with early-stage dementia in participatory research?	195
8.3.1 The need of leading and training	195
8.3.2 The training and support	199
8.3.3 Preparation for data collection	204
8.3.4 Participatory data analysis	205
8.3.5 Evaluation	206
8.3.6 Dissemination	207
8.4. “How to interact and collaborate with people with early-stage dementia in participatory research?”	209
8.4.1 The establishment of a trusting relationship	210
8.4.2 Peer-learning and Peer-support	211
8.4.3 Humour	214

8.5. Conclusion	214
Chapter 9. Conclusion	216
9.1. Introduction.....	216
9.2. Summary of the thesis	216
9.3. The “ <i>Balanced Participation</i> ” model.....	218
9.3.1 Illustration of the “ <i>Balanced Participation</i> ” model	221
9.4. Limitations and recommendations for future research	224
9.5. Policy implications.....	226
Literature list.....	228
Appendices.....	253

TABLE OF ILLUSTRATIONS

Box 1: Approach in the study.....	24
Table 1: Three dimensions of empowerment	41
Box 2: Levels of PPI	43
Box 3: Changes in participatory research	53
Figure 1: Arnstein´s ladder.....	55
Table 2: White´s Interests in participation	56
Figure 2: Partners in projects	59
Figure 3: Authentic partnerships	61
Figure 4: The project within a project in the study	78
Figure 5: Organisation of the study.....	79
Figure 6: Project diagram.....	80
Figure7: Participant recruitment	86
Box 4: Inclusion criteria for the teacher advocates	86
Table 3: Recruited teacher advocates.....	87
Box 5: Inclusion criteria for the teachers	87
Table 4: Recruited teacher participants	88
Table 5: Recruited pilot participant.....	88
Box 6: Inclusion criteria for the student participants	89
Table 6: Recruited student participants	90
Table 7: Example of the analysis process	99
Table 8: The identified themes.....	101
Table 9: Example of the analysis process	105
Table 10: The identified themes and its organisation.....	107
Box 7: Justification for non-therapeutic research.....	111
Table 11: MMSE-score of student participants.....	123
Box 8: Attaining consent.....	126
Picture1: Folder and work plan	147
Box 9: Structure of the work	149
Picture 2: Pictures and drawings	152
Table 12: Possible project ideas	153
Picture 3: The Monday groups´ voting	153
Picture 4: The information leaflet and the consent form.....	156
Picture 5: Possible data collection methods	157
Picture 6: The Tuesday group´s themes	163
Picture 7: Possible creative methods	177
Figure 8: The “Balanced Participation” model	222

CHAPTER 1. INTRODUCTION

1.1. INTRODUCTION

At a societal level, people living with dementia are often described as a stigmatised and marginalised group (Alzheimer Europe 2013). This marginalisation is also seen within research, leading to a silencing of their voices and the sharing of their experiences. This thesis details the process and findings of a study designed to support people with early-stage dementia to become less marginalised by developing a qualitative participatory research model, enabling them to participate in research as active research participants¹.

Chapter 1. The study was completed as part of collaboration between Aalborg University in Denmark and University of Northampton in United Kingdom in a joint PhD degree. The data collection was conducted in Denmark. The setting was a Danish Adult School of Special Education and Communication, where people with early-stage dementia attend classes for people with dementia (VUK 2013). It is essential that the voices of people with dementia are heard in order to create a more nuanced picture of the illness; until now few qualitative studies have included people with dementia as active research participants (Wilkinson 2002). With the development of the participatory research model as described in this thesis it is anticipated more people with early-stage dementia will be supported to be involved in future research activities, engaging in decision-making and service development and thus enhancing the support available to them and ultimately their quality of life.

In this thesis, dementia is described as an illness and condition using the same expressions the participants used around dementia. They are referred to as people or persons with early-stage dementia, which is in accordance with the “*Dementia Language Guidelines*” from Alzheimer’s Australia (Alzheimer’s Australia 2016).

This chapter describes the background of the study with a focus on dementia, dementia research and participatory research. Furthermore, the aim, context and design of the study is presented together with an outline of the thesis.

¹ In the study the participants with early-stage dementia are named active research participants instead of research partners which often is a term used in participatory research. This term was not used in the study as the participants were recruited as normal research participants and it was the researcher who took the lead of the participatory research project, leading to a restricted co-production and partnership.

1.2. BACKGROUND

1.2.1 INTRODUCING DEMENTIA

In the 19th century dementia was a broad clinical concept including mental illness and different types of incapacity. In the 20th century, dementia was rare, like other diseases associated with aging, because it is most prevalent in people over 80, and such lifespans were less common in the 20th century (Berrios 1987). Traditional stereotypes of dementia portrayed senile old people who have lost their mind and ability to reason (Wilkinson 2002). Historically, dementia was often associated with old age, which was attributed to "*hardening of the arteries*" and was often referred to as senility or senile dementia. A formerly widespread, but incorrect, belief was that serious mental decline was a normal part of aging, which meant there was no particular interest in researching dementia (Alz.org. 2015a).

Dementia was first placed as a disease category in the 1970s because of shifting population demographics and an ageing population worldwide with concerns of the financial significance of dementia (Wilkinson 2002). In 1976, neurologist Robert Katzmann claimed that much of the senile dementia occurring after the age of 65 was pathologically identical with Alzheimer's disease occurring before age 65 and therefore should not be treated differently. The fact that "*senile dementia*" was not seen as a disease kept millions of aged people with dementia from being diagnosed (Katzman 1976). A helpful finding was that although the incidence of Alzheimer's disease increases with age, there is no age at which all people develop Alzheimer's disease. Because of these findings dementia was recognised as a disease and no longer as a part of normal ageing. The searches for a cause and cure became the focus of research from the 1970s; studies were grounded in a medical pathophysiological focused model. As a result, during the 21st century, a number of different types of dementia were identified (Dougall, Bruggink et al. 2004).

Until the 1990s, dementia was usually described from a medical perspective, which portrayed those with dementia as having diseased brains rather than focussing on them as individual people (Wilkinson 2002). People with dementia were viewed as unable to contribute directly to an understanding of the condition, to communicate their experiences and to make meaningful contributions to their own lives and lives of others (Dupuis, Gillies et al. 2012, Hellström, Nolan et al. 2007, Pipon Young 2012). Research has also focused on the stress and burden of family carers and their point of view, overlooking the voices of those with dementia because the validity of studies that investigated their perspective was questioned (Knight, Lutzky et al. 1993, Wilkinson 2002). In the 1980s a few attempts to involve people with dementia in design, planning, implementation or evaluation of their services or to act as research guides to help interpret the lived experience of people with dementia were published. Also development of the main concepts surrounding data collection, ethical practice and social research with people with dementia occurred (Clarke, Keady 2002).

One of the pioneers in challenging the medical perspective was the psycho-gerontologist Thomas Kitwood, who argued that every person with dementia was a meaning-maker, who forms opinions and understandings of actions (Kitwood 1997b). He made a case for more person-centred values, where the person is seen first and the dementia second by describing a new paradigm in dementia care that replaced the deterministic “*old culture of care*” (Borresen, Hansen et al. 2004). Regardless of this positive development, studies until 2000, which sought personal perspectives on dementia, were still relatively sparse (Clarke, Keady 2002), meaning there still is a need for exploring the perspective of people living with dementia, an area in which this research makes a key contribution.

This study challenges former attitudes towards dementia by demonstrating that people with dementia can be involved in research, based upon the assumption that they have views and experiences that should be heard. It challenges the stereotypical medical and social psychological perspectives on dementia, thus hopefully contributing to building a growing knowledge base around involving people with dementia in research.

1.2.2 DEMENTIA AND RESEARCH

Today, dementia is still associated with negative connotations because of its progressive terminal nature. The etymological meaning of dementia, which is taken from Latin, has also negative associations whereas it originally means madness and insanity. It is understood as being out of one’s mind or without any mind (Ridder 2011). Objectively, dementia is an umbrella term characterising several cognitive and behavioural symptoms from degenerative conditions of the central nervous system (Tanner 2012). It can be defined as:

“... a set of symptoms that includes loss of memory, mood changes, and problems with communication and reasoning. There are many types of dementia. The most common are Alzheimer’s disease and vascular dementia. Dementia is progressive, which means the symptoms will gradually get worse” (Greater Manchester West Mental Health 2016, website)

The progression of dementia is described in three stages; the early stage, the middle stage and the late stage (Videncenter for demens 2013). This thesis focuses on people living with early-stage of dementia, where the cognitive impairment causes only slight deterioration of performance in everyday life (Videncenter for demens 2013). The general view of dementia in society is that people with dementia will inevitably lose their own self and control of life during the progression of the illness (Dewing 2007, Hubbard, Downs et al. 2003). Negative metaphors of dementia creating zombies and empty shells can also be identified in the present literature (Behuniak 2011, Dupuis, Gillies et al. 2012). These illustrate that dementia is a feared illness in society for which we have no cure or preventative measures (Rafii, Aisen 2009). However,

dementia can be described differently, which this study illustrates by offering an opportunity for people with early-stage dementia to share their opinions and experiences. The social opinion about dementia can be too negative and dogmatic seen from a research and citizen perspective.

“People think having dementia is the same as lying in a bed in a nursing home staring up at the ceiling. But it is possible to live some good years with dementia and that’s important to tell...”

This quote by me and the participants from this study indicates the importance of conducting more research about dementia including the perspective of those living with the condition to get a more nuanced picture of dementia and to develop adequately designed projects where people with dementia come to the fore. It is about enhancing understandings of how participatory research can be conducted with people with early-stage dementia.

Internationally, there is a growing need for research into dementia because of the current increase in the number of people who have it (Alzheimer Europe 2013, Nomura 2009, Videncenter for demens 2016). In 2012, 86,886 persons were diagnosed with dementia in Denmark and it is anticipated that the number will increase to 100,873 persons in 2020 and to 156,150 persons in 2040 (Alzheimerforeningen 2015b). The same increase is seen globally with 46,8 million people with dementia in 2015. It is anticipated that 74, 7 million people will live with dementia in 2030 and 131, 5 million people in 2050 (Alzheimer’s Disease International 2015). Since the risk of developing dementia increases with age, dementia incidence increases due to our increasing life expectancy (Alzheimerforeningen 2015b). It affects 5 % of the population older than 65 and 20–40% of those older than 85 (Sadock, Sadock 2008). At the same time the number of elderly people is growing, while there is a decline in birth rates in Denmark. The consequence is that a smaller group in Denmark will have to support a growing elderly population in society, where more people are diagnosed with dementia following a focus on early diagnosis and because of the increase in average age. It means dementia is a huge problem, also because of the associated rise in cost to society for dementia care. Worldwide, the annual economic cost of dementia has been estimated as US\$ 818 billion in 2015 (Alzheimer’s Disease International 2015).

More research is therefore needed to identify relevant services due to the general rationing in services for a growing frail and vulnerable group of people with dementia, which risks putting them at a low priority if no research documents their needs (Staniszewska 2009, Whitehouse 2000). It is therefore relevant to seek the perspective of those living with dementia to design appropriate services to be developed to support people with dementia to stay as independent as long as possible, which often is a great desire among people with dementia (Pipon Young 2012, Sundhedsstyrelsen 2013b). Further, it might have an economic advantage for society. I therefore estimate it is

important to develop knowledge on how to involve the group in research activities; otherwise their voices might not be heard.

Dementia research in general still offers people with dementia few, if any, opportunities to take part in research because of the negative stereotype about the condition (Behuniak 2011, Dupuis, Gillies et al. 2012). It is important to change this negative stereotype, allowing their voices to be heard and challenging the research which continues to be dominated by psycho-sociological and pathophysiological approaches, where researchers define the knowledge base about dementia (Pipon Young 2012). Within these approaches people with dementia are considered to have little to contribute within research (Dewing 2007, Pipon Young 2012). The perspectives of people with dementia are therefore denied legitimacy because they are assumed to no longer pose a sense of self (Hubbard, Downs et al. 2003). This social construction of dementia has resulted in a stigma where people with dementia are seen as synonymous with incapacity (Wilkinson 2002). On the other hand, it is important to be aware that these psycho-sociological and pathophysiological approaches also have contributed important knowledge about dementia and the recognition of dementia as a disease. However, this study challenges the existing stigma around dementia by anticipating that people with early-stage dementia can make an important contribution to research.

Currently, people with dementia do not have access to alternative discourses that can challenge the dominant view of dementia (Dupuis, Gillies et al. 2012). Such exclusion can frustrate the growth of scientific knowledge denying future patients and carers the benefits. With the exclusion of people with dementia from research, it can result in the further silencing of their voices, which is not a desirable scenario, because knowledge about what people with dementia wish and hope for will then not be explored. At the moment, knowledge of understanding the experiences of people with dementia in a variety of areas is missing, including how they adjust to a diagnosis of dementia and an understanding of what is meaningful and helpful on a daily basis in order for them to manage their condition and maintain quality of life (Pipon Young 2012). As a researcher, I assume it is vital to introduce an alternative discourse that confront the traditional view on dementia and develop an alternative research approach so people with dementia can be included in research and be empowered to share their views.

1.2.3 DEMENTIA AND PARTICIPATORY RESEARCH

Moves towards more person-centred research have resulted in increased acknowledgement that people with dementia have rights including the right for their experiences to be explored through research (Mckillop 2004, Wilkinson, Hubbard 2003). Increasingly, there is a consensus that people with dementia can be involved in research as active participants and there is growing evidence that they want to participate in research, can make a valuable contribution and benefit from

involvement in it (Dewing 2007, Hellström, Nolan et al. 2007, Hubbard, Downs et al. 2003, Pilon Young 2012). The benefits can be in terms of enhanced self-esteem by making a meaningful contribution, enjoying the social elements of project work and sharing stories. It can give a sense of purpose and value, thereby countering the feelings of powerlessness more usually associated with dementia (Pilon Young 2012, Tanner 2012). At a wider level, it is anticipated that involvement in research can challenge the marginalisation of people with dementia and promote social inclusion in society (Tanner 2012).

Today, it is accepted that the views of people with dementia are essential to understand the experiences of the diagnosis and the management of the condition (Mckillop 2004, Wilkinson, Hubbard 2003), which is positive but there is still a long way to go before it is implemented because of the existing stereotype and stigma of dementia. Law et al. (2013) state that no one has specifically sought the opinion of people with dementia on what type of research priorities they value even though people with dementia have a major role to play in bringing about change in dementia prevention, treatment and care by becoming partners in research (Dewar 2005). People with dementia want research to focus on early-stage dementia when people live at home and experience functional challenges (Law 2013). Thus it is important that more research is conducted to raise the profile of research into the early-stage dementia with researchers and professionals working within dementia care. Little is known about what people with early-stage dementia experience in life because advanced-stage dementia has often been the major focus of dementia research; research on the early-stage is therefore relatively scarce (Nomura 2009).

I see this movement has led to more democratic and inclusive research approaches than what 'traditional' dementia-focussed research offered. However, it is important to acknowledge that 'traditional' research into dementia also has included people with dementia as participants but only with limited power and involvement. Research approaches that are democratic and inclusive are often defined as participatory research. This approach allows people to be involved in research around issues affecting their lives by telling their stories and analysing their situation in terms of having dementia (Wilkinson 2002). Participatory research often links to qualitative methodologies and methods, which have the strength to produce stress fields from reality and show important aspects of the lived life (Malterud 2011, Wheeler, Holloway et al. 2010). The lived life can be seen within the concept of 'lifeworld', which in its totality is understood as a natural and social world. It is the arena as well as it sets the limits for humans' reciprocal actions (Schütz, Luckmann 1973). The idea of lifeworld developed by Habermas is limited to a cultural conception, in which:

“ . . . the cultural patterns of interpretation, evaluation and expression serve as resources for the achievement of mutual understanding by participants who want to negotiate a common definition of a situation and

within that framework, to arrive at a consensus regarding something in the world” (Habermas 1987, p. 134)

The world is immediately or directly experienced in the subjectivity of everyday life. Lifeworld approaches express the idea that individuals’ realities are influenced by the world they live in; individuals can make free choices but the freedom is not absolute because it is circumscribed by the conditions of daily life (Bengtsson 2006, Pahuus 1988). This participatory study allows the participants to choose their lifeworld perspectives that they want to explore with the aim of developing a participatory research model so hopefully more people with dementia can be involved constructively in research activities.

In participatory research, it is acknowledged that marginalised groups often are in a weak position to participate in research because they do not have sufficient research knowledge and skills to undertake the role. Therefore, training in research methods and facilitation in the research process is necessary but formal models of training in research methods and models for participatory research involving people with dementia are lacking (Bergold, Thomas 2012, Conder 2011, Dupuis, Gillies et al. 2012). A reason is that it has been seen as pointless to intervene and train the group because they get worse anyway (Yu 2009). Today, it is acknowledged that the cognitive impairment of people with dementia is a product of multiple factors and individual differences, meaning that people with dementia have different cognitive reserves and cognitive capacities (Yu 2009). Thus training is possible but more knowledge about how to train people with dementia is needed (Tanner 2012). Difficulties in involvement arise because of a lack of knowledge about how to train and involve people with early-stage dementia as active research partners (Dupuis, Gillies et al. 2012). Sometimes, participatory research can be criticised for not conducting authentic partnerships but more pseudo-like collaborations where the participants only are asked for their comments (Dupuis, Gillies et al. 2012). This indicates a need for more knowledge about how to train and conduct participatory research with people with dementia which is the focus of this study.

To summarise, I note not much research in dementia has explored the most effective and empowering ways to involve people with dementia in research to hear their perspectives, which is needed to get a more nuanced picture of the condition. Because knowledge is missing in understanding the experiences of people with dementia in a variety of areas, incorporating their perspective might support appropriate services to be developed. Participatory research allows people with dementia a voice in research by focussing on their experienced lifeworlds but knowledge is lacking about how to include the group constructively in participatory research. It is essential to explore their lifeworlds because of a lack of knowledge in the area and because it is judged important by people living with dementia. This study provides a voice for people with early-stage dementia to be heard in research with the purpose of developing a participatory research model to allow more people with early-stage dementia to be involved in research to ensure their lifeworlds are explored.

1.3. THE STUDY

1.3.1 THE AIM AND OBJECTIVES

This study builds upon previous qualitative participatory research in order to underpin own qualitative participatory research project involving people with early-stage dementia as active research participants about their lifeworld perspectives. The aim of the study is:

To develop a participatory research model based on qualitative participatory research on the lifeworld perspectives of people with an early-stage dementia.

By extension, the purpose is to capture the reflections and guidances that are essential, when conducting qualitative participatory research with people with early-stage dementia.

To this end the research considers and reflects on how people with early-stage dementia can be trained to be involved in participatory research and on the importance of research environment and support mechanisms in participatory research. Finally, it draws on the learning obtained from conducting participatory research to inform a participatory research model for use with people with early-stage dementia and to describe the reflections and guidances required in participatory research with people with early-stage dementia.

The aim can be broken down into the following components as illustrated in box 1.

Box 1: Approach in the study

- An in-depth literature review underpins the study, informing the approach vis-a-vis previously published work in the field of dementia research and participatory research.
- Participant observations and individual interviews with people with early-stage dementia inform the development of the training in participatory research skills together with relevant literature in the field.
- Delivery of participatory research skills training in focus groups to a group of people with early-stage dementia in order to understand the best and most accessible way for preparing them to participate in participatory research. The training incorporates support mechanisms based upon the knowledge gained from the literature, observations and interviews by people with early-stage dementia.

- Completion of a participatory research project with the use of focus groups based upon the training with a group of people with early-stage dementia about their chosen lifeworld perspectives. The participatory research project follows a qualitative research process and methods incorporating the necessary support mechanisms for people with early-stage dementia.
- Evaluation in focus groups of the process and outcomes with a group of people with early-stage dementia who have participated in the participatory research project.
- Development of a participatory research model and the reflections and guidances necessary in participatory research with people with early-stage dementia based upon the data collected through the participatory research project and the evaluation.

The study defined the exploration of the lifeworlds to be those perspectives which people with early-stage dementia consider important to examine, meaning that the project was not a full-scale phenomenological lifeworld study exploring the phenomenon of living with dementia. Instead the study sought to develop a participatory research model through a participatory methodological framework, where the participants had the power to decide what lifeworld perspectives they wanted to investigate. It was through the knowledge gained by investigating these lifeworld perspectives that the participatory research model with the reflections and guidances was developed. The study was based upon well-established qualitative methods and approaches, contributing with reflections about how already well-known qualitative methods could be used with support in collaboration with people with early-stage dementia.

1.3.2 THE CONTEXT AND DESIGN

Twelve elderly (65-82 years old) people with early-stage dementia were recruited to the study from the Adult School VUK (Voksenskolen for Kommunikation og Undervisning) in Denmark (VUK 2013). The school focuses on compensatory special education for adults. The school works with lifelong learning regardless of functionality, and they look at the individual's resources rather than the person's diagnosis. At the school people with early-stage dementia receive cognitive training and stimulation, physical training and training in various creative disciplines (VUK 2013). People who attend VUK are named students. In the study the participants formulated the research question(s) about what lifeworld perspectives they wanted to explore. The qualitative participatory research approach was chosen because the goal

of qualitative research is to understand the social phenomena, giving emphasis to the meanings, experiences and views of the participants (Parahoo 2014) and participatory research allows people to be involved in research about matters affecting their lives (Wilkinson 2002). The approach was therefore relevant because the participatory research project focused on the perspectives of the participants' experienced lifeworlds. It means that the results of this study are based upon these participants' participatory research works.

Within the study well-known traditional qualitative data collection methods were used. These methods were adjusted to the participants with the purpose to investigate to what extent they were possible to use with people with an early-stage dementia in a participatory framework of understanding. The methods were participant observations, semi-structured interviews and focus groups. The participant observations were conducted at VUK in the participants' normal teaching environment to get a first impression of the participants and their learning abilities and challenges. Participant observation was used because it has been shown to be relevant for understanding the context of the experiences of people with dementia (Hubbard, Downs et al. 2003). The knowledge gained from the observations was used to design the interview guide for the semi-structured interviews. Semi-structured interviews were conducted to get an in-depth knowledge about each participant in the project. Interviews make it possible to explore peoples' interpretations of daily events, and to elicit subjective accounts of their daily experiences (Hubbard, Downs et al. 2003). This knowledge was used in the planning of the training and in the participatory project. Finally, focus groups were used within the training and the project to allow all participants a voice in a shared structured project. Focus groups in participatory research allow a co-construction of meaning between the researcher and participants and generate high-quality interactive data (Salmon 2007).

The field notes from the participant observations were read through several times and analysed with the purpose of informing the design of the semi-structured interview guide and the planning of the training. The data material from the semi-structured interviews were analysed from a hermeneutic phenomenological lifeworld perspective inspired by Max Van Manen (1997) with focus on the four life existentials; spatiality, corporeality, temporality and relationality. This thematic analytical approach was chosen because it opened up for the participants' lifeworld perspectives. The analysis of focus group data was inspired by Braun and Clarke's systematic thematic analysis (Braun, Clarke 2006). This approach was chosen because it can identify themes within the interaction and collaboration with participants (Braun, Clarke 2006), supporting the development of the participatory research model.. The methodology and methods used within the study are further described in the methodology and methods chapter.

1.3.3 OUTLINE OF THE THESIS

The following provides an overview of the thesis, signalling key themes and offering the reader an understanding of the content of the thesis.

Chapter 2 is the literature review about dementia and the challenges associated with the condition, the stigma of dementia and the reactions towards it. Also participatory research, patient and public involvement and learning and training possibilities are discussed in the chapter. This chapter lays the basis of the thesis by arguing for the importance of involving people with dementia in research and discussing how it can be possible to train them to be able to participate. This is important knowledge to have to succeed with involving people with early-stage dementia in participatory research.

In Chapter 3 the participatory methodological framework of the study is presented. Three key patient and public involvement models “*Arnstein’s ladder*” (Arnstein 1969) and Jules Pretty’s and Sarah White’s typologies of participation (Cornwall 2008) are outlined together with two participatory models, the “*Partners in projects*” (Parkes, Pyer et al. 2014) and “*Authentic partnerships*” (Dupuis, Gillies et al. 2012). Finally, the human science tradition and qualitative research is described together with the hermeneutic phenomenological lifeworld approach and analysis. The methodological basis is important to set because it is from this perspective the world that is investigated is seen. It shows what is possible to see from the researcher’s standpoint.

Chapter 4 details the recruitment strategy together with a justification for the methods used in the study and an explanation of how they were applied. The methods were participant observations, semi-structured interviews and focus groups. The analytical approach to the project is explored and discussed, drawing on the hermeneutic phenomenological lifeworld analysis inspired by Van Manen (Van Manen 1997) and the thematic analysis inspired by Braun and Clarke (Braun, Clarke 2006). The different methods were chosen from a pragmatic perspective allowing the participants’ voice to be best heard throughout the research process.

In Chapter 5 the ethical considerations relating to the study are outlined, focusing on involving people with dementia in research and the need of moral sensitivity throughout the research process. The process of gaining consent is described and ethics is described as a practical approach throughout the research project. When collaborating with vulnerable people such as people with early-stage dementia it is important to consider how to do this ethically because of several barriers but done well it can have positive outcomes for both participants and the research project.

In Chapter 6 the lifeworld analysis of the individual interviews is presented by focusing on the following themes: “*We live a social and active life regardless of difficulties*”; “*We try to look at the bright side of life with dementia*”; “*It takes time*

to adapt, at the same time we are losing time"; *"We can still learn but it is challenging"* and *"We try to remember but keep forgetting"*. The analysis contributes knowledge about how the participants experience life and learning before and with dementia relevant for planning the training in research skills and the participatory research project.

Chapter 7 unfolds the thematic analysis of the focus groups. Here the following themes emerged *"Others don't have a clue, let's change it"*; *"You may be our conductor"*; *"We are still the same even though we are not the same"*; *"To be with the likeminded is liberating"*; *"Why does it have to be so negative?"* and *"It is nice that some will collaborate with us"*. The knowledge gained through this analysis contributes knowledge about the participants' experiences of dementia, the service they attend and about their interaction and collaboration in the participatory research project relevant for developing the participatory research model.

Chapter 8 discusses the results of the analysis of focus groups supplemented with the analysis of the interviews and previous literature. The discussion is structured around three questions: *"How to plan and establish participatory research with people with early-stage dementia?"*; *"How to train and support people with early-stage dementia in participatory research?"* and *"How to interact and collaborate with people with early-stage dementia in participatory research?"*. Discussion of these questions contributes knowledge about how to conduct a participatory research project, informing a participatory research model including the reflections and guidances that are needed when conducting this type of research.

An overall conclusion, summarising the whole thesis is presented in Chapter 9. Also the developed participatory research model and the reflections and guidances that are essential when conducting qualitative participatory research with people with early-stage dementia is presented. Furthermore, the limitations of the study and recommendations for further research are described. Finally, policy implications are discussed. This chapter concludes the study.

In the next chapter (Chapter 2), the literature review provides an overview of the literature this thesis is built upon and that has contributed to the development of the participatory research model.

CHAPTER 2. LITERATURE REVIEW

2.1. INTRODUCTION

Chapter 1 described the background and presented the aim, context and design of the study together with an outline of the thesis with the purpose to introduce the study.

This chapter offers a review of relevant literature in order to contextualise the study. It draws on previously published literature into dementia, participatory research, and learning and cognitive training. The review reveals that dementia as a progressive and terminal condition has become a major problem nationally and internationally (Alzheimerforeningen 2015b). Dementia and the challenges associated with the condition are explored in the beginning of the chapter. Chapter 1 began to signal the stigma attached to the term ‘dementia’; this chapter takes these discussions further before offering a detailed account of the importance of a participatory research approach. This approach can include the voices of people with dementia in research (Dupuis, Gillies et al. 2012, Eisner 2013, Wilkinson 2002). At the end of the chapter, it is reasoned that learning and cognitive training towards people with dementia is possible and necessary even though it earlier has been questioned if people with dementia can be trained, leading to missing models for training and involving people with early-stage dementia in research (Conder 2011, Yu 2009).

2.2. DEMENTIA AND ITS CHALLENGES

2.2.1 DEMENTIA

Dementia is a syndrome and umbrella term for several cognitive and behavioural symptoms, resulting from degenerative conditions of the central nervous system. The changes are characterised by being beyond what is expected from normal ageing (Martin, Augusto et al. 2013, Tanner 2012). It is a progressive terminal illness, where median life expectancy on being diagnosed is 4-5 years, although people can live longer (Xie, Brayne et al. 2008). It is experienced simultaneously as a psychosocial and physiological phenomenon, affecting not only cognition, but also the behaviour and the physical abilities of a person (Hubbard, Downs et al. 2003). The most common forms of dementia are Alzheimer's disease, vascular dementia, front-temporal lobe dementia, semantic dementia and dementia with Lewy bodies (Alz.org. 2015a). Alzheimer's disease accounts for 60-80 % of all cases of dementia, and is the most common cause of cognitive impairment in elderly (Tsolaki 2010).

Dementia affects primarily the neurons of the brain, and causes gradual but irreversible loss of function of these cells. Different types of dementia are associated with particular types of neuron damage in particular regions of the brain (Alz.org.

2015b), meaning that the symptoms of dementia vary according to the type of dementia and the severity of the syndrome. Each person's experience of dementia is individual (Martin, Augusto et al. 2013), because it is also influenced by factors such as coping skills, social and relational network, coping patterns, intelligence, use of methods for processing tasks, occupation, education, work environment, choice of cognitively stimulating leisure pursuits and use of health services (Keady, Williams et al. 2005, Yu 2009). Events such as anxiety, fatigue, aging, trauma, other diseases, drugs etc. also affect dementia (Wesnes 2003). The cognitive reserve of people with dementia is therefore very individual (Winblad, Amouyel et al. 2016). As a researcher, I have to correspond to this in a constructive way when involving people with dementia in research.

The various forms of dementia have differing prognoses and differing sets of epidemiologic risk factors. The causal aetiology of many of them remains unknown, although many theories exist such as accumulation of protein plaques as part of normal aging, inflammation, inadequate blood sugar and traumatic brain injury (Alz.org. 2015b). Some known risk factors for developing dementia and Alzheimer's disease are smoking, diabetes, hypertension, high cholesterol, being overweight or obese, and depression (Barnes, Yaffe et al. 2012, Barnes, Haight et al. 2010, Chen 2012, Diniz, Butters et al. 2013, Lu, Lin et al. 2009, Profenno, Porsteinsson et al. 2010, Qiu, Xu et al. 2010). On the other hand, light-to-moderate alcohol consumption, regular physical activity, high educational achievement, cognitive and mentally activity is associated with reduced dementia risk, as social engagement and maintenance of a social network (Anstey, Mack et al. 2009, Barnes, Yaffe et al. 2012, Blondell, Hammersley-Mather et al. 2014, Diniz, Butters et al. 2013, Ilomaki, Jokanovic et al. 2015, Meng, D'Arcy 2012). Currently, no medications have been shown to prevent or cure dementia (Rafii, Aisen 2009). Available medications only temporarily treat the behavioural and cognitive symptoms but have no effect on the underlying pathophysiology (Lieó, Greenberg et al. 2006), meaning that there is no cure (Eisner 2013). Basic biomedical research has provided insights into the causes and pathogenesis of neurodegenerative diseases and currently several dementia drugs are in the late phases of clinical development (Winblad, Amouyel et al. 2016).

Dementia advances over time and is often described in three stages; early, middle and late stage or as mild, moderate and severe/advanced dementia (Videncenter for demens 2013). No single way to describe the stages is agreed on and by describing dementia in stages the temporal and complex structure of the condition can be missed. Kitwood argued that to describe dementia in stages is misleading; it is too deterministic and fails to capture how the social environment adversely affects someone with dementia (Kitwood 1997a). The same critique can be raised to Reisberg's (1984) concept of retrogenesis, which describes a progressive reversal of development stages in a person with dementia, comparing the stages with the age of children going from 14 years old to infancy (Eisner 2013). Thus with this awareness in mind, I find that the stages illustrate the progression of dementia, which is helpful knowledge when engaging

with people with dementia. Simply, during the ‘early stage’, every day and leisure activities are still possible together with an independent living (Videncenter for demens 2013) but complex tasks as using the internet and instrumental activities frequently cause problems (Burgener 1999, Müller 2009, Nomura 2009). The memory problems are often the most notable symptom in this stage especially in relation to short-term memory (Hubbard, Downs et al. 2003). In the ‘middle stage’, the cognitive impairment results in a significant degradation of performance and language. The person can no longer cope with everyday life without help and can rarely be left alone. Symptoms such as disorientation, mood swings, confusion, serious memory loss, behavioural changes, difficulties in speaking and swallowing and problems with walking can be observed. In the ‘late stage’, the person is totally dependent on help from others, inactive and often has lost the ability to communicate verbally. Moving to sheltered housing is often necessary (Müller 2009, Videncenter for demens 2013). According to World Health Organisation (WHO), people can expect to live the first and second year with early-stage dementia, the middle stage from the second to the fourth and live from the fifth year in the late stage of dementia (WHO 2012).

Memory problems in early-stage dementia often start with memories for recent events and gradually extend to events in the past, as well as to memories of concepts, words and people (Hellström, Nolan et al. 2007). It is typically the episodic memory sub-system, containing memory for personally relevant events and episodes that are significantly impaired. Other sub-systems as semantic memory (knowledge of facts about the world) and procedural memory (performance of skills and routines) are only mildly affected. The difficulties lie primarily in taking in new information and forming new memories (Clare, Woods 2008, Wesnes 2003). There is also often a reduction in the speed with which individuals can recognise information as words, pictures and faces. Attention spans can also be affected, because people with dementia are easily distracted (Wesnes 2003).

Among the earliest symptoms in spoken language are word-finding problems, which may lead to an overuse of empty vocabulary. This often results in having problems generating coherent speech, or understanding the spoken or written word (Hellström, Nolan et al. 2007). Conversations tend to become more repetitive because of short-term memory problems (Müller 2009). Furthermore disorientation, sleep disturbance, sun drowning and wandering may emerge as the condition deteriorates (Martin, Augusto et al. 2013). In the past these behaviours were referred to in medical terms as challenging behaviours and behavioural problems (Hubbard, Downs et al. 2003). Today, these symptoms are defined as BPSP (Behavioural and Psychological Symptoms of dementia) to try to avoid a stigmatised vocabulary. It is recognised that the symptoms increasingly occur as dementia progresses (DBMAS 2015). As a researcher, I have to be aware of that the above-mentioned symptoms will affect the person’s ability to participate in research.

The symptoms of dementia affect an individual's quality of life. People with dementia can experience loss of communication abilities, meaningful relationships, positive leisure activities, control of life decisions and fear of embarrassment even in the early-stage (Burgener 1999, Nomura 2009, Tanner 2012). These losses can have a major impact on self-confidence and lead to anxiety, depression and social withdrawal, resulting in difficulties seeming worse (Clare, Woods 2008, Wesnes 2003). It leads to a picture of people with dementia being frail, passive and depressed, but studies show that they try to be positive towards the condition; that it is possible to manage it and delay the progression of dementia by keeping up meaningful interests, activities and maintain relationships (Clare, Rowlands et al. 2008, Papon Young 2012). They find things to hold on to and remain hopeful. They try to take control and responsibility for their lives as long as possible, whilst along acknowledging the losses associated with dementia (Clare, Rowlands et al. 2008, Papon Young 2012). This shows a more positive picture of people with dementia, where they compensate for difficulties and try to stay in control for as long as possible, which supports my arguments for the possibility of involving them in research activities around their lifeworld perspectives.

2.2.2 DEMENTIA HAS BECOME A NATIONAL AND GLOBAL CHALLENGE

As Chapter 1 showed dementia has historically been viewed via a lens of traditional stereotypes; stereotypes of old people who had lost their minds and abilities to reason (Wilkinson 2002). In the 21st century, different types of dementia have been identified based on pathological examination of brain tissues, symptomatology, and by different patterns of brain metabolic activity in nuclear medical imaging tests such as SPECT and PET scans of the brain (Dougall, Bruggink et al. 2004). Despite these positive developments, insufficient diagnostic services remain a major barrier to the provision of appropriate care for people with dementia. Although disease-modifying treatments do not exist, timely and correct diagnosis is important to access support services and symptomatic treatment. It is estimated that only 20–50% of people with dementia have a diagnosis in primary care (Prince, Bryce et al. 2011). With the possible future availability of effective treatments, early identification of pathological changes is important (Winblad, Amouyel et al. 2016).

Today, dementia is of serious concern (Alzheimer's Disease International 2013, Nomura 2009), leading to the WHO in 2012 and 2015 concluding that dementia should be a global public health priority (WHO 2015, WHO 2012). The impact of dementia is enormous, and in the view of the predicted rise in prevalence over the next decades, dementia represents a huge challenge for any society (Winblad, Amouyel et al. 2016). At the moment it is the sixth-leading cause of death worldwide (Eisner 2013). However, some recent studies have shown that the prevalence of dementia might be lower than originally predicted (Boseley 2012, Matthews, Arthur et al. 2013), indicating that the estimated prevalence is too pessimistic. Even if this is true dementia is already a global economic problem, because of the associated rise in

cost to society for dementia care. In 2013, it was concluded that the total momentary cost of dementia in USA represents a substantial financial burden on society, one that is similar to heart disease and cancer (Hurd, Martorell et al. 2013). In Denmark, the cost was estimated by the Danish Alzheimer's Association to be around 9-15 billion per year in 2010, based on the World Alzheimer Report 2010 (Alzheimerforeningen 2010) whereas the total societal cost estimated for dementia in Europe in 2010 was between \$238 billion and €105 billion (Gustavsson, Svensson et al. 2011, Wimo, Jonsson et al. 2013). The burden of dementia therefore poses a serious threat to the sustainable development of economies and the social welfare systems of Europe (Winblad, Amouyel et al. 2016). However, it is important to be aware of differences in how costs are defined because cost can be estimated on other countries' cost as in Denmark. Having said this, it is obvious that dementia is a huge global economic problem, particularly in light of the ongoing global downturn caused by the global economic crises with economic constraints and the demographic reality worldwide (Winblad, Amouyel et al. 2016).

Worldwide this has led to the decision to find a cure before 2025 and countries such as United States, Germany and Japan have taken the lead in the process (Long 2015). Many countries consider the care of people with dementia to be a national priority, and invest in resources and education to inform health and social service workers, unpaid caregivers, relatives and members of the wider community. In Denmark, dementia is recognised as a strategic area, and the Danish Dementia Research Centre was established in 2007 to strengthen dementia research. They have conducted national research projects such as the Danish Alzheimer Intervention inquiry (DAISY) and the Preserving quality of life, physical health and functional ability in Alzheimer's disease: The effect of physical exercise (ADEX). Here focus was on the effect of supportive interventions for people with dementia and their relatives and the effect of physical training for people with Alzheimer's disease (Videncenter for demens 2015, Videncenter for demens 2006).

A National Action Plan for Dementia was launched in 2010 (Sundhedsstyrelsen 2013b), followed by the National Clinical Instruction for analysis and treatment of dementia from 2013 (Sundhedsstyrelsen 2013c). The campaign "*Dementia is something we talk about*", launched the same year by the Danish Health and Medicine Authority, was also an attempt to raise societal awareness of dementia (Sundhedsstyrelsen 2013a). In 2015, The Dementia Alliance launched a vision for dementia treatment and care for 2025 focusing on improved diagnosis, treatment and more knowledge about dementia to better support people and their relatives living with dementia (Demensalliancen 2016b). In the same year five dementia friendly municipalities were brought together to launch relevant services for people with dementia with the purpose to support other municipalities in Denmark (Demensalliancen 2016a).

In 2015, work also began with a new national action plan for dementia with the aim to make Denmark a more dementia friendly society and strengthen the support towards people with dementia and their caregivers. The National Dementia Action Plan was signed ultimo 2016 (Sundheds og Ældre ministeriet 2017, Sundheds og Ældreministeriet 2015). Also a national dementia team and a new model for care of people with dementia in assisted living facilities are being tested in several municipalities in 2016 (Sundhedsstyrelsen 2016, Sundhedsstyrelsen 2015a). All these initiatives indicate an awareness of the challenges around dementia. However, there has been a notable absence of the voices of people with dementia and their carers in these developments, which mostly have been formulated by professionals and authority figures. This does not correspond well with the view of the patient having self-treatment competences in the Healthcare system and in society (Pedersen 2011).

As an answer to this critique, it can be argued that the Danish Alzheimer's Association has a voice in society, where they focus on bringing more openness about dementia (Alzheimerforeningen 2015a). The Association also involves younger people with dementia and people with early-stage dementia in a national Think Tank. The purpose is to show that people have cognitive resources despite dementia, and they want to put dementia more on the political agenda (Alzheimerforeningen 2015c). Recently, in 2016, the dementia friend campaign was launched to develop a more dementia friendly society in Denmark inspired by the Alzheimer's Society's Dementia Friends initiative (Alzheimerforeningen 2016). Also the work in building a "City for life" for 200-300 people with dementia in Odense municipality includes caregivers and people with dementia. It is the first of a kind in Denmark with the goal to create a framework for a life of independence and quality despite dementia (Byen for livet 2015). This shows that moves are being made in the right direction; however, there is still a long way to go. I hope this study will succeed with contributing with knowledge about how to involve people with dementia in research around issues concerning them. This fits with the present moves described above.

2.2.3 A MARGINALISED AND STIGMATISED GROUP

As Chapter 1 indicated, people with dementia are often marginalised, and their voices are overlooked both in society and through research. This occurs on both a national and international scale. It can be compared with what people with disabilities experience. An UN Convention from 2006 described how persons with disabilities continue to face barriers in their participation as equal members of society and violations of their human rights in all parts of the world despite various instruments and undertakings (UN 2006). Over the years much has been written about the stigma and discrimination associated with dementia (Graham, Lindsay et al. 2003). An Alzheimer Europe report refers to the way in which dementia is described as a stigma by lay people and healthcare professionals, Alzheimer associations, national governments, the European Commission and the WHO (Alzheimer Europe 2013). The stigma influences the way people with dementia are valued and treated within

society, as Wilkinson argues, elderly people with dementia are one of the most excluded groups in western society, experiencing a double jeopardy of stigmas: being old and having a cognitive impairment (Wilkinson 2002). Stigma, defined by Goffman, is:

“The term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself... Reduces the bearer... from a whole and usual person to a tainted, discounted one... We believe that a person with stigma is not quite human ...” (Goffman 1963, p. 13)

To be stigmatised means that a person no longer is seen as normal. The person gets discredited and reduced from what is normally seen as a whole person. Swane (2014) develops this further, taking Goffman's notes of worth and applying it to dementia in three ways. First, she describes stigma, which promotes a negative view of the person with dementia, meaning people no longer talk directly to the person themselves, instead focussing on those around them. Second, she argues that dementia can be seen as shameful and as a taboo that is not talked about. Finally, it can be experienced as discrimination, because society is not prepared to care for the persons' needs. To be stigmatised can negatively influence a person's self-image, so they are reduced in identity and social role leading to isolation (Swane 2014). This means there is a strong argument for involving people with dementia in research, to give them a voice that they have not had until now. However, it is difficult to estimate if having a voice in research will reduce the societal stigma associated with dementia, as it can be difficult to challenge dominant discourses.

Often people with dementia are aware of the stigma and express dissatisfaction with the stigmatised discourses that discriminate them and highlight otherness and accounts of defectiveness. It can create harm and suffering on a day-to-day basis. The stigmatisation can lead to a feeling of being less than the whole person they were prior to their diagnosis (Dupuis, Gillies et al. 2012, Dupuis, Gillies 2014, Swaffer 2015). They experience difficulties in accessing alternative discourses that can challenge the stigma and the prominent tragedy discourse; it is difficult to generate personal and social change when having dementia (Dupuis, Gillies et al. 2012, Dupuis, Gillies 2014). A reason as to why it is difficult to establish alternative discourses can be that within the medical discourse, it is assumed that the pathology of dementia prevents people from taking action and representing themselves actively (Brown, Zavestovski 2004), which is also the case with many media stories. Here people with dementia are typically represented as dementia 'sufferers' who are completely dependent on their families and society (Bartlett 2015).

To be seen as a dementia sufferer has been experienced Nurse, BPsych Kate Swaffer who has dementia. She describes how most healthcare professionals advise people

with dementia to give up their pre-diagnosed life. This is a prescribed dis-engagement, which sets up a chain reaction of defeat and fear that negatively impacts the person. This increases the stigma and discrimination of people with dementia because it disempowers, devalues and demeans the person. The stigma leads to beliefs that people with dementia cannot speak up for themselves; they do not have the right to do so (Swaffer 2015). A change of view on dementia seems to be necessary, to change the stigma, to allow their voice to be heard.

I assume this change is probably already happening, motivated by the person-centred approach and the activism of people with dementia themselves (Brown, Zavestovski 2004). Even though it is unusual to see people with dementia as activists together with capacity of agency and growth following a diagnosis of dementia (Bartlett 2015, Bartlett, O'Conner 2010). However, in recent years a growing subculture of people with dementia has begun to campaign for social change. Rather than passively accepting the medicalised and reductionist view of dementia, those living with dementia are seeking justice and opportunities to grow (Bartlett 2015). In the UK, a rise in the number of individuals engaged in dementia-related activism is emerging (Bartlett 2012). This type of movement is not yet seen as strongly in Denmark. Worldwide, Swaffer is known as an example of such an activist, who argues that it is important to remove the myths about dementia and discrimination, stigma and isolation (Swaffer 2015).

Another example is “*The Scottish Dementia Working Group*” who illustrate the capacity of people with dementia to unite and influence policy (Weaks, Wilkinson et al. 2012). Similar is the “*European Dementia Working Group*” which has the aim to influence public policy and attitudes (Bartlett 2015). Globally, “*The Dementia Alliance International*” advocates for the voice and needs of people with dementia to enforce their human rights around the world (Dementia Alliance International 2014). This dementia activism is a newly emergent phenomenon, and with few exceptions activism by people with dementia has not been the prime focus of research. However, it is clear from the few studies available that people with dementia want to be involved, but still face constraints (Bartlett 2012). They have the capacity and willingness to contribute to public life post-diagnosis, and feel a strong sense of collective strength when they do unite (Bartlett, 2012). Here it is of course important to be aware that not all have the capacity to activate, which can lead to status gap between different groups of people with dementia (Bartlett 2012).

2.2.4 THE MOVE TOWARDS A PERSON-CENTRED APPROACH

A reason as to, why the stigma of dementia exists can be found in the historical way of approaching dementia, because it has mostly been described from a medical perspective (Wilkinson 2002). Even today the biomedical paradigm continues to dominate the understanding of dementia, reducing people with dementia to patients with experiences of loss and decline: loss of neurones, memory, self-identity,

awareness and eventual loss of life (Bartlett 2015, Bartlett, O’Conner 2010). This means, besides not knowing much about their experiences, little is known about how to involve people with dementia as research participants in a constructive and conducive way (Dupuis, Gillies et al. 2012). But it is important to gain knowledge about their lived experiences because they are the ones living with dementia. The experience of dementia cannot be developed from proxy reports, and Wilkinson (2002) questions how service providers and policy makers know what people with dementia want if they are not asked for their views. Research also shows that relatives often underestimate their kin, with dementia and think they experience a low quality of life. The result can limit their opportunities to enjoy a better life (Hellström, Nolan et al. 2007).

Kitwood challenged the malignant social psychological and medical perspectives, which have and surround the experience of dementia. In 1992, he founded the Bradford Dementia Group. Its philosophy is based on a person-centred approach, quite simply to *"treat others in a way you yourself would like to be treated"* (Clarke, Keady 2002). This, in practice, means a move towards a more sensitive and inclusive approach to people with dementia (Clarke, Keady 2002). Especially the *"Dementia Care Mapping"* model is known, even though it is more a model of collecting data about people than with them as it is used to observe the care relation between professionals and people with dementia.

The move to a more person-centered and rights-based approach to dementia research and care illustrates an increasing acceptance in research that the views of people with dementia need to be accessed, and are essential to the understanding of the experiences of diagnosis, and management of the illness (Mckillop 2004, Wilkinson, Hubbard 2003, Wilkinson 2002), although only few qualitative studies include people with dementia as active research participants because the stigma still exists (Dewing 2007, Hubbard, Downs et al. 2003). If researchers want to work with people with dementia according to this new culture innovative and creative methodologies within the research process are needed to ensure that people with dementia are included, heard and understood (Knight 2005). Previous research has mostly focussed on cure instead of improving the outcomes for people diagnosed (Law 2013, Swaffer 2015). A consequence seen from my point of view is that the research might not focus on the important aspects seen from lay people’s perspective, which is problematical for the development of knowledge about dementia.

2.3. RESEARCH AND TRAINING IN DEMENTIA

2.3.1 PARTICIPATORY RESEARCH

Participatory research is a relatively new approach, which has gained increasing importance as a research strategy within qualitative research in English-speaking countries (Bergold, Thomas 2012, Cornwall, Jewkes 1995), which means it is less

established in a Danish context. This is further reflected upon in the PPI paragraph later within this chapter. It is possible to identify different research approaches with a participatory focus such as participatory action research, community-based participatory research, participatory rural appraisal, participatory design and others (Blumenthal 2011, Cornwall, Jewkes 1995, Ehde, Wegener et al. 2013, Hanson, Magnusson et al. 2007, Knobzi, Flicker 2010, Stacciarini, Shattell et al. 2011), which means there are many different ways in talking about participatory research (Knobzi, Flicker 2010). It is therefore as a researcher important to define exactly how a study is characterised as participatory. In the forthcoming methodology chapter the participatory framework within this thesis is described and defined.

Often the purpose of participatory research is described as to involve the active participation of all partners throughout all stages of the research process - from research design to knowledge production to dissemination with the aim of changing the lives of people (Conder 2011). From this perspective, the researcher has to maintain a close relationship with the participants throughout the study, so that the persons' stories and experiences are cast in their terms and meanings to gain an understanding of their mental constructions of situations and contexts (Keady, Williams et al. 2005). It is anticipated that people are the best experts about the problems they face and to be involved encourages them to take action to speak out about the issues that concern them (Dewar 2005). This can change the nature of the evidence produced (Fenge 2010) by promoting more radical knowledge and practice (Baldwin 2011).

What also can make it difficult to define participatory research is that it is not shaped by particular theories or methods but by who defines the research problems and who generates the analysis, represents, owns and acts on the information which is sought (Cornwall, Jewkes 1995). This means that an acknowledgment of power differentials and a willingness to share professional power are fundamental to establish participatory research (Schneider 2010). This is a key difference from other research methodologies. If research is to be participatory in practice, openness, flexibility, sensitivity and responsiveness are required by the researcher. The need for flexibility is particularly needed when collaborating with people with dementia (Littlechild, Tanner et al. 2015), which means I as a researcher can experience difficulties in planning participatory research with this group beforehand.

The approach questions if there is one truth and argues that if a researcher searches for a single truth, there is a risk of oversimplifying social reality. It also acknowledges that a researcher's own values and ideology influence the research, meaning it is unrealistic to achieve objectivity and a strict separation between the researcher and the subjects (Pant 2006). The research knowledge is practice-driven rather than theory-driven, contributing to an opposition to traditional academia, which may be sceptical of the generalisation and validity of participatory research given ideas around objectivity (Knobzi, Flicker 2010). The fundamental questions to be asked

around the process of knowledge creation from a participatory perspective are: *"Who has the right to create knowledge?"*; *"Who controls the knowledge?"*; *"Who should benefit from the research?"* and *"How is the knowledge used?"* (Pant 2006). These questions I interpret indicate a shift, from focusing on a professional perspective on research, to opening up for collaboration and co-produced knowledge. Furthermore, it shows a need for broadening the way traditional academia defines valid research.

There are both moral, political and methodological arguments for participatory research. The moral arguments focus on seeking the democratic rights of citizens, where the political arguments are around the new roles of the users of the welfare state (Domecq et al. 2014). Finally, the methodological arguments are about the effect of involvement. Here the main difference between participatory research and conventional health research is often explained as most participatory research focus on knowledge for action (Cornwall, Jewkes 1995), whereas conventional health research can tend to generate knowledge for understanding, which may be independent of its use in practice. Thus it can be difficult to explain to the wider community, whereas participatory research is more close to praxis and praxis change (Boote, Collins 2011, Florin 2004), which makes the research more accessible and relevant for society. In this critique it is of course relevant to state that also traditional research can be close to practice (Boote 2002) but to include the public can mean a more holistic real-world interpretation of findings that complements the view of the traditional academic researcher (Beresford 2005). Thus, involving lay people in research is anticipated to both enhance effectiveness and save time and money in the long term (Cornwall, Jewkes 1995). A systematic review around participatory research shows that the involvement can improve the inclusion of participants in research, qualify the study design and improve the dissemination of results. It can contribute to the partnership and involvement of different perspectives, support the research process, the transfer and implementation of results in practice and create empowerment for those who participate (Domecq et al. 2014). From an international societal perspective there has been increasing pressure from policy makers, development managers and civil society groups to keep people at the centre of development initiatives. Therefore research strategies which emphasise participation are gaining greater respectability and attention within research. It is recognised that participatory approaches are valuable in health research challenging the marginalisation of patients' and clients' knowledge in relation to the knowledge claims evident in providers' professional practice (Salmon 2007). The methodologies can be carried into health research, enabling services to be responsive to local priorities and committed to change. With this critique of conventional research, it almost seems like participatory research is the only way forward in research, but it is important to regard conventional methods as complimentary, and that they may be more suitable than participatory research in some circumstances (Cornwall, Jewkes 1995). This can be the case in, for example, studying disease aetiology.

Participatory research has roots back to social science, influenced by adult teaching and development programs of e.g. agriculture and communities. Many of the techniques applied in participatory research stem from Paulo Freire's work in education (Cornwall, Jewkes 1995). Also the fields of learning difficulties, disabilities and feminism research have contributed to the paradigm since the 1990s (Faulkner 2004). Different participatory approaches exist in the disability field: praxis research, critical research, democratic research, emancipatory research, co-research and participatory research. Research in mental health has also long since incorporated participatory, user-controlled and user-led research (Dupuis, Gillies et al. 2012, Richardson 1997). As well as the field of dementia, the field of learning difficulties and disability has been seen from a medical perspective based upon a personal tragedy model. This has meant that for most of the 20th century people with learning difficulties and disabilities were excluded from society's concept of normality (Richardson 1997). As a result, their needs were discussed for them rather than being enabled to speak for themselves, which I assume is comparable with what people with dementia can experience.

Since the 1960s, the rise of the disabled rights movement has challenged traditional assumptions about learning disability and disability research (Richardson 1997). The inclusion of the accounts of 'disabled' people's experiences show that in order to make society more accommodating, there is a need to understand personal narratives and recognise differences and diversities in the experiences of 'disabled' people (Beresford 2007). Compared with people with dementia, the inclusion of their voice might also have a positive impact on society's attitude towards dementia, as it has been the case for disability. This is, for instance, seen in the disability activist movement "*Disabled Peoples International*" (DPI) whose slogan is "*Nothing about us without us*". It is committed to protect the rights of people with disabilities and promote their full and equal participation in society (DPI 2016). Another example is Professor Tom Shakespeare who has achondroplasia (dwarfism) and is a professionally successful researcher (Koch 2008), focusing on qualitative research, including public involvement about the lives of disabled people and the barriers they face (UEA 2016).

Positively, participatory research can be transformative because the participants can become better equipped to make sustainable personal changes and challenge structural inequalities (Knobzi, Flicker, 2010). Inclusion of the participants' perspective in research can provide vulnerable and marginalised groups opportunities to feel valued, included and heard (Elstad, Eide 2009, Knobzi, Flicker 2010). This can lead to empowerment, benefiting from connecting and identifying with others and getting more knowledge about existing services. Furthermore, it can enable the participants to transcend dementia through acceptance, hope and experience of empowerment, getting a feeling of control in their lives by obtaining more knowledge about dementia (Dupuis, Gillies 2014). To be empowered is to be enabled to reflect on one's own

situation and develop a capacity to participate rationally and critically in public life. Empowerment operates within three dimensions as illustrated in table 1.

Table 1: Three dimensions of empowerment

Personal empowerment	Developing a sense of self and individual confidence and capacity	Power within
Relational empowerment	Developing the ability to participate, negotiate and influence the nature of relationship and decisions made	Power to
Collective empowerment	Individuals work together to achieve a more extensive impact including collective action based on cooperation	Power with

(Pant 2006, p. 6)

The table shows how empowerment can be personal, relational and collective. It can be felt as a power within the person but it can also be a feeling of doing and a power shared with others. To participate in participatory research can lead to empowerment, but there is often a gap between people learning new skills, and being able to perform these, and it will be over time that they demonstrate whether this has led them to feeling empowered (Conder 2011). Difficulties in assessing the impact of participatory research therefore become apparent because it is difficult to isolate the influence of involvement and capture the outcomes (Littlechild, Tanner et al. 2015). I assume, this is even further complicated when involving people with dementia as their progressive illness challenges a long-term learning and empowerment as their cognitive impairment increases.

Another uncertainty in participatory research is that marginalised groups often lack sufficient research knowledge and skills to undertake the role. Other barriers are culture, language, poor health and lack of resources (Fudge N., Wolfe et al. 2007). I anticipate that a lack of education can also be a barrier. However, individuals can be supported with effective preparation and support mechanisms (Leamy, Clough 2006). Therefore training in research methods and facilitation of the research process is necessary (Conder 2011) but formal models of training in research methods and models for participatory research have overlooked specifically involving people with dementia as active research partners (Dupuis, Gillies et al. 2012). Consequently, not many models involving people with dementia in participatory research have been identified through the literature review process. Those relevant are presented in the methodology chapter.

Although it is important to be aware that an uncritical attitude about the need for training can produce participants as subjects requiring development, marginalising local knowledge, leading to tensions between expecting participants to employ recognised research skills on the one hand and honouring and facilitating their unique contribution on the other (Reed, Cook et al. 2006). Training can produce disciplined participants so that the researchers' control is retained (Littlechild, Tanner et al. 2015, Milligan 2015). The consequence can be tokenistic collaborations, where the participants only are asked for their comments. Finally, it can legitimise neo-liberal programmes that deploy participatory approaches and techniques. This means that participatory methodology can mask a superior attitude, with the potential to disempower rather than empower. It is therefore important to remain reflexive and critical throughout the research process (Carey 2010, Milligan 2015); participatory research does not *per se* guarantee better data, improved understandings, democratising processes or power-free relations between researcher and participants (Roy 2012). Different relations of power between different actors, each with their own projects, shape and reshape the boundaries of action (Cornwall 2008). Furthermore, there is a risk in accessing certain groups and treating them as if they are homogenous.

It has been shown that participatory processes can serve to deepen the exclusion of particular groups unless explicit efforts are made to include them. It raises a number of questions about the basis on which legitimacy is accorded to such *de facto* representatives both with regard to those they come to represent and also in the eyes of outsiders (Cornwall 2008, Ross, Donovan et al. 2005). Voices can therefore be silenced as well as enhanced by participatory research; for example, people with more advanced dementia and more severe cognitive impairments are often excluded from research. It can lead to an involvement that empowers those are expected to get the most in the first place. The consequence can be disempowerment of those with the lowest possibilities. The mechanisms of participatory involvement can negatively function as technologies of legitimation for managerial agendas (Littlechild, Tanner et al. 2015). However, as a researcher I also have to consider whenever it is ethical to involve vulnerable groups of people with dementia in research as it might be unethical to involve people with more advanced dementia and more severe cognitive impairments if they do not understand what consequences a participation might have.

2.3.2 PATIENT AND PUBLIC INVOLVEMENT

In health and social care, participatory research is increasingly referred to as 'patient and public involvement' (PPI), and has increased particularly around the potential for involvement in Health services and research (Staniszewska 2009). PPI can be defined as "*doing research with and by the public rather than to, about or for the public*" (Hanley, Bradburn et al. 2003). Patient involvement refers to the involvement of individual patients, whereas public involvement refers to the involvement of members of the public (Florin 2004). It is a meaningful partnership with the aim of collecting

views and feeding outcomes back to stakeholders (Darling, Parra 2013). Often three main levels of PPI are referred to as illustrated in box 2.

Box 2: Levels of PPI

- Consultations where the researcher seeks the views of the public on key aspects of the research;
- Collaboration with an on-going partnership between researchers and the public throughout the research process;
- Public led where the public designs and undertakes the research. Here researchers are only invited to participate at the invitation of the public

(Boote, Collins 2011)

This shows a great variety in involvement based upon former models of citizen participation as Arnstein's ladder (Arnstein 1969), Jules Pretty's typology of participation (Cornwall 2008) and the typology advanced by Sarah White. These models offer insight into the different interests at stake in participation (White 1996) and are described in more detail in the methodology chapter to define the degree of participatory research within the study.

In the UK, PPI has become an established theme within health research policy in the last 10-15 years to improve not only the quality of services but also health research (Boote, Collins 2011). As an example, INVOLVE was established in 1996 to promote PPI in all stages of research in the UK (INVOLVE 2004). INVOLVE encourages collaborative involvement, where patients and public are seen as active partners (INVOLVE 2004, Staniszewska 2009).

In Denmark, the same development around participatory research and PPI in research is not seen. At a political level it is not possible to identify a focus on PPI in research in the government's present health policy proposals, which means that there is no nationally driven focus on PPI research initiatives in Denmark. This makes it difficult to get an overview of the area, because it is being driven by small and local initiatives (Hørder 2011). However, the importance of involving patient and public is recognised, and in 2011 the Danish Knowledge Centre for User Involvement in Health Care (ViBIS) was established. The aim of the centre is to develop a knowledge base for the involvement of patients and relatives in the Danish health care system (ViBIS 2015), because the country is considered to be behind other countries such as the UK and Australia in respect to PPI in research (ViBIS 2015). To meet the challenge the National Forum of Health Research is also developing a framework for user involvement in research inspired by INVOLVE (Hørder 2011). I expect that more

political initiatives are needed to strengthen the participatory research approach in Denmark. It could be relevant to implement the developed framework nationally.

However, it is not only in research Denmark is behind other countries. An OECD report from 2013 states that Denmark in general faces challenges with patient involvement in the healthcare system because of no formal tradition of involvement. To counter this, the Danish government allocated, in 2013, 20 million DKK to develop a national strategy for patient involvement focused on influence on own care, shared decision making and patient education within the health care system (Ministeriet for sundhed og forebyggelse 2013). According to Holen (2015), patient involvement has developed into a political slogan in Denmark with the purpose of reforming health institutions. Since the 1980s neoliberalism has influenced the Danish healthcare system and has transformed patients to become users who want evidence based treatment and care. The patient's role has changed from being seen as an object under investigation to become an active one where each person is responsible for their own health (Holen 2015). The concept of patient involvement is therefore a result of turning the patient to an active user of the health care system (Holen 2015), but not all patients have the same opportunities to exert their influence, which might be the case for people with dementia. It is therefore important that they are supported both in research and in the healthcare system so it is possible for them to participate. Internationally, the attempts to involve some patient groups have been more comprehensive than others. This is especially in the cancer field where there have been many initiatives to promote PPI in research (Boote, Collins 2011). Also a growth of participatory research with older people is seen (Littlechild, Tanner et al. 2015), even though it is not as effective as it might be (Dewar 2005). The assumption is often made that older people are not able to participate in research because growing older inevitably results in reduced capacity for involvement (Dewar 2005). This assumption is also held towards people with dementia, meaning dementia has been overlooked in these attempts because of the view of people with dementia as not having capacity to contribute to research (Littlechild, Tanner et al. 2015). PPI in research is therefore not common in dementia research, especially in Denmark. Such exclusion of people with dementia restricts the opportunities to increase the knowledge base around the experiences of those with the condition, ultimately denying patients and carers the potential benefits (Behuniak 2011). On the other hand, it is important to be aware that involving people with dementia in research is complicated because the ability to take part changes and varies for the participants, so it is about finding new ways to make sure participation can continue (McKillop 2004).

With these challenges in mind, it could be argued that it is not desirable to involve people with dementia in PPI research but, according to McKeown et al. (2010), it is possible to involve people with early-stage dementia along models of involvement such as consultation, collaboration, commissioning and conducting the research, although it is unrealistic and undesirable to involve people with advanced dementia under such models (McKeown 2010). As a researcher I therefore have to find ways

to enable people with dementia to contribute to research because it can be a way of making a valued contribution to family, community and civic life, because people with dementia often want to help others with dementia even though the research might not help them (Mckillop 2004, Tanner 2012, Wilkinson 2002).

To be involved in research can give the participants a sense of purpose and satisfaction that they can contribute to important changes as well as increase their knowledge, skills and self-confidence (Fudge N., Wolfe et al. 2007). It gives them an opportunity to develop social relationships with peers. To contribute to a shared project can have psychological and cognitive benefits too (Littlechild, Tanner et al. 2015). It can also challenge negative attitudes and change awareness amongst practitioners and service providers to shift services towards more user-centered directions (Littlechild, Tanner et al. 2015). For the researcher, patient involvement can open new doors, give legitimacy to the study and help with the recruitment and engagement of participants, which can lead to rich descriptive data and deeper understanding of data. It can change the research questions, research tools and bring up new ways of collecting and explaining culturally grounded data, which can increase the credibility and validity of the findings. At the same time, they can ensure that the outcome of the research benefits society, by making research documents and findings more accessible (Barber, Beresford et al. 2011, Beresford 2007, Blair, Minkler 2009). PPI can increase the research process, relevance, credibility, dissemination and transferability of findings (Blair, Minkler 2009, Ward 2009). I here see the potentials for PPI if a true collaboration between the participants and the researcher is established.

However, critical voices are also seen towards PPI because of little evidence of the impact of PPI in research, and because the methods are not evidence based and often more qualitative than quantitative. Little is known about which approaches work best, when, why or under what circumstances successful outcomes can be achieved (Florin 2004, Staniszewska 2009). It is argued that PPI experiences only can contribute with a non-scientific subjective view based on individual and that it is opposite the medico-scientific paradigm of knowledge development (Boote, Collins 2011). This means that PPI is questioned from a quantitative perspective, illustrating the long ongoing discussion between quantitative and qualitative paradigm. The questioning challenges the acceptance of this type of research. As a researcher, I can therefore be sceptical about PPI will be accepted as valid research. If not, it is difficult to argue for the involvement of people with dementia in participatory research due to their vulnerability.

The literature also indicates that the field is difficult to navigate because of the plethora of different and allied terms, definitions, methods and models for involvement which exist (Staniszewska 2009, Ward 2009). It means a variation of concepts and terminologies which limit consistency and clarity, leading to relevant criticism from more traditional research. In essence, I interpret that PPI seems to have its justification in research with people with early-stage dementia, even though it can

be criticised by more traditional research. It is therefore vital with definition and argumentation around how the participatory research is understood within the study so it is possible to judge whether it can be characterised as being participatory in relation to existing definitions and models.

2.3.3 TRAINING PEOPLE WITH DEMENTIA

In order to fully enable participants to contribute to research, training is required. This is especially a challenge with people with dementia because previously it has not been seen relevant to train them due to the progressive cognitive impairment (Yu 2009). People with dementia have been excluded from even leisure education due to the stigma of dementia with the assumption that they lack the capacity for growth and new learning. Leisure education can be understood as education as leisure with the aim of developing the optimal use of leisure, increasing life satisfaction and enhancing quality of life (Sivan, Stebbins 2014). As a result leisure education has focused on educating caregivers. This has reproduced the existing power relations predominant in society serving to maintain the silence of people with dementia (Dupuis, Gillies 2014).

What can be overlooked here is that people with dementia are not a homogeneous group and dementia should be seen as a disability, with focus on remaining strengths and abilities (Clare, Woods 2008, Pison Young 2012, Swaffer 2015). It is therefore central to find ways to train people with dementia. Leisure education as transformational learning provides collective engagement where people together can reflect on their assumptions, images, understandings and situations and actively work to improve their lives. It can be used in a collaborative way to help break stigma, create a new face of dementia and enhance the quality of life of all experiencing dementia (Dupuis, Gillies 2014). Leisure education can help coping with negative life events, generating hope and a sense of purpose in life, aiding a reconstruction of the life story with personal transformation (Hutchinson, Loy et al. 2003, Kleiber, Hutchinson et al. 2002). I anticipate it might be relevant as a researcher to look at existing leisure education for people with dementia to get inspired of how to teach and train the group.

Another contribution towards the possibility of training people with dementia is that research today suggests that after damage, the brain can reorganise and experience functional improvements, even in cases of neurodegenerative diseases such as Alzheimer's disease, because neurons are now understood to be plastic and regenerative. Earlier damage was seen as irreversible (Mogensen 2013). "*The Reorganization of Elementary Functions*" model describes how training can rehabilitate people with brain injuries by supporting a changed neural basis taking over and reorganising the function. The learning happens directly from the cognitive activity in the specific situation, which means that the teaching has to be similar to the reality in which the person is going to use the learned skill. The pedagogical initiatives

therefore have to optimise the learning in relation to the real world and to the situations where the person is going to use the trained skills (Mogensen 2013). If a person's feeling of self-relevance and identity construction is taken in to consideration in the learning situation an extra cognitive dimension is activated and the person will remember better because of the meaning in the learning situation (Lieberoth 2013).

People with early-stage Alzheimer's disease have demonstrated increased activation of several cortical areas when engaged in cognitive tasks, indicating functional compensation for neuronal loss. It is therefore relevant to improve or maintain cognitive function by people with dementia via training in relation to activities they find relevant. This is something I as a researcher can use when planning the training in research skills. Also, studies show that the enhancement of cognitive reserves has the potential to delay progression of cognitive impairment and improve quality of life with dementia (Bach-y-Rita 2003, Yu 2009). However, it is important to be aware that in a progressive illness such as dementia, it may not be possible to maintain gains in cognitive or functional abilities for a longer period (Sitzer, Twamley et al. 2006). The knowledge about the effect of social engagement, cognitive training, and mentally stimulating activities is still poor (Winblad, Amouyel et al. 2016), although studies have shown that psychosocial factors can modify the neurodegenerative pathologies with cognitive function such that cognitive ability can remain high in individuals with a heavy burden of global neuropathology if they engage in cognitively stimulating activities or have high levels of education or rich social networks (Bennett, Arnold et al. 2014, Bennett, Schneider et al. 2006, Brayne, Ince et al. 2010). It is therefore difficult to anticipate what learning potential the training in research skill will have.

Cognitive training is often used as a non-pharmacological informal education intervention with people with dementia. The aim is to provide individuals with strategies to improve cognition (Winblad, Amouyel et al. 2016) and focuses typically on functioning such as basic and instrumental activities of daily living, social skills and behavioural disturbances (Yu 2009). It can include cognitive stimulation and cognitive rehabilitation (Yu 2009). Cognitive stimulation is designed to keep the brain active based on the *use-it-or-lose-it* philosophy (Winblad, Amouyel et al. 2016). Within cognitive stimulation, cognitive stimulation therapy is the most used. It involves a range of activities and discussions in groups to enhance cognitive and social functioning (Aguirre, Spector et al. 2014, Spector, Thorgrimsen et al. 2006). A Cochrane review has shown benefits in the language subscale, but no significant changes in memory and orientation after attending this type of therapy (Spector, Orrell et al. 2010) while a single blind study showed benefits in quality of life in the treatment group compared with a control group (Orrell, Spector et al. 2005). Increasing evidence is also validating cognitive rehabilitation programs for dementia (Mimura, Komatsu 2007). This is an individualised approach to help identify personally relevant goals, and strategies for addressing these goals and strategies in the real-life context (Bahar-Fuchs, Hampstead et al. 2014, Bahar-Fuchs, Clare et al. 2013).

Cognitive training strategies can be divided into two basic categories: compensatory and restorative. Compensatory training aims to teach new ways of performing cognitive tasks by working around cognitive deficits. Restorative techniques include e.g. spaced retrieval, vanishing cues, errorless learning, reality orientation therapy and reminiscence therapy. These strategies arose in clinical populations such as traumatic brain injury and schizophrenia, but apply well to Alzheimer's disease (Sitzer, Twamley et al. 2006). Spaced retrieval and errorless learning have been found to improve rates of learning and memory among people with mild dementia, relating to learn names of objects and people, orientation times, items of general knowledge and how to program electronic aids (Mimura, Komatsu 2007).

In reality orientation verbal interaction, aids such as calendars and clocks, and sensory stimuli such as distinctive sights, sounds, and smells are used to improve orientation and sensory awareness (Winblad, Amouyel et al. 2016). A Cochrane review concludes that cognitive stimulation and reality orientation approaches produce improvements in cognition, and in some cases in self-reported quality of life and well-being, primarily for people with mild to moderate dementia (Woods, Aguirre et al. 2012). Reminiscence therapy uses tools such as life histories, shared memories, and familiar objects from past periods to improve wellbeing (Winblad, Amouyel et al. 2016). A Cochrane review on reminiscence therapy shows improvement on cognition, mood and of general behavioural function (Woods, Spector et al. 2009). Knowledge about these different teaching strategies is judged important for me as a researcher in the study, while training in research skills and conducting the participatory research project with the participants, to allow the best suited strategies to be used. This gives me the opportunity to choose the most appropriate strategies.

The different positive results of cognitive training shows that people with dementia to some extent, given appropriate support, can learn or re-learn personally relevant information, maintain learning over time and apply it in an everyday context. They can develop compensatory strategies, identify and achieve personal rehabilitation goals (Forbes, Thiessen et al. 2013, Müller 2009, Woods, Aguirre et al. 2012, Yu 2009). Studies also show that a combination of cognitive training and acetylcholinesterase-inhibiting medications may enhance the effects of pharmacological therapy alone, and delay the cognitive decline (Loewenstein, Acevedo et al. 2004, Requena, Maestú et al. 2006). However, many of the positive studies are judged to be of low to moderate quality (Bahar-Fuchs, Clare et al. 2013). In a systematic review only three out of eight studies about cognitive training with people with Alzheimer's disease showed significant benefits (Spector, Orrell et al. 2012). None of the trials of high quality reported a significant advantage of cognitive training. Nevertheless the review concluded that there was sufficient evidence of benefit of cognitive training to merit further, larger intervention studies (Spector, Orrell et al. 2012).

Another Cochrane review concluded that the available evidence about cognitive training remains limited, requiring further studies of cognitive training and rehabilitation to provide more definitive evidence (Clare, Woods 2008). Bahar-Fuchs et al.'s (2013) review also revealed no positive or adverse effects of cognitive training, even though trial reports indicated that some gains from the intervention was probably not captured by the available standardised outcome measures. I therefore have difficulties in determining anything conclusively about cognitive training because the results are influenced by the way studies and reviews are conducted in relation to a positive, neutral or negative outcome. It is therefore not possible, based upon the existing research, to identify a certain way to train people with dementia. It is necessary in this study to develop a training approach that suits the participants. At the same time it is important to be aware of the amount of training, and the threshold of positive effect because there can be a ceiling effect as a result of concurrent training. So it is not necessarily positive just to add more training to people with dementia. It is difficult to determine the right dose of an intervention (Bahar-Fuchs, Clare et al. 2013, Kwok, Chau et al. 2011). It is therefore essential to be aware of the moral and ethical aspects of training and involvement. This is to be elaborated in Chapter 5.

2.3.4 PREPARATION FOR PARTICIPATORY RESEARCH

Existing literature offers a range of debates about the involvement of people with dementia in research and especially whether it is ethical to train them to be involved in research, when there is diverse evidence towards the benefits of training (Sivan, Stebbins 2014, Yu 2009). Also the morality in challenging them intellectually and confronting them with their cognitive impairment is discussed (McKeown 2010). I anticipate that if people never have been fond of learning, they probably will not be interested in training settings as those mentioned above. Some early studies have also shown frustration or depression for participants receiving cognitive training, and have highlighted the importance of addressing individual needs and emotional responses (Clare, Woods 2008). It can also be anticipated that training and participation in research is not relevant for all with dementia. Also, cognitive training, which shows great potential in the early-stages of the condition, may not be applicable to later stages or different types of dementia (Stewart 2006, Yu 2009). Moreover, studies show that a higher awareness of own impairment is a predictor of more successful outcome (Clare, Wilson et al. 2004, Koltai, Welsh-Bohmer et al. 2001). So training can be ineffective in later stages of dementia, when the awareness of own impairment declines (Clare, Woods 2008, Koltai, Welsh-Bohmer et al. 2001). I can summarise, there is some evidence according to leisure education, "*The Reorganization of Elementary Functions*" model, and cognitive training that people with early-stage dementia can learn for a certain amount of time, which means people with early-stage dementia can be trained for participating in participatory research but it is important to consider for how long it is relevant to be involved in training and research initiatives.

A review of educational courses which prepare people to take part in participatory research shows that few courses exist and that they focus on learning tasks the same way as research students to try to meet the demands of academic rigor (Dewar 2005). The provision of research training is limited; it is often locally-based and invariably associated with particular research projects. Arguably, more systematic approaches to training are necessary to build more lay capacity for the future (INVOLVE 2004, Parkes, Pyer et al. 2014). It is important that high quality training is delivered to support, enable and empower lay representatives to become confident, effective and equal partners of the health and social research community more routinely (Boote 2002, Parkes, Pyer et al. 2014). To meet the challenges of involving people with dementia in research, “*The Scottish Dementia Working Group*” has developed core principles for involvement focusing on mutual relationships and support for and counselling of people with dementia. To develop their research skills, creative methods and new ways for creating knowledge are needed (Keyes 2014). Dupuis et al.’s (2012) model focusses on the ethical and moral aspects of the research partnership with people with dementia. However, it seems that the models existing at a broad level for involvement do not cover the training necessary to enable people to fully take part in participatory research. This is also the case with the core principles from “*The Scottish Dementia Working Group*”. In Littlechild et al.’s (2015) project co-researchers with dementia received training around all stages of the research project, which led to an experience of gaining knowledge, enhancing skills, and developing networks and new opportunities for involvement. Unfortunately, the training process is not revealed.

One exception to this rule is the work of Dewar (2005) who offers some advice for training the elderly to participate in research, using creative techniques such as collage work and interactive theatre. Interviews can also be used to establish individual learning needs, but a specific model of training is not described (Dewar 2005). I therefore see a lack of training models in participatory research for people with dementia. A more generic training model “*Partners in Projects*” focusing on preparing, for example, people with learning disabilities is also identified, related to health and social research (Parkes, Pyer et al. 2014). Here people are trained in the research process. Within the training, reflection and support from the trainer is essential, which means that, in addition to research knowledge, the researcher also needs educational experience to undertake the training (Parkes, Pyer et al. 2014). I assume this model can be difficult to transfer because of the personal reflection requirement within the model, which can be challenging for people with dementia. Other generic models of participatory research involving the elderly can also be identified but they focus on the steps in the participatory research process, not addressing what training needs they have (Hanson, Magnusson et al. 2006). Also from developing countries different models exist, but the focus is on the process, only mentioning that support and facilitation is important due to participant involvement (Krishnaswamy 2004). So further development of theory that guides involvement is needed because most theories today guide the levels of involvement in partnership

processes, but not the different types of support that are required at these levels, nor do they reflect organisational and process issues inherent in involvement (Dewar 2005). It is therefore relevant that the developed participatory research model in this study takes in to consideration how to illustrate both the training and the research process together with relational and organisational aspects.

2.4. CONCLUSION

To summarise, this chapter outlines that research is still needed in dementia as people with dementia are one of the most stigmatised groups in society and in research, which means a lack of knowledge about dementia in various ways. Positively, the stigma has led to a more person-centred approach and to dementia activism. It has led to the acknowledgement that people with dementia can contribute to research, but it is still uncommon to involve them as active participants in participatory research. Thus, training is needed before involvement, but it has previously been seen as irrelevant to train them because of the progressive cognitive decline. Today this is changing, but different views on the effect of different training approaches exist together with a lack of training models for people with dementia to prepare them for participatory research. This study is therefore relevant in contributing a participatory research model, allowing people with early-stage dementia to be involved in research.

The next chapter describes the methodology of the study, illustrating the philosophical considerations around the study. It is based upon the methodology that the exact methods are chosen.

CHAPTER 3. METHODOLOGY

3.1. INTRODUCTION

The previous chapter reviewed the relevant literature in dementia, participatory research and learning and cognitive training with the aim of contextualising the study.

This chapter outlines the participatory methodological framework of the study, building upon the presentation of participatory research in Chapter 2. A number of existing participatory models inspired the project's development and completion; this chapter discusses each of these, justifying their importance. Furthermore, the human science tradition and the characteristics of qualitative research are described because the framework related to this way of seeing the world and research. Also how a participatory research model can be based upon a qualitative generalisation is discussed. Finally, a short presentation of phenomenology, hermeneutic and hermeneutic phenomenology is given to introduce Van Manen's hermeneutic phenomenology lifeworld inspired approach and analysis (Van Manen 1997).

3.2. METHODOLOGY

3.2.1 THE PARTICIPATORY METHODOLOGICAL FRAMEWORK

The philosophical and methodological framework within this study is grounded in a participatory methodology, which assumes that ordinary and marginalised people are knowledgeable about their social realities and are able to articulate this knowledge (Ramsden, Cave 2002). A participatory approach is therefore not value-neutral but is committed to the marginalised voice, related to social transformation and action (Ramsden, Cave 2002). The purpose of participatory research is participation of co-producers in a joint process of knowledge-production with the aim of getting new insights (Bergold, Thomas 2012). This results in capacity building as the participants identify research questions, carry out research activities, and develop research skills and techniques (Krishnaswamy 2004). In participatory research, an enhancement of the participants' understanding of a particular situation will happen together with taking action to change it to their benefit. This way of conducting research enables participants to step back from familiar routines, existing forms of interactions and power relationships in order to question and rethink established interpretations of situations. For that reason it can lead to a reconstruction of knowledge and understanding together with a feeling of empowerment (Bergold, Thomas 2012). Normally, three types of changes are recognised in participatory research. See box 3.

Box 3: Changes in participatory research

- Development of critical consciousness of researcher and participants
- Improvement of the lives of those involved and transformation of fundamental societal structures
- Relationships

(Tandon 2005)

In the study, it was assumed that the participants had knowledge about dementia, could articulate perspectives of their lifeworlds, and learned during the participatory research project. However, I as a researcher questioned how much transformation and empowerment the project could achieve. Also the empowerment might be limited because of the ongoing cognitive decline and that social transformation take a long time.

Participatory research is a process of ongoing learning, which includes openness for the participants' suggestions and steps in the research process (Conder 2011). This makes a participatory methodological framework a suitable research approach when involving people with early-stage dementia because it allows adjustments continuously through the research process, which I found important because their ability to contribute to research can change during the research period. Participatory research involves an educative experience for those engaged because they become aware and more knowledgeable about methods of knowing and analysis; they become aware of their situation and possible ways to change it. This component of learning makes participatory research a distinct research approach (Bergold, Thomas 2012). In the study, the learning included knowledge about research skills, which was tailored to the participatory research project. Here I as a researcher was both a teacher and a researcher close to the research field, but as Chapter 2 discussed it was necessary to give the participants skills so they could understand and contribute to the research otherwise they could have felt insecure and uncomfortable if they did not feel competent in the collaboration (Cornwall 2008). This closeness to the field allowed me to tune into the participants and learn through the research process, enabling the research project to be formed and sculpted to what was relevant and constructive for the participants.

3.2.2 PARTICIPATORY RESEARCH MODELS

Since the 1970s, participation has become a mainstream approach in research but unfortunately it has remained elusive and today a diversity of practices is labelled "*participatory*" (See Chapter 2) (Cornwall, 2008). Often Arnstein's (1969) ladder of citizen participation is referred to as a touchstone for policy makers and practitioners promoting public involvement (Tritter, McCallum 2006) and for giving an overview

of participation in research (Unger 2012). It was developed in the late 1960s and looks at participation from the perspective of those on the receiving end (Cornwall 2008). It provides eight rungs of citizen participation (Arnstein 1969). *Therapy* and *Manipulation* (rungs 1 and 2) are described as non-participative, because their focus is on education or cure of the participants. *Informing*, *Consultation* and *Placation* (rungs 3, 4, 5) are considered degrees of tokenism, which allow the participants a voice, but not power to secure their views which is retained by power holders. Interestingly, these forms of tokenism are sometimes argued as promoting participation (Cornwall 2008). The remaining rungs (6, 7 and 8) are *Partnership*, *Delegated power* and *Citizen control* which are degrees of citizen power. Here participants negotiate and engage with traditional power holders. Within rung 7 and 8, the participants obtain the majority of decision-making, also named full marginalised power. The graduations of participation are illustrated in Arnstein's ladder in figure 1.

Figure 1: Arnstein's ladder

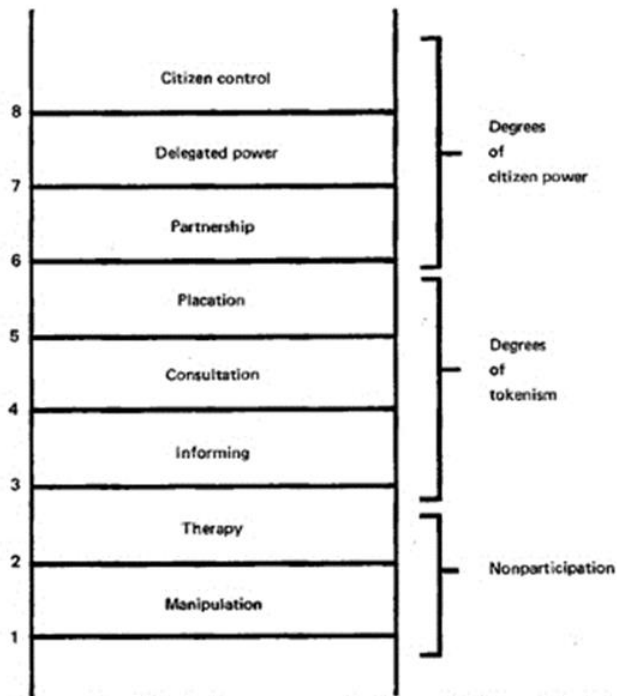


FIGURE 2 *Eight Rungs on a Ladder of Citizen Participation*

(Arnstein, 1969, p. 217)

The ladder illustrates how the researcher still holds the power in some rungs of involvement even though it can be promoted as being participatory. As a researcher, I was aware of this risk when collaborating with the participants to ensure the collaboration did not become tokenistic.

Jules Pretty's typology of participation is another way to describe the different forms of participation (Cornwall 2008). He speaks more to the users of participatory approaches than Arnstein does. The typology is normative going from bad forms of participation to better forms. The bad forms are token representatives with no power, which are *Manipulative participation* and *Passive participation*, where the decisions are already taken. The better forms are different types of consultation with *Functional participation*, which captures the form of participation that is most often associated with efficiency arguments. Another positive form of participation is *Interactive participation*, which is described as a learning process through which local groups take control over decisions. The last is *Self-mobilization* where people take the initiative and retain control (Cornwall 2008). To be faithful to the outlined methodological framework, interactive participation was a relevant way to collaborate in the study. Both Arnstein's and Pretty's typologies describe a spectrum defined by a shift of control by authorities to control by people, which is important to be aware of when conducting participatory research (Cornwall 2008).

A third well-known typology is proposed by Sarah White (1996) who offers insight into the different interests at stake in participation. It identifies conflicting ideas about why and how participation is being used (Cornwall 2008). It means that participation does not necessarily mean sharing power because incorporation can be the best way to control (White 1996). Being involved in a process is therefore not equivalent to having a voice. If participation is to mean more than a façade of good intentions, it is vital to distinguish what the interests are. According to White, fully participatory participation is when the participants take part in management and decision-making (White 1996). The table "*Interest in participation*" is illustrated in table 2.

Table 2: White's Interests in participation

Table 1 Interests in participation			
Form	Top-Down	Bottom-Up	Function
Nominal	Legitimation	Inclusion	Display
Instrumental	Efficiency	Cost	Means
Representative	Sustainability	Leverage	Voice
Transformative	Empowerment	Empowerment	Means/End

(White, 1996, p. 144)

The first column shows the form of participation, the next two show the interests from the top down (the researcher) and the bottom up (the participants), and the final column characterises the function of each type of participation. In reality, any project involves a mix of interests which change over time. *Nominal* participation is for legitimisation to display an inclusion of participants and *Instrumental* participation serves the interests of outsiders while the participants' participation is seen as a cost. Its function is to achieve cost-effectiveness and local facility. *Representative* participation allows people a voice, ensures sustainability and is an effective way to let people express their interests. *Transformative* participation involves the participants in considering options, decisions and taking collaborative action to fight injustice. This is empowering by transforming people's reality and their sense of it (White 1996). It can therefore be seen as the best way to conduct participatory research, but even the most nominal forms of participation can give citizens a foot in the door if there has been no constructive engagement before. Much depends on the context and on those within it (Cornwall 2008).

The participants in the study was a group that had not been engaged before in research collaborations, which meant that the study gave them a foot in the door regardless whether a full scale participatory research project was achieved or not. I planned that the participatory research project would be between placation and partnership according to Arnstein's ladder, between functional and interactive participation seen from Pretty's typology and between representation and transformation in relation to White. A full-scale participatory research project was not planned because I judged it too difficult due to the participant's lack of experiences with research, and the possible memory, attention and language problems that are present with early-stage dementia and the time restriction within the study.

The different types of classification can elaborate whether participatory research is research driven (primarily intended to advance research objectives) or development driven with poverty alleviation and empowerment objectives. Participatory research is theoretically situated at the collegiate level of participation, but this level is rarely achieved. Much of what passes as participatory research goes no further than contracting people into projects which are entirely scientist-led, designed and managed. In many cases people participate in a process which lies outside their control because researchers continue to set the agendas and take responsibility for analysis and the representation of outcomes (Cornwall, Jewkes 1995).

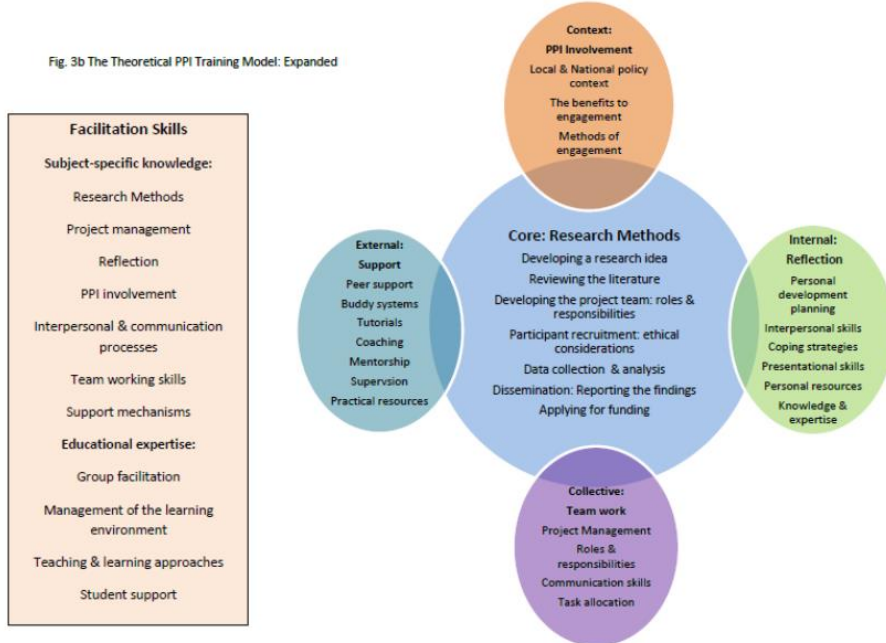
As a researcher, I therefore had to include ethical considerations around how to ensure that the project continued to be participatory. It was important to be aware of the degree of participation and to consider the activities the participants took part in because involvement can come in many guises and does not need to include all components of the research process (Conder 2011). Bergold and Thomas (2012) argue for the importance of the participants having the same rights as the researcher when it comes to decision-making. Otherwise it cannot be participatory research (Bergold,

Thomas 2012). It was therefore important to be clear about what decisions the participants could make in the decision-making processes. A participatory process approach might advocate for the participants to be involved at all stages in the process, but greater clarity is needed to discern what is contained within a process and what is beyond its bounds (Cornwall 2008). In the study, I planned that the participants participated in the whole research process and had the power of decision-making. However, I assumed that it was not constructive and ethical to leave all decision-making to the participants due to their lack of knowledge about research, and their assumed problems with making decisions caused by the dementia.

3.2.3 PARTICIPATORY TRAINING AND SUPPORT MODELS

In the literature about dementia and health, few participatory training and support models seem to exist (Dewar 2005, Dupuis, Gillies et al. 2012). One generic patient and public involvement (PPI) model “*Partners in projects*” focuses on training in research skills and supports the participants in conducting research. This model inspired the training in research skills in the study. I chose the model because it systematically trains people to develop research capacity so they can engage in research within a health and social context (Parkes, Pyer et al. 2014). International experiences show that if users are not educated, they find it difficult to contribute constructively to the process both in terms of having difficulties in understanding it, but also due to a lack of trust in relation to what they can contribute. They need to be provided with the knowledge, understanding, and skills through the provision of tailor-made training (Cornwall 2008). This qualifies their contribution, gives them self-confidence and a belief that they have important knowledge to contribute within research (Parkes, Pyer et al. 2014). The model is organised with a central core with four themes. See figure 2 for illustration of the model.

Figure 2: Partners in projects



(Parkes, Pyer et al., p. 406)

The *Core* is about developing an understanding of the research process from problem identification to dissemination of findings. Within *Developing a research idea* the participants work with what research is and reflect on everyday life experiences to develop a research idea. They also *Review the literature*. *Developing the project team, roles and responsibilities* is fundamental to the “Partners in projects” model. Within *Participant recruitment & ethical considerations* design, ethics and data storage is taught. In the *Data collection & analyses*, the participants are trained in planning and conducting data collection. Within the *Dissemination: Reporting the findings*, the training and research process are also evaluated. Finally, *Applying for funding* focuses on writing a project proposal and seeking funding.

The theme *Context* is about introducing PPI involvement within a local and national policy context and the benefits and methods of engagement. The *Collective* theme is about demonstrating an ability to contribute to project design and development. It focuses on team work, project management, roles and responsibilities, communication skills and task allocation. The next theme is *Internal* which emphasis identifying

personal and group learning points while engaged in project development. It focuses on reflection with personal development planning, interpersonal skills, coping strategies, presentational skills, personal resources, knowledge and expertise. The last theme is *External* which describes the sources of support and practical resources needed for participants engaged in research-related activities and focuses on support, peer-support, buddy systems, tutorials, coaching, mentorship, supervision and practical resources. To succeed with the training *Facilitation skills* are needed by the researcher together with *Subject-specific knowledge* and *Educational expertise*. The *Subject-specific knowledge* is about research methods, project management, reflection, PPI involvement, interpersonal and communication processes, team working skills and support mechanisms. The *Educational expertise* focuses on group facilitation, management of the learning environment, teaching and learning approaches and student support (Parkes, Pyer et al. 2014).

In planning the training I was recognised that it was not possible to apply all elements from the model because of the possible attention, memory and language problems. The model was therefore modified to what was judged relevant when collaborating with people with early-stage dementia. In the study, the purpose of the training was to qualify them to identify and define a research question, participate in a research project and to disseminate the result in collaboration with the researcher, which meant that the level of the training was less ambitious than in the “*Partners in projects*” model. Elements from the *Core* within the model such as writing project proposals and seeking funding, together with the *Context* of PPI research, and the *Internal* theme with developing plans were not taught (Parkes, Pyer et al. 2014), acknowledging that the learning would be missed again in the progression of dementia. Furthermore, I decided to train and conduct the participatory research project as one continuous process because of potential attention and memory problems. I assumed it would be difficult for the participants to recall the learning over a longer period. Finally, it was anticipated that it would be difficult to completely follow a traditional qualitative research process, so the project was modified to a peer-research project. These decisions were reached based upon the background knowledge gained through the literature review, the participant observations and the individual interviews. The participants were not involved in these decisions because they had no prior research knowledge, and many expressed in the interviews that they were insecure about the project and the lead of it. Together these would have challenged them significantly for making any decisions in relation to the use of the “*Partners in project*” model.

Another model “*Authentic partnerships*”, addresses what it is important to be aware of when collaborating with people with dementia (Dupuis, Gillies et al. 2012). This model supplements the training model by focusing on the special needs people with dementia have when conducting research. It reorganises the collective capacity people with dementia have to empower themselves by seeing knowledge as power and education and learning as important vehicles for social change, transformation and liberation. For that reason, it challenges the supremacy of higher order or expert

knowledge and instrumental rationality by acknowledging, valuing and incorporating the lived knowledge of partners with dementia. Moreover, the model incorporates a systematic process of critical reflection and dialogue with the partners (Dupuis, Gillies et al. 2012). See figure 3 for illustration of the model.

Figure 3: Authentic partnerships



(Dupuis, Gillies et al., p. 10)

Three guiding principles and five factors mobilise an authentic partnership. The guiding principles are *Genuine regard for self & others*, *Synergistic relationships* and *Focus on the process* (Dupuis, Gillies et al. 2012). *Genuine regard for self & others* focuses on demonstrating mutual caring and concern for the welfare and enhancing the humanness of all involved in the partnership. It involves recognition of and responsibility to uphold individual rights including the right to respect, dignity, full engagement in life and self-determination (Dupuis, Gillies et al. 2012). *Synergistic relationships* recognise the interconnectedness and interdependence of all and focus on the development of relationships that are characterised by interdependence and reciprocity rather than perpetuating notions of dependence and independence. All voices are valued and incorporated. *Focus on the process* is the third guiding principle, which recognises that new learning and unlearning are never ending, and that we cannot have all the answers or know all of the possibilities at the beginning of the process. It requires flexibility and responsiveness to change and requires that the partnership is open to learning from mistakes and embraces creativity and non-traditional ways of doing (Dupuis, Gillies et al. 2012).

Five factors are also required to enable and sustain the partnership. One factor is *Connecting and committing* so that all understand and share the same goal. It is important to discuss the needs, roles, expectations and responsibilities of each partner. It involves identifying the strengths, talents and resources each member possesses and

identifying, how to support involvement. Another factor is *Creating a safe space* where people feel comfortable. It is necessary to foster emotional support and attune to indicators of discomfort or frustration such as body language, posture or facial expressions. A physical environment free of distractions is essential so that the participants are encouraged to slow down, relax, be truly present and engage in a meaningful way (Dupuis, Gillies et al. 2012). The third factor is *Valuing diverse perspectives* where all voices count. The different styles and types of engagement have to be valued and the partners should be provided with a range of ways to participate and contribute to the process. The fourth factor is *Establishing and maintaining open communication* where communication is defined as a dynamic two-way process involving verbal and non-verbal forms as well as active listening and engagement in dialogue involving a range of alternative communication forms that meet individual needs. It is important to keep a record of discussions and decisions made as this provides all partners with cues to previous decisions. The last factor is *Conducting regular critical reflection and dialogue* to provide self and group reflections. It can be done by creating a list of statements and questions. These statements can stimulate critical thinking and dialogue (Dupuis, Gillies et al. 2012).

In the study, the guiding principles and factors were implicit to ensure a constructive and conducive collaboration with the participants throughout the training and the participatory research project. I anticipated that it would support the modified use of the “*Partners in project*” model because it focused on the relationship being supportive throughout the process, describing in more detail how to act responsibly towards the participants.

3.2.4 PARTICIPATORY RESEARCH PHASES

Participatory research is viewed as involving several steps. In the beginning, a planning and preparation phase is conducted with a framework with agreed upon principles, which define how the entire research process will unfold (Ramsden, Cave 2002). The next step is to identify the participants. They can be any person, group or institution that affects or is affected by the research. Most participatory processes cannot involve everyone so in practice choices are made as to who can take part (Cornwall 2008). It is important to make it clear from the beginning of the process how the participants will benefit by participating in the research (Krishnaswamy 2004) and to spell out what they exactly are recruited for, what purpose and who is involved and who is not (Cornwall 2008). When the participants are identified, building a trusting relationship is the starting point because it is a necessary stage prior to developing a research question. Informal communication and regular interaction amongst research partners is relevant together with building common understandings by discussing the goals, strengths and planning the project from a strengths-based approach (Conder 2011, Dupuis, Gillies et al. 2012, Stacciarini, Shattell et al. 2011). In participatory research, the researcher acts as a change agent and carries forward and disseminates the knowledge in collaboration with the participants (Conder 2011).

It is critical to the process that all are actively engaged in building a common understanding. A memorandum of understanding that outlines what the research wants to accomplish can be relevant (Krishnaswamy 2004).

Following this, accessible yet robust questions are generated which form the focus of the work. The list of issues and concerns developed during the stage of building a common understanding can be used (Krishnaswamy 2004). The next phase is gathering and analysing data, which involves several essential tasks such as providing necessary training in data-gathering and -analysis techniques (Stacciarini, Shattell et al. 2011). The raw data can require organisation into readable narrative descriptions. The emphasis of the qualitative aspect in a project will be on illumination, understanding and extrapolation rather than causal determination, prediction and generalisation. After this, the data are delivered to the community. Community meetings can be one way to share information with people providing them an opportunity to reflect upon data, interpret the findings and make recommendations for change. The last phase is reflecting and taking action (Ramsden, Cave 2002). This study was inspired by these phases building upon already well-establish knowledge about participatory research, but I needed to modify the phases to suit the participants with early-stage dementia as the phases described above do not consider the challenges existing with a cognitive impairment.

3.3. THE METHODICAL APPROACH

3.3.1 HUMAN SCIENCE AND QUALITATIVE RESEARCH

The study drew upon the human science tradition since the focus was on the participants' lifeworld perspectives and thus on human experiences, essential within human science. The term human science derives from the German word *Geisteswissenschaften* translated as the study of science of mind (Van Manen 2014). It includes a general orientation to life, a view of knowledge and a sense of what it means to be human, which is associated with or implied by certain research methods (Van Manen 1997). To be human is to have consciousness and act purposefully in the world by creating objects of meaning. As people we are incomparable, unclassifiable, uncountable and irreplaceable (Dilthey 1976). In contrast, natural science studies natural objects, natural events and the way objects' behave from an objective stance. As Dilthey stated:

"We explain nature but human life we must understand" (Van Manen 1997, p. 4 quoting Dilthey, 1976)

Human science aims to show the meaning of human phenomena and understand the lived structures of meanings (Van Manen 1997). A humanistic approach was therefore judged relevant since the study focused on the participants' lifeworld perspectives with the aim of developing a participatory research model based upon the experiences

gained through a participatory research project, where the participants' experiences and interactions were in focus.

However, it is important to be aware that lived human experience is always more complex than the result of any singular description and that there is always an element of the indefinable in life. Nonetheless, to recognise that life is fundamentally mysterious does not need to make human science mystic. It is a naive rationalism to believe that the phenomena of life can be intellectually crystal clear or theoretically transparent. The language of thinking cannot capture human experience in abstract concepts and in logical systems because it flattens rather than deepens our understanding of human life (Van Manen 1997). This study sought to capture perspectives of the participants' lifeworlds in a participatory research project with the aim of developing a participatory research model. I anticipated that a complete picture of the participants' lifeworlds would not be gained but that a deeper insight was possible, relevant for developing the participatory research model.

Qualitative research follows human science. The goal of qualitative research is to understand the social phenomena in natural, rather than experimental settings, giving emphasis to the meanings, experiences and views of the participants (Parahoo 2014). Qualitative studies often provide a rich, contextualised understanding of some aspect of human experience through the intensive study of particular cases (Polit, Beck 2012, Polit 2010). It shows important aspects of the life lived because it can display the contradictions and paradoxes of life (Malterud 2011). Qualitative research methods can therefore be useful over or alongside quantitative methods when there is little known about a subject or the subject is complex, as it enables the generation of new theories rather than testing existing hypotheses (Wheeler, Holloway et al. 2010). Qualitative methods were chosen in the study to reveal the complexity of the experiences of the participants, noting that qualitative research can enable the generation of new theories, which was relevant for its aim.

In qualitative research the importance or attainability of generalisability is discussed. On the one hand it is argued that generalisation requires extrapolation that can never be fully justified because qualitative findings are always embedded within a context. According to this argument, knowledge is idiographic, to be found in the particulars (Polit, Beck 2012, Polit 2010). On the other hand it is argued that in-depth qualitative research is well suited for revealing higher-level concepts and theories that are not unique to a particular participant or setting (Polit 2010). In this view, the rich, highly detailed, and potentially insightful nature of qualitative findings make them suitable for extrapolation. Groleu et al. (2009) argue that an important goal of qualitative studies is to shape the opinion of decision-makers whose actions affect people's health and well-being (Groleu, Zekowitz et al. 2009). The end product of qualitative research is therefore a generalisation, regardless of the language used to describe it (Ayres, Kavanaugh et al. 2003). This study aimed to develop a participatory research model and I see the model as an analytical generalisation from one participatory

research project with twelve people with early-stage dementia. However, I recognise that a generalisation is an ideal with a risk of overgeneralisation (Thorne, Darbyshire 2005). It was anticipated that the participatory research model could become relevant when involving other people with early-stage dementia and perhaps other vulnerable groups with cognitive impairment in future research. In the case of transferability, which involves the use of findings from an inquiry to a completely different group of people or setting, it is the researcher's job to provide detailed descriptions that allow readers to make inferences about extrapolating the findings to other settings. To support transferability a detailed description is needed about the research setting, participants, and any observed transactions and processes. It involves all forms of critical information that helps to understand the study's context and participants (Polit 2010). The remainder of this thesis details the choices I as a researcher made in the process, making it possible to judge the quality of the model that was developed and its associated guidance.

3.3.2 PHENOMENOLOGY AND HERMENEUTIC PHENOMENOLOGY

With a humanistic view within the participatory research project a hermeneutic phenomenological approach was chosen because it allowed the investigation of the human lifeworld of the participants with both the perspective of letting the participants' lifeworlds be shown as they were and the possibility of interpreting them. The hermeneutic phenomenological approach is both influenced by phenomenology and hermeneutics so a short explanation of these approaches is required before presenting the hermeneutic phenomenological approach used within this study.

In qualitative participatory research, phenomenology is frequently used as a theoretical research approach and analytical method. It is a broad adaptable movement that includes many different topical interests, talents, sensibilities and unique styles of investigators. It often involves creative modifications of the methodological attitude and analytical procedure (Wertz 2011), and therefore it is difficult to commit oneself to one certain phenomenological research method because there is no single phenomenology and no single technique (Van Manen 2006). Phenomenology can instead be understood as a movement with different traditions up to the modern hermeneutics (Bengtsson 2006). Phenomenology accounts to taking up a certain attitude and practicing a certain attentive awareness to the things of the world as we live them rather than as we conceptualise or theorise them (Van Manen 2006). The word phenomenon is from Greek and means "*what shows it*", meaning nothing can show itself without showing it to someone. There is an inter-dependent relationship between the object and the subject (Bengtsson 2006).

Phenomenology should be the method of choice when aiming to understand the meaning of the lived experience of a phenomenon. It is useful when the task is to understand an experience as it is understood by those who experience it (Dowling 2012). Phenomenology addresses the human experiences as they are lived in health

and illness (Kumar 2012). It is discovery oriented and focuses on finding out what a certain phenomenon means and how it is experienced by reducing the experience to a description of a universal essence (Van Manen 2014). Reality is seen as a construction of the individuals participating in the research and their voices and interpretations are key to understanding the phenomenon of interest. Subjective interactions are the primary way to access the area and the findings are a result of interaction and co-creation between the researcher and the participants (Flood 2010, Polit, Beck 2012). The aim in phenomenology is to faithfully conceptualise the process and structures of mental life, how situations are meaningfully lived through as they are experienced with nothing added and nothing subtracted (Giorgi 2009). It sets aside theories, hypotheses and explanations and investigates what and how it is experienced (Wertz 2011). Knowledge is maximised when the distance between the researcher and the participants in a study is minimised (Dowling 2007), which corresponds very well with a participatory methodology.

The phenomenological paradigm began as a countermovement to positivism. Within phenomenology a movement from pure philosophy towards a more critical humanistic methodology has occurred (Kumar 2012). Phenomenology has its roots in the philosophy of Edmund Husserl (1859-1938) who argued that all knowledge is human made (Dowling 2007). Husserl defined lifeworld as what people experience pre-reflectively and pre-scientifically, without resorting to categorisation or conceptualisation and quite often includes what is taken for granted or those things that are common sense (Bengtsson 2006, Lavery 2003). Schütz described the lifeworld as:

“By the everyday life-world is to be understood that province of reality which the wide-awake and normal adult simply takes for granted in the attitude of common sense” (Schütz, Luckmann 1973, p. 3)

For Habermas the very existence of a lifeworld (Lebenswelt) was the background convictions common to all subjects acting communicatively. The lifeworld itself contributes to a minimum content that ensures all actors share a certain horizon of meaning, despite the enormous complexity and fragmentation of modernity (Habermas 1984). The work of Husserl has formed the Edetic or descriptive phenomenology (Dowling 2012) where the phenomenological reduction or bracketing is distinguishing (Dowling 2012). Husserl described two fundamental procedures as necessary for exploring the experience. *“The epoché of natural science”* and *“The epoché of the natural attitude”*. The first is putting aside natural science and other knowledge and instead returning to the things themselves (bracketing prior knowledge), which allows the researcher to attend the lifeworld. The second is also called phenomenological reduction, where the researcher abstains from the natural tendency of consciousness to unreflectively focus on the existence of objects independent of experience. This allows the researcher to closely examine how situations present themselves through experience (Wertz 2011).

Husserl also described intentional analysis and eidetic analysis. Intentional analysis concerns describing the how and the what of experience – how experiential processes proceed and what is experienced through them. It denotes the transcendental quality of consciousness that consciousness is of something (beyond itself). Intentional analysis shows that human experience is embodied, practical, emotional, spatial, social, linguistic and temporal. In eidetic analysis, the researcher uses the free imaginative variation towards a single example in order to clarify its essence - to understand what is essential. It is a generalising procedure that clarifies the essence of phenomena (eidetic reduction). Phenomena can be described eidetically at various levels of generality ranging from the lower limit of individuals' experiences to various types of highly general characteristics of experience (Wertz 2011).

Husserl's assistants, students and followers extended and developed the philosophical work further. The hermeneutic phenomenology formulated by Heidegger (1889-1976) draws on phenomenology along with such related traditions as hermeneutics and idiograph (Wertz 2011). It is also defined as existential phenomenology (Dowling 2012). The meaning of phenomenological description as a method lies in interpretation seen from Heidegger's perspective:

“Phenomenology is hermeneutic in the primordial signification of this word, where it designates this business of interpreting” (Heidegger 1962, p. 37).

It seeks to answer the question of the meaning of being the lifeworld or human experience as it is lived. The focus is to illuminate details and trivial aspects within experience that may be taken for granted in our lives with the aim of creating meaning and achieving a sense of understanding (Lavery 2003). Contrary to Husserl, Heidegger saw bracketing as impossible, as one cannot stand outside the pre-understandings and history of one's experience (Lavery 2003). Instead, he wanted to uncover hidden meaning and move beyond description to interpretation. The difference between Husserl and Heidegger is that Husserl focuses on questions of epistemology – the nature of knowledge while Heidegger is concerned with ontological questions – on the nature of being (Dowling 2012). Heidegger believed that humans are hermeneutic beings capable of finding significance and meaning in their lives. For Husserl, context was of peripheral importance, but for Heidegger context was a central concern because the understanding cannot occur in isolation of its culture, social context and historical period. Heidegger introduced the concept of *dasein* (the situated meaning/ a human way of being in the world) to emphasise that individuals cannot abstract themselves from various contexts that influence their choices and give meanings to lived experience. It addresses the situated-ness of individual's *dasein* in relation to the broader social, political and cultural contexts (Flood 2010, Kumar 2012).

3.3.3 HERMENEUTICS

Hermeneutics is the philosophy of understanding gained through interpretation with the aim of communicating between different worlds. In classic hermeneutics the communication was around historical distances and texts, closely connected to history and linguistic science (Bengtsson 2006). Gadamer is a prominent figure within modern hermeneutics and he developed a hermeneutic philosophy grounded in a textual approach. He argued for the importance of having the means to clarify the conditions under which understanding takes place (Bjørner 2015b, Dahlberg, Dahlberg et al. 2008). The modern hermeneutics is developed from the existential philosophical phenomenology. According to the philosophy of Gadamer, interpretation is an aspect of all forms of human understanding (Lawn 2006). Therefore hermeneutics occurs no matter which aspects of our cultural and social world we seek to understand (Lawn 2006). We can therefore never have direct access to things themselves because they are always presented by subjects' relation to, for example, a historical period, a social environment or a language. It is an understanding structured with a hermeneutic circle trying to interpret things and about trying to understand the things by building a bridge to the historical, social and language obstacles. Here it is important to confront the pre-understandings to change the understanding (Bengtsson 2006). Hermeneutics starts from the position that a person seeks to understand something, has a bond to the subject matter that comes into language through the traditionary text and has or acquires a connection with the tradition from which it speaks (Gadamer 1998b).

Dahlberg et al. (2008) outline core principles in Gadamer's philosophy. The first overall methodological principle is openness, which is affected by tradition and its power over human understanding. The second concerns an awareness of the power of tradition understood as personal history, which includes a healthy suspicion towards oneself as a researcher. A conscious use of theory to prevent pre-understanding from controlling the process of understanding is the third principle. The fourth principle is searching for the otherness for an understanding of the phenomenon that is not given by one's pre-understanding. The scientific attitude is reflective with openness and a critical view of the pre-understanding. It treats it cautiously and explicitly in the process of understanding (Dahlberg, Dahlberg et al. 2008). Gadamer expresses:

"The important thing is to be aware of one's own bias so that the text can present itself in all its otherness and thus asserts its own truth against one's own fore-meaning" (Gadamer 1995, p. 269).

Interpretational explanations can stem from theory and prior research findings but it can be complicated to use and should only be used to help see data and its meaning better. Gadamer argues that theory serves the purpose of controlling the pre-understanding because it supports the scientific attempt to see something else than what is offered by the natural attitude (Gadamer 1998a). Theory should however not be chosen until data has suggested the need for it, which means that a theory cannot

be a fact already in the background of a hermeneutic study. It is also worthwhile to keep more than one theory in the interpretational process and let them compete (Dahlberg, Dahlberg et al. 2008).

A pillar in hermeneutics is the hermeneutic circle, which is comprised of connecting parts with the whole. This is a process in constant movement and according to Lawn (2006) an actual clue in this process is that pre-existing interpretations are necessary to make new interpretations possible (Høiseth, Keitsch et al. 2014, Lawn 2006). In order to come to a new whole, a main interpretation is laid out in hermeneutics with a structure at a higher abstract level than earlier interpretations during the analysis process. The main interpretation cuts through and concludes all the tentative interpretations. It guides the reader through the reading and contributes to the reader's "aha" experience of the text. This opens up the possibilities of generalisation. Different from the hermeneutics, the essence will cut through all meaning variations in the data when working with phenomenology. In hermeneutic research, the researcher strives to find an interpretation that connects the different perspectives that emerges in the analysis. The level of abstraction in the interpretation is connected with the principle of parts and whole. There must be consistency in the system of interpretations in the sense that interpretations with a higher degree abstraction, for example the main interpretation, frame the interpretations at more concrete levels such as the interpretations of parts. The consistency of the interpretations can be affirmed when the researcher ensures that no important parts fall out of the interpreted whole. A good interpretation is one that is necessary to illuminate all data. Then other interpretations can be excluded, which is a necessary criterion when evaluating the validity of the main interpretation (Dahlberg, Dahlberg et al. 2008). An interpretation that is congruent with well-known facts and accepted theories is probably a fair interpretation. However, it can also prevent the emergence of new understandings through the interpretive process. The researcher has to create interpretations that are consistent with a common understanding but also be open towards understandings that go against already accepted meanings. Researchers must hunt for new information and at the same time create an interpretation, which gives a complete and reasonable explanation of the data. The trying out of interpretations constantly involves a serious awareness and an open scrutiny of the researcher's own pre-understanding (Dahlberg, Dahlberg et al. 2008).

3.3.4 MAX VAN MANEN'S HERMENEUTIC PHENOMENOLOGY AND LIFEWORLD INSPIRED ANALYSIS

In the study a hermeneutic phenomenological approach inspired by Van Manen was used to focus the researcher's attention to the participants' lifeworld perspectives since it opened up the investigation of the perspectives that rose in the interaction between the participants and the researcher. The approach also balanced the researcher's attitude in the research process by both allowing descriptive and interpretive elements. Hermeneutic phenomenology is a philosophy that aims to

achieve understanding through interpretation and adopts a process that clarifies the phenomenon of interest in its context (Dowling 2012). There exists no clear distinction between phenomenology and hermeneutic phenomenology. What can be said is that phenomenology is foundationalist as it seeks a correct answer or valid interpretation of texts not dependent on the biographical, social or historical position of the interpreter while hermeneutic phenomenology is non-foundationalist, as it focuses on meaning that arises from the interpretive interaction between historically produced texts and the reader (Lavery 2003).

Professor Max Van Manen (1942-) represents a hermeneutic phenomenology tradition with a movement from pure philosophy towards a more critical humanistic phenomenological methodology. He has developed a method to describe how to work with phenomenology so it is possible to describe how results are gained (Bengtsson 2006). Phenomenological human science is discovery oriented and focuses on finding out what a certain phenomenon means and how it is experienced. It is a methodology that reduces any tendency toward concepts that would rule-govern research (Van Manen 1997). This hermeneutic phenomenological approach, which combines descriptive and interpretive phenomenology, is also described as the Dutch (Utrecht) school of phenomenology (Dowling 2012). The Utrecht school shied away from technical philosophical issues and focused on phenomenology as a practical and reflective method with the aim of understanding the practices of everyday life (Van Manen 2007).

Van Manen describes hermeneutic phenomenology as a method of abstemious reflection on the basic structures of the lived experience of human existence. By abstemious he means that reflections aim to abstain from theoretical, polemical, suppositional and emotional intoxications. Hermeneutic reflections aim for discursive language-sensitive interpretive devices that make phenomenological analysis possible. The lived experience means for him that phenomenology reflects on the pre-reflective or pre-predicative life of human existence. He argues that there will both be descriptive and interpretive elements at work in phenomenological inquiry. Phenomenology is in some sense always descriptive and interpretive, linguistic and hermeneutic, which I interpret means much phenomenology has hermeneutic elements. Many methodical possibilities exist when engaging in phenomenological practice, but they cannot be reduced to procedural schemes or series of steps. There is no method to human truths (Van Manen 2014). The best way to think of the basic method of phenomenology is to have a certain attitude to and awareness of the things of the world as we live them rather than as we conceptualise or theorise them (Van Manen 2014). It is important to be aware that the scientific process and writing distances and idealises the reality, which is transformed into concepts and verbal expression. This can have a negative effect with a scholastic idealism for language and text being enough (Bengtsson 2006). Van Manen argues:

“A phenomenology that is sensitive to the lifeworld explores how our everyday involvements with our world are enriched by knowing as in-being” (Van Manen 2007, p. 13)

When focusing on everyday situations and relations phenomenology becomes pragmatic and a phenomenology of practice. This phenomenology is open for creating formative relations between being, acting and thoughtfulness and tact (Van Manen 2007). The phenomenology of practice operates in the space of the formative relations between who we are and who we may become, between how we think or feel and how we act (Van Manen 2007). In the writing, one tries to understand the lived meanings of the lifeworld, which requires attention to others. The writing work evolves textual material that possesses hermeneutic and interpretative significance. It is in the process of writing that the data are gained and interpreted so the fundamental nature of the research question is perceived (Van Manen 2006). A phenomenology of practice sees new thinking as an invitation to openness searching for the experience of lived meaning in human life. It is not only sensitive to the concerns of professional practices but also to the personal and social practices in everyday living. In this way phenomenology of practice distinguishes itself from more purely philosophical issues. Phenomenology of practice is sensitive to the realisation that life as we live and experience is not only rational and logical and in part transparent to reflection – it is also subtle, enigmatic, contradictory, mysterious, inexhaustible, and saturated with existential and transcendent meaning that can only be accessed through poetic, aesthetic and ethical means and languages (Van Manen 2014).

The lifeworld is focused on the immediate subjective experiences in daily life (Van Manen 1997). The lifeworld is anonymous and functions implicitly in the background. It is a social world with human created objects and human organisation of life, given from one human to another. This means the lifeworld is an historical world with a differentiated and complex reality which cannot be reduced. The lifeworld implies both physical and psychological qualities and cannot be captured by reductionist synthesis as objectivism, psychologism, physicalism etc. (Bengtsson 2006). The lifeworld is possible to explore and talk about because it is the concrete existence we meet every day, relate to and share with others. Thus there is nothing that prevents us from investigating our own and others' lifeworlds, but we may not forget that we always will be a part of a lifeworld; even though we study it, we cannot get around it. This means the researcher can either escape the lifeworld or observe it from an outside perspective. The existence is a co-existence, which makes it possible to understand other people. This means that the people who are studied and the researcher who studies them are inseparably connected with their lifeworlds. When studying other peoples' lifeworlds it is important that actual concrete connections and their networks are taken into consideration. It is only in this connection that single events, things and human beings are fully comprehensible. It is not enough just to see the lifeworld in its connection; it must also be respected on its own terms. For that reason a disease must be understood in terms of human being connections because a disease is not objective but related to the person, the life story, the life situation etc.

However, at the same time, the whole lifeworld cannot be investigated because some horizontal boundaries exist although a particular region can be chosen (Bengtsson 2006). This means:

“...we can even speak of the multiple and different lifeworlds that belong to different human existences and realities” (Van Manen, 1997, p. 101)

This can e.g. be the lived world of work and the lived world of home (Van Manen 1997). The research question predicts the region with its horizontal boundaries. The lifeworld includes all the regions the person moves between and can be described as the world of everything that is possible to do and experience. The lifeworld can therefore both grow and shrink. This means that daily life is a region or a part of the lifeworld and not identical with it. In daily life reality is taken for granted as something certain until somehow it becomes problematic and is no longer possible to maintain. Only parts change since not everything can be lifted at the same time and the lifeworld cannot in its whole be omitted. What is questioned will be replaced with some new truism (Bengtsson 2006).

Five fundamental existential themes exist and pervade the lifeworlds of all human beings regardless of their historical, cultural or social situated-ness. They are as following: spatiality (lived space), corporeality (lived body), temporality (lived time), relationality (lived relation) and materiality (lived things or technology). They guide the reflection in a research process because they are the existential ground in which all human beings experience the world, although not all in the same modality. Van Manen argues:

“Therefore, spatiality, corporeality, temporality, and relationality are productive categories for the process of phenomenological question, reflection and writing” (Van Manen, 1997, p. 102)

In a research project it is possible to study the existentials in their differentiated aspects but one existential will always call forth the other aspects. Although there is no compelling reason for structuring a phenomenological description in one particular way, it can be helpful to organise the writing to the essential structure of the phenomenon itself grounded in a hermeneutic phenomenological reflection (Van Manen 1997). To uncover the thematic aspects of a phenomenon in a text the selective approach can be useful. Here the researcher looks at sentences or part-sentences that seem to be thematically important for the phenomenon (Van Manen 1984).

In the phenomenological question, reflection and writing there can be a tension between staying true to the lived experiences of the participants and achieving a level of abstraction from the data in order to uncover the essential structures and meanings of a particular lived experience. A way of resolving this tension is through the application of theoretical coding frameworks. Van Manen's four lifeworld existentials can offer a lens through which to uncover the essence of lived experience, without

imposing categories, predetermined or predefined themes upon the data itself of what is considered significant to the lived experience. Rather, it provides four areas through which the phenomenon under investigation can begin to be understood and explored (Rich et al. 2013). This ensures both staying true to the exploratory and inductive nature of qualitative inquiry and in supporting methodological congruence (Plazas et al. 2016, Rich et al. 2013). The existentials present a holistic and valuable method and suitable organising device for reflective practice, in coming to understand lived experience (Rich et al. 2013). It can help make tangible the more abstract components of the experiences that the participants discuss and help the researcher to uncover the commonalities and shared structures in the experience of being (ibid). The existentials lead the researcher to access the lived experience of human beings and to develop a deeper understanding of the nature and meaning of everyday experience. I therefore assumed that spatiality, corporeality, temporality, and relationality were productive categories for the process of phenomenological questioning, reflecting and writing in the thesis (Plazas et al. 2016). The Spatiality is the “*felt*” space. The experience of lived space is largely pre-verbal and we do not ordinarily reflect on it even though it affects the way we feel. There are cultural and social conventions associated with space, which we learn to act in accordance with. A special space is home because it has something to do with the fundamental sense of our being. Home is a secure inner sanctity where we can feel protected and be ourselves (Van Manen 1997). This existential can guide the reflection to ask how space is experienced. It can focus on interiorities and exteriorities. A person will always shape the space but the space will also shape the person and the space can be experienced differently when being sick from when being healthy (Van Manen 2014). Corporeality refers to the fact that we are always bodily in the world. When we meet other people we meet them through our bodies. In our bodily presence we both reveal something about ourselves and conceal something at the same time – not necessarily consciously or deliberately but rather in spite of ourselves. When the body is the object of someone else it may lose its naturalness or it goes enhanced in its modality of being. The body knows how to do things such as routines, habits, motor skills and memories, conventions, rules etc. (Van Manen 2007, Van Manen 1997). This existential can guide the reflection to ask how the body is experienced. Is the body experienced as a subject or object? Normally, when a person is bodily engaged in the world he or she does not really pay attention to the body itself (Van Manen 2014).

The third existential is temporality, which refers to subjective time as opposed to objective time. Lived time speeds up when we enjoy ourselves and slows down when we feel bored or anxious. It is our temporal way of being in the world. The temporal dimensions of past, present and future constitute the horizons of a person’s temporal landscape. What you encounter in the past leaves traces on being – the way I carry myself, the gesture, the words and the language that ties me to my past and so forth. The past changes under the pressures and influences of the present. As I make something of myself I may reinterpret who I once was and who I am now. The past changes itself because we live toward a future, which we already see taking shape of

which we suspect as a secret mystery of experiences (Van Manen 1997). The existential can guide the reflection by asking how time is experienced. The temporality and spatiality are mingled because space is an aspect of time and time is experienced as space. Time is also experienced as *telos*: the wishes, plans and goals for which a person strives for. The identity is experienced in terms of the times of our childhood, the periods of our working life or love life and so forth (Van Manen 2014).

The fourth existential is relationality, which is the lived relation we maintain with others in the interpersonal space that we share with them. We approach the other in a corporeal way: through a handshake or by gaining an impression of the other in the way he or she is physically present to us. When we meet we are able to develop a conversational relation, which allows us to transcend ourselves. In a larger existential sense, human beings search in this experience of the other for a sense of purpose in life, meaningfulness, and grounds for living as in the religious experience of God (Van Manen 1997). In reflection, it can guide us to ask how self and others are experienced. In the lived relation, family, love and friends and how a person experiences him or herself in a relation can be reflected upon (Van Manen, 2014). The last existential is materiality. The things are our world in its material things like reality. With almost any research topic we can ask how things are experienced and how do the experiences of this contribute to the essential meaning of the phenomenon. We see and recognise ourselves in the things of our world. Things tell me who I am. Things are extensions of our bodies and minds. Things can be intimate or strange and be on a different scale of importance. This existential may guide the reflection to ask how things are experienced (Van Manen 2014).

In the study, a hermeneutic phenomenological lifeworld approach was used as it allowed me as a researcher to establish a relation with the participants to investigate together with them their chosen lifeworld perspectives. When having an hermeneutic phenomenological approach in the study it was important that I was aware of own pre-understandings not taking over the understanding inappropriately, because of the challenges, when the participants' points of view were implied, embodied or explained in a different way from normal, or where the participants were not able to end sentences. However, my pre-understandings were also necessary to avoid the understanding becoming superficial, inconsistent and misunderstood because of incomplete sentences, different use of words and going back and forth in the telling. This made me a translator and catalyst, by using the pre-understanding in a more hermeneutic way. I tried to keep the pre-understanding in the background when necessary, but also allowed it in the participants' favour, to let their voices to be heard and understood. Within the study I was aware that the participants' lifeworlds were under pressure because of the dementia, meaning that elements of the lifeworld existentials might not be accessible. This reality restricted the entire research process.

Furthermore, Van Manen's four existentials: spatiality, corporeality, temporality and relationality inspired the analysis of the interviews with the participants². The four existentials guided the coding and analysis (See Chapter 4 and Chapter 6). A selective hermeneutic phenomenological analytical approach was chosen for the parts that revealed the meaning of the participants' lifeworld perspectives, related to person, memory and learning and relevant for informing the researcher about how to train and support the participants in the participatory research project. However, it could be seen as the beginning of the interpretation of the material, but this was not case as the existentials were planned to offer a lens through which I could uncover the essence of lived experience, without imposing categories, predetermined or predefined themes upon the interview material itself of what was considered significant to the lived experience. It raised my awareness for the lifeworld aspects and gave the analysis structure. The analysis was therefore not planned as a pure phenomenological lifeworld analysis with the aim to identify the essence of the phenomena of living with dementia instead the purpose was to get an insight in to their lifeworld perspectives with the aim to develop a participatory research model. Therefore, both phenomenological and hermeneutic elements were incorporated into the analysis in order to identify the themes within the interviews. As Van Manen argues all or much phenomenology has hermeneutic (interpretive) elements which meant that the analysis also included interpretation inspired from a more hermeneutic approach but which was compatible with Van Manen's hermeneutic phenomenology (Van Manen 2014). It moved the analysis beyond seeking purely descriptive categories of the perceived world in the narratives of the participants (Flood 2010, Kumar 2012, Van Manen 1997). It meant the analysis described and interpreted the interview material within a lifeworld context.

3.4. CONCLUSION

To summarise, this chapter describes the participatory methodological framework of the study, which focuses on collaboration between the researcher and the participants. Also different participatory research models are presented, showing the variety in how participatory research can be defined. This indicates the importance of defining how a research project is participatory in nature. Also the "*Partners in projects*" model and the "*Authentic partnerships*" model are outlined in the chapter as they inspired the participatory research project with the participants together with the defined participatory research phases identified in the literature.

Furthermore, human science and qualitative research are introduced as the participatory research project drew upon these approaches, illustrating how traditional

² The fifth existential the materiality was not included in the analysis because the book, "*Phenomenology of Practice: Meaning-giving methods in phenomenological research and writing*" (Van Manen 2014), where he accounts for the fifth existential was first launched in 2014 by when the interviews and analysis already were planned and conducted.

research approaches can be relevant within participatory research. Phenomenology, hermeneutics and hermeneutic phenomenology especially with a focus on Van Manen's approach are also introduced illustrating the researcher's attitude towards the research field. Furthermore, Van Manen's four life existentials inspired one of two analysis approaches within the study. It introduces the importance of both describing and interpreting in research.

The next chapter introduces the methods used within the study to illustrate how knowledge was gained in the study.

CHAPTER 4. METHODS

4.1. INTRODUCTION

Chapter 3 described the participatory methodological framework of the study together with the hermeneutic phenomenological lifeworld inspired approach and analysis.

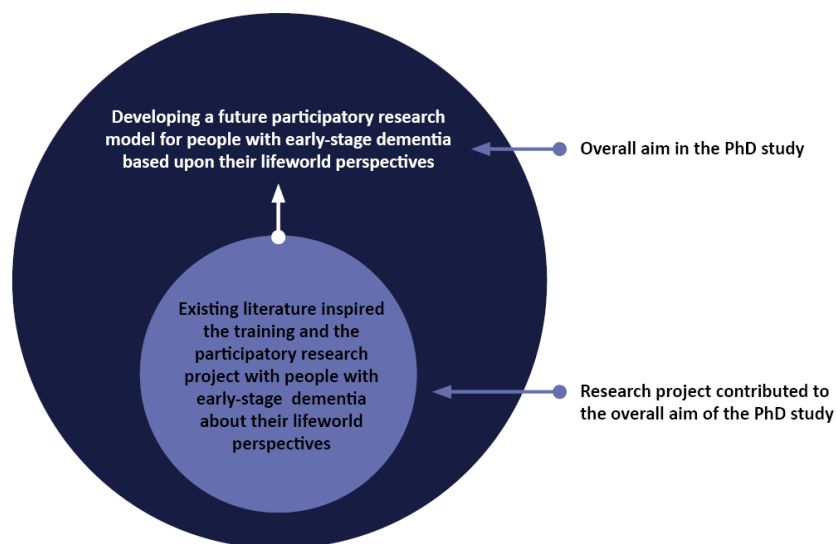
This chapter outlines the chosen methods for the study, illustrating how knowledge was gained in the project. In the beginning of the chapter, the context and the setting together with the organisation of the study are presented to give an understanding about the complexity of the study with its different levels and phases. The chapter then explains the recruitment and the ethical permissions necessary when involving people with early-stage dementia. The data collection methods are then described and justified. Qualitative methods were applied in the study, including participant observation, semi-structured interviews and focus groups, each designed to meet the participants' needs, enabling them to share their views. The analytical process is described, giving an understanding of how the analysis of the materials was conducted. The analytical approaches were a hermeneutic phenomenological lifeworld analysis inspired from Van Manen's four lifeworld existentials (Van Manen 1997) and the thematic analysis described by Braun and Clark (Braun, Clarke 2006).

4.2. CONTEXT

4.2.1 CURRENT STUDY

The aim of the study was to develop a future participatory research model, allowing people with early-stage dementia to have a voice in research. In order to achieve this, a participatory research project was conducted with people with early-stage dementia which served both as an independent study in its own right, and an opportunity for researching how to collaborate with people with dementia in research. See figure 4 for illustration of the study.

Figure 4: The project within a project in the study



The other project was to train for, and conduct, a participatory research project inspired by existing literature in the field, to inform the participatory research model. The participants with early-stage dementia focused on their lifeworld perspectives in the project. The organisation of the study was dynamic and flexible in accordance with the participatory methodology described in Chapter 3, so changes were made when necessary.

At an overall level an advisory group was established to discuss, comment and make decisions about the training, the participatory research project, and the analysis of data for the development of the participatory research model. Selected student participants also involved in the participatory research project were part of the group. The collaboration was characterised as cooperation where priorities were decided together, but the responsibility for directing the process was with me as the researcher (Milligan 2015). Decisions made in the advisory group influenced the pilot study. In this pilot study, testing was an ongoing activity with one former student at VUK with early-stage dementia not involved in the participatory research project. This ensured that the materials and methods were continuously developed and tested throughout the research process in accordance with a participatory process. It meant project sessions were piloted before introducing them into the participatory research project. The pilot study and the training and participatory research project were therefore conducted in parallel. Results from the pilot and participatory research projects were continuously discussed in the advisory group, allowing the training and project to develop constantly informing the next pilot. The organisation of the study is illustrated in figure 5.

Figure 5: Organisation of the study



The figure illustrates the circularity in the study, which supported the researcher to adjust the training and the participatory research project to the participants' needs.

4.2.2 RESEARCH PHASES

As described in the methodology chapter, the study was inspired by the principles and phases of participatory research and the models "*Partners in projects*" (Parkes, Pyer et al. 2014) and "*Authentic Partnerships*" (Dupuis, Gillies et al. 2012). A project diagram illustrates the phases in the study illustrated in Figure 6.

Figure 6: Project diagram



4.2.3 PHASE 1: RECRUITING AND ESTABLISHING RELATIONSHIP AND TRUST

In the initial stages of the study, an open and exploratory period existed to identify what organisation was relevant. During this period, I joined a class of students with early-stage dementia at VUK. The class reviewed and commented on drafts of information leaflets and consent forms before I finalised them. This exemplified a consultation process where the class gave their opinions and I decided what actions to take, based upon their contributions (Milligan 2015). At this stage, the students, teachers and I had the opportunity to familiarise with each other in an informal way. It was possible to explain the study in a sensitive and unhurried manner, allowing potential student participants time to ask questions. It established the level of competence to conduct the research (Bartlett, Martin 2002). Hereafter, two teacher advocates, one pilot participant and twelve student participants were identified and recruited. To establish trust and to develop a constructive relationship such as the one described in the “*Authentic partnerships*” model (Dupuis, Gillies et al. 2012) and to get knowledge about the recruited students and their competences and challenges in the teaching environment at VUK, a period of participant observation was conducted.

4.2.4 PHASE 2: PLANNING THE TRAINING AND THE PARTICIPATORY RESEARCH PROJECT

In order to support the active participation of the student participants in the research project, phase 2 focused on planning the training in research skills and the participatory research project. The planning was inspired by the literature review,

participant observations, and formal semi-structured interviews conducted with the participants in this phase. The focus of the interviews was to gain knowledge about the student participants in relation to person, memory and learning. Before the formal interviews a pilot interview was conducted, which showed that it was possible to conduct an interview while supporting the participant. The planned training was tailor-made for the student participants so that their attention, short-term memory problems and problems with taking in new information were carefully considered. Two identical personal folders, one for home and one for VUK, were created for each student participant with text, illustrations, visualisations, drawings and photographs. Each session was planned to start with allowing the student participants to have time to look in their folder, and recall what they worked on in the last session, giving them an opportunity to enhance episodic memories by generating opportunities to talk about the activities (Staniszewska 2009). The training was planned in the late morning, when people with dementia often have a clearer picture and more cooperation is possible (Mckillop 2004), thus giving them the best learning possibilities.

4.2.5 PHASE 3: INTRODUCTION TO PROJECT AND ESTABLISHMENT OF PROJECT GROUPS

Phase three focused on the training and participatory research project sessions with the aim to inform the participatory research model. To give the student participants the best learning opportunities, two focus groups were established: a Monday group with 6 students and a Tuesday group with 6 students (See Recruitment paragraph). In all sessions, video recordings and participant observation, from my perspective, were used. The purpose was to capture verbal and non-verbal signals about how the student participants received and experienced the training and research project. In the first introduction session, the role and type of partnership was debated. A pilot was done of the introduction, showing it was possible to discuss the topics within the session. The student participants' beliefs and values were discussed to gain a mutual understanding about the participatory research project and wanted results. I wrote this up in a collaboration agreement with agreed upon roles. This was in accordance with the "*Partners in projects*" model (Parkes, Pyer et al. 2014), and it laid the foundation for an equal partnership concerning the roles the student participants preferred as defined in the "*Authentic Partnerships*" model (Dupuis, Gillies et al. 2012). In the session, the student participants were also introduced to the personal folder.

4.2.6 PHASE 3.1: THE RESEARCH QUESTION

Session 2 focused on choosing a research idea and formulating the research question. The session was inspired by the "*Partners in projects*" model (Parkes, Pyer et al. 2014) focusing on what research was, research ideas and research questions. After the pilot, some minor changes were made to the explanations of what research ideas were, because it was confusing with too many explanations. In the session, the student participants chose a research idea from those they had brainstormed and ideas revealed

in the interviews conducted earlier. Two research questions appeared. The Monday group's research question was: "*How do we experience attending VUK?*" and the Tuesday group formulated the question: "*How is it experienced to live with dementia?*". The chosen research idea was decided by a democratic voting system, where I could not vote. This gave the student participants the voice as described in the "*Authentic partnerships*" model (Dupuis, Gillies et al. 2012).

4.2.7 PHASE 3.2: THE DATA COLLECTION METHODS

This session focused on inclusion criteria, research ethics and data collection methods inspired by the "*Partners in projects*" model (Parkes, Pyer et al. 2014). The pilot showed it was difficult to understand research ethics, even though it was simplified by using the familiar information leaflet and consent from the study. Highlighting the most important aspects with yellow in the information leaflet resulted in more clarity. The session with the student participants revealed that they, in collaboration with me, could formulate inclusion criteria and the highlighted points were helpful in discussion of research ethics, even though it was challenging. The student participants were introduced to four different qualitative data collection methods; interview with cue cards, story with a gap, storytelling with pictures and a diary. These methods were considered relevant based upon a brainstorming session, where the participants talked about how to find answers to their research questions. The results of this brainstorming session showed that structured qualitative methods, allowing their experiences to be investigated, were relevant to use as long as they supported their focus. Based upon this knowledge the above mentioned methods were presented. The participants did not participate in the decisions about finding methods since it was considered too difficult for them, not having any former experience of qualitative data collection methods. Both groups chose to work with interview with cue cards. Again democratic voting was used to choose the data collection method to ensure a synergetic relationship.

4.2.8 PHASE 3.3: THE DATA COLLECTION

Sessions 4 and 5 focused on designing the cue cards for interviews, practicing the interviews and conducting the interviews. For that reason the training and the data collection became a continuous process which is different from the "*Partners in projects*" model (Parkes, Pyer et al. 2014) where the whole training is delivered before a real research project is conducted. Because of the student participants' attention and short-term memory problems this was not considered appropriate. In the pilot it was possible for the participants to identify interview questions for the cue cards based upon a brainstorm. I as a researcher assisted the process by writing down the chosen questions, ensuring no duplication. Afterwards, the participants and I numbered the cards so they were structured in what was considered a natural order. Thereafter, the participants and I practiced the interviews. In the pilot it was difficult for the participant to keep the structure, even when using the numbered cards but it was not

difficult to answer the questions. It was acknowledged that further introduction to the interview was needed and therefore it was decided to illustrate the interview visually so it was easier for the participants to understand what an interview with cue cards meant. After the introduction where I demonstrated the interview with one student participant, all participants understood the structure and were able to interview and be interviewed using the cue cards. In the interview some needed support while others did it independently. All interviews were video recorded.

4.2.9 PHASE 3.4: THE PARTICIPATORY DATA ANALYSIS

Sessions 6-8 for the Monday group and sessions 6-9 for the Tuesday group focused on the data analysis. Before the analysis, I transcribed the interviews into typewritten text with big letters. Repeated words were removed and sentences with long pauses were simplified in content. The text was anonymised for each group with the interview question written first and the answers to the question afterwards. These precautions were taken to ensure an analysis was possible. It was anticipated that an anonymised coherent text would minimise the risk for the participants to get emotional. This approach worked successfully in the pilot.

The participatory data analysis was inspired by a thematic analysis, which is also presented in the “*Partners in projects*” model (Parkes, Pyer et al. 2014) but not taught on own data material in the training period. This method was chosen because it is a fundamental analytical method that both include description and interpretation – also without the use of theory (Braun, Clarke 2006). The analysis began with the participants and me reading the text and highlighting the phrases that they found relevant for their research questions. I wrote down the highlighted sentences on post-its and a data clustering was conducted by moving the post-its around in the order the participants thought correct. This meant that all post-its ended up by being grouped after themes and each theme was given a heading decided by the participants. Then the participants interpreted the themes from their own perspective, which was recorded.

Afterwards, the text was read again and the participants found quotes for each theme. When a quote was identified and accepted by the group I wrote it down. This data analysis was conducted in the pilot with one participant alone but was complicated in a group setting. The participants did not decide how to prepare the data material for the analysis neither did they decide about how to analyse the material. This was judged to be too difficult for them, not having any former experience in processing interview material and analysing it. Furthermore, it would have prolonged the process significantly if they had to prepare the data material for the analysis because of their reading and writing challenges caused by the dementia. After the sessions I wrote up the analysis for each group with their interpreted themes and quotes.

4.2.10 PHASE 3.5: PLAN THE DISSEMINATION

Session 9 for the Monday group and session 10 for the Tuesday group focused on preparing for the dissemination. The analysis was presented to the student participants and they were encouraged to be critical towards the text. In the pilot this was a very important aspect of the research process because the participant wanted the quality of the analysis to be acceptable for public disclosure. In this session the participants were also presented with three different creative methods to supplement their written analysis. The methods were: pictures, paintings and poems. I chose them based on the fact that visual illustrations and short texts could support the participants' memory about the identified themes. Both groups chose, by voting, to supplement their analysis with pictures and so did the pilot participant. I did not participate in the decision-making. The student participants brainstormed about what pictures they found essential for each theme and I drew an example to illustrate visually how the picture could look. It was then agreed that I found a picture that illustrated the example for their approval. This approach was different from the "*Partners in projects*" model (Parkes, Pyer et al. 2014) which focuses on designing a newsletter or poster.

Together it was decided to disseminate the results to fellow students at VUK and to a journalist and photographers from the local newspaper and television station. This was based upon their motivation articulated in the first session. The participant of the pilot decided to disseminate the results to his wife. I prepared the dissemination with the student participants by going through the written analysis and highlighting essential points. This was especially done in the Monday group. The Tuesday group did not find it necessary and there was a time pressure of getting the written analysis finished. Before the journalist met the participants the written analysis was presented to him to ensure a constructive dialogue with the participants.

4.2.11 PHASE 4: EVALUATION

In phase 4 the student participants had one session (session 10 for the Monday group and session 11 for the Tuesday group) where they approved the pictures I had found to supplement their analysis. This was done without any indications from me. In the pilot the participant found it very important that the used pictures illustrated the themes in the best way, otherwise they were rejected. Hereafter, the student participants evaluated the training and research project within their established focus groups. It was conducted as semi-structured focus group interviews aimed at an overall evaluation. I assumed that the interview questions would help them to remember and evaluate the process. The focus group interviews were conducted within their project groups because it allowed them to support each other in the evaluation. In the pilot a semi-structured interview was conducted revealing that the questions enabled to guide the participant to evaluate the process. This was different from the "*Partners in projects*" model where the participants evaluated via a questionnaire (Parkes, Pyer et al. 2014). During the whole process each session was

also evaluated in the focus groups with use of three questions related to the way each topic had been presented. This was in accordance with the “*Authentic partnerships*” model where regular critical reflection and dialogue is needed to develop a constructive working relation (Dupuis, Gillies et al. 2012).

4.2.12 PHASE 5: DISSEMINATION

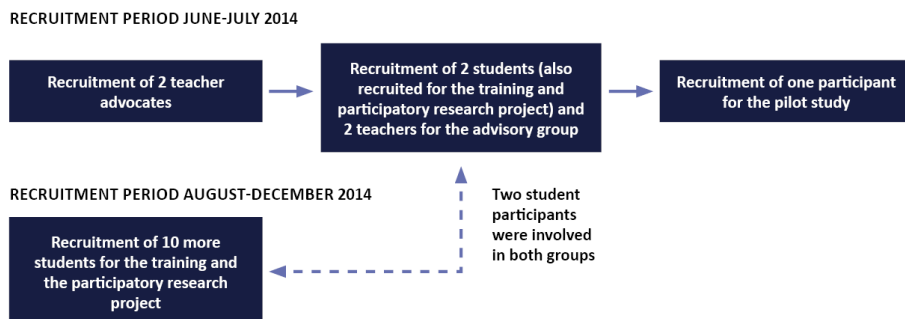
After the evaluation the student participants presented their results to their fellow students and celebrated the end of the project with coffee and cake. In the presentation, I supported the participants when needed. It was by giving key words, telling what came next and asking questions about the project work if the participants forgot what to say. In the pilot the participant was able independently to present the project work to his wife after the preparation. In relation to the journalist, informal interviews were conducted with some of the student participants to capture the results of their project work. In accordance with the “*Authentic partnerships*” model, all participants were supported to be able to raise their voice (Dupuis, Gillies et al. 2012). Finally, a report was delivered to the student participants with the results. This report included contact details of me to request more details if needed. This final step is not included in the “*Partners in projects*” model (Parkes, Pyer et al. 2014) because the participants are trained to conduct a project after the training.

4.3. RECRUITMENT STRATEGY

4.3.1 RESEARCH SETTING AND PARTICIPANT RECRUITMENT

The study was conducted in collaboration with the Adult School VUK in Denmark (VUK 2013) and the participants were recruited from this school. The school provided a safe and supportive atmosphere in which to conduct the study and enabled the researcher to work within an established organisation. The recruitment was characterised as being a convenience sampling also known as accidental or opportunity sampling. It is composed of who are readily available and easy to contact and provides participants and data quickly (Bjørner 2015a). To recruit from VUK, allowed me to collaborate with participants, who knew each other in advance in an environment well-known to them, meaning there were good opportunities for successful collaboration. It was also possible to recruit a certain number of people in a relatively short period of time, which otherwise can be challenging with vulnerable groups (Dewar 2005). Seen from a quantitative perspective, this recruitment was not a random representative group, which was not the gold standard in the study; instead the focus was on who had the capacity and willingness to be involved. All names of the presented participants are pseudonyms. Before the recruitment, the study was presented for both students and relatives at a social event at VUK in March 2014. The recruitment period lasted between June-December 2014 and is illustrated in figure 7.

Figure7: Participant recruitment



In June, two teachers (teacher advocates) were recruited to ensure the future recruited students would not be harmed in the study. They were familiar with the students, which was important if any unpleasant situations occurred e.g. situations with insecurity, sadness or aggressiveness. In such situations the teacher advocates were expected to support and shield the participant concerned if necessary. The Inclusion criteria for the teacher advocates are illustrated in box 4.

Box 4: Inclusion criteria for the teacher advocates

- Was an experienced teacher, who normally taught the students at VUK
- Had knowledge about the students' individual dementia progression
- Could conduct the Mini-Mental State Examination test (MMSE-test)
- Was willing to act as the students' advocate

See table 3 for illustration of the recruited teacher advocates with pseudo names.

Table 3: Recruited teacher advocates

Recruited teachers	Gender	Age	Occupation	Teaching experience in dementia
Teacher advocate 1	Female, Eva	57	Social and health care assistant	23 years
Teacher advocate 2	Female, Lisa	60	Teacher	5 years

Two teachers and two students were recruited in the same period to establish the advisory group. The inclusion criteria for the teachers are illustrated in box 5.

Box 5: Inclusion criteria for the teachers

- Was an experienced teacher, who normally taught the students at VUK
- Had knowledge about the students' individual dementia progression
- Was willing to contribute to research about dementia

The recruitment of the teacher advocates and teacher participants were discussed with the Head at VUK and I was allowed to recruit in accordance with the inclusion criteria. The recruitment of the two students to the advisory group is described later when the recruitment of other students is described. See table 4 for illustration of the recruited teacher participants with pseudo names.

Table 4: Recruited teacher participants

Recruited teachers	Gender	Age	Occupation	Teaching experience in dementia
Teacher participant 1	Male, Keld	52	Teacher, diploma in dementia	10 years
Teacher participant 2	Female, Helen	48	Psych motoric therapist and social and health care assistant	1½ years

A pilot study was conducted with one individual, who was a former student at VUK. This student could not participate in the main study because he decided not to attend VUK, but he was interested in the study. It was decided to include the former student as a pilot participant because he was familiar with VUK and the teaching environment. The pilot participant was recruited using the same inclusion criteria as the student participants (see below). The participant decided not to have a teacher advocate supporting him in the recruitment process. See table 5 for illustration of the recruited pilot participant with a pseudo name.

Table 5: Recruited pilot participant

Recruited student	Gender	Age	Occupation	Type of dementia	Marriage status
Former student	Male, Hans	82	Managing director	Alzheimer's disease	Married

The teacher advocates were actively involved throughout the recruitment of the student participants to ensure they were recruited in ways which met their needs and ongoing changing capacity. The inclusion criteria for the student participants are illustrated in box 6.

Box 6: Inclusion criteria for the student participants

- Was diagnosed at least 6 months before recruitment
- Had an early-stage dementia
- Could give an informed written consent
- Was aware of the diagnosis and its implication i.e. memory problems and was comfortable about talking about the situation
- Was interested in cognitive training
- Was willing to contribute to research about dementia

Potential student participants were screened by the teacher advocates using the inclusion criteria, and every potential student participant was discussed between the teacher advocates and I to ensure a student had the ability to participate. Participants, who met the criteria, were then approached by me, informed about the study remit, and invited to participate.

In total, 15 potential student participants (65-82 years old) with early-stage dementia were invited to take part. Three of those decided not to participate. Examples of the reasons cited for this included escalating experience of cognitive decline and acute illness in the family. Three of the 15 potential participants decided to have a teacher advocate with them in the recruitment period for different reasons; one because of difficulties in finding words, another for general support, and a third because of support to me. Two student participants participated in both the advisory group and the participatory research project. Their position, in both groups, was seen as a way to ensure continuity in the study. The study therefore had 12 student participants, including three women and nine men, reflecting the normal distribution of male and female students with dementia at VUK. They were divided in two groups a Monday group with 6 students and a Tuesday group with 6 students. See table 6 for illustration of the recruited student participants with pseudo names.

Table 6: Recruited student participants

Recruited students	Gender	Age	Occupation	Type of dementia	Marriage status
Johan (Tuesday + advisory group)	Male	68	Electrician	Alzheimer's disease	Divorced
Ernst (Monday + advisory group)	Male	65	Bricklayer	Vascular dementia	Married
Victor (Tuesday group)	Male	74	Nursing assistant	Alzheimer's disease	Married
Emma (Tuesday group)	Female	76	Nurse	Alzheimer's disease	Widow
Elsa (Monday group)	Female	73	Librarian	Alzheimer's disease	Widow
Bent (Monday group)	Male	79	Auditor	Unspecific dementia	Married
Henrik (Tuesday group)	Male	66	Pedagogue	Unspecific dementia	Married
Jette (Tuesday group)	Female	78	Teacher	Alzheimer's disease	Widow
Wilhelm (Monday group)	Male	74	Director	Unspecific dementia	Married
Peter (Monday group)	Male	72	Engineer	Vascular dementia	Married
Ove (Monday group)	Male	74	Lifeguard security	Alzheimer's disease	Married
Kurt (Tuesday group)	Male	72	Trade union	Unspecific dementia	Married

4.4. ETHICAL PROCESS

The framework of the study and permission to conduct the participatory research project was agreed with the adult School VUK (Appendix 1). Also registration and approvals were gained from The Committee on Health Research Ethics of the Northern Region in Denmark, and The Danish Data Protection Agency (in liaison with the relevant University Committees) (Appendix 2, 3). Further considerations about ethics in participatory research with people with early-stage dementia are discussed in the following chapter.

4.5. DATA COLLECTION PROCESS

4.5.1 PARTICIPATORY METHODS

Participatory research is an approach more than exact methods and it is possible to use both qualitative and quantitative methods within participatory research (Stacciarini, Shattell et al. 2011). The methods used in the study were well-established qualitative methods as participant observations, semi-structured interviews and focus groups with use of video recordings. The methods were applied in different phases of the study and modified within the participatory framework to secure the methods suited the student participants. Participant observation

4.5.2 PARTICIPANT OBSERVATION

Participant observation was used in the study to shed light on the student participants' lifeworld at VUK, revealing the competences and challenges they experienced (Appendix 4). The observation period lasted from August to September 2013 with observations of one class for 25 hours in total. Participant observation collects data in naturalist settings, to observe and take part in the activities of the participants being studied. It gains insight into the relations, behaviours, processes and activities of people (Bjørner 2015a, Hammersley, Atkinson 2007), covering complex interactions and social norms and giving a deep understanding of their needs, values and behaviour (Groes 2015). In the study, observations gave me a first impression about the participants' competences and challenges.

In ethnographic research, the most suited method to the situation to be investigated emerges out of the situation because it is discovery driven rather than hypothesis driven. The researcher begins with broad topics of investigations, and more specific areas of interest and research questions are formulated as part of a cyclical research process (Hubbard, Downs et al. 2003). In the study detailed field notes were written structured after: Program, activities, persons, interactions, competences and challenges. The field notes were written, when with the students, allowing them to ask questions about the notes and their use in the study. Video recordings were not used in the observation period because I anticipated it could disturb the establishment of a

trusting relationship. In observations the knowledge gained depends on the relationship between the participants and the researcher. Empathy is therefore central in participant observation (Groes 2015), because observation can become erratic, as the observer becomes familiar with and responds to the research setting (Bowling 2013, Vallgård, Koch 2011). The researcher here needs to resolve challenges within the fieldwork notes, and also continuously reflect upon the fieldwork practice (Hammersley, Atkinson 2007).

The field notes were analysed from the structure used during the observation period with focus on identifying questions for the following interviews. Using participant observation allowed the participants to formulate their views and experiences in a less demanding way than communicating in an interview. Studies have shown that observation can be relevant to use with people with aphasia and dementia. It can shed light on what is meaningful to individuals with dementia (Hubbard, Downs et al. 2003, Müller 2009) by allowing them to communicate in their own way because in an observation period there is less expectation on either the researcher or the participants to focus on specific questions or talk about particular topics. Topics of conversation can arise from everyday situations, and is embedded in the actuality of daily events (Hubbard, Downs et al. 2003). By using participant observation, the participants could decide what relation they wanted towards me and what they wanted to communicate.

4.5.3 SEMI-STRUCTURED INTERVIEWS

Semi-structured interviews were used in the study to gain a deeper understanding of each student participant, focusing on lifeworld perspectives related to person, memory and learning (Appendix 5). In the interviews, my pre-understanding of each student participant was needed, to help the person to fully explain themselves, meaning the knowledge gained from the participant observations were used in the interviews. Together the observations and interviews supported the participants to express themselves in terms of the differences between learning and memory before and after the diagnosis of dementia, and how the teaching environment was experienced at VUK.

The qualitative interview is a professional conversation that has a structure and purpose. By using interviews, a systematic approach to generating new knowledge about phenomena in the social world is achieved (Kvale, Brinkmann 2009). In a qualitative interview, the researcher listens to what the interviewees talk about, focusing on their experiences in their own words. Interviews enable the researcher to explore persons' interpretations of daily events, and to elicit subjective accounts of their daily experiences (Hubbard, Downs et al. 2003). It enables an insight into subjectivity, voice and lived experiences (Rapley 2007). The semi-structured interviews help focus the interview on important aspects (Kvale, Brinkmann 2009) by using an interview guide with questions arranged with themes. It also allows

additional questions in response to participants' answers and reactions in the interview situation (Bjørner 2015a).

Interview, as a method, is popular amongst researchers to find ways of ensuring the views of people with dementia (Mckillop 2004, Pratt, Wilkinson 2003). It is possible for people with dementia to participate in interviews, when their cognitive impairment is taken into consideration (Mckillop 2004). The interviews were scheduled at a time convenient for the student participants, and lasted no longer than one hour. They were conducted in a separate classroom at VUK, so the environment was known and comfortable for them. It is important to be aware that the ability to verbally communicate can vary from day-to-day, within the same day, and from one week to the next. A flexible interview schedule is therefore important as is an awareness of the body language shown by the participants, for example anxiety or embarrassment if they cannot remember the answers to questions (Mckillop 2004). On the other hand, interviews can also be a positive experience, providing an opportunity to reflect and talk about events (Mckillop 2004). The interviews helped to tailor the training and participatory research project together with the knowledge gained from the literature review and the participant observations as it revealed more about their personality and their experienced competences and challenges when living with dementia.

4.5.4 FOCUS GROUPS

Focus groups, characterised by being a discussion and a working group using different creative elements were used in the training and participatory research project. Focus groups capitalise on the interaction within a group to elicit rich experiential data (Kevern, Webb 2001). It explores issues that require the knowledge and expertise of those the research concerns because it gives them an opportunity to voice their opinions (Darling, Parra 2013). The group interactions involve discussion and hearing from others and give participants an opportunity to refine what they have to say. This is useful in research requiring creative thinking, solutions and strategies (Lewis, Nicholls 2014). It encompasses a wide range of practices – from formal structured interviews with people assembled around clearly delimited topics to less formal, more open-ended conversations (Kamberelis, Dimitriadis 2013). Newer types of focus groups include creative elements and alternate between individual and collective activities and between writing and talking (Brunnberg 2013).

The focus groups allowed the student participants to have a voice and to be inspired by each other. In a focus group, the researcher can be more or less interventionist by raising topics directly, calling some participants and holding off others, cutting off lines of talk that seem unproductive and challenging some apparent contradictions or vagueness (Macnaghten, Myers 2007). The researcher guides the participants as they work through the agenda. Typically focus groups are a mixture of structured and less structured moderating styles, active/directive and passive/nondirective approaches (Bjørner 2015a). In the focus groups, I functioned as a moderator who tried to

establish an authentic partnership. Focus groups are frequently applied in participatory research where a group of research participants are given the opportunity to enter into conversations with each other in a safe setting (Salmon 2007). An open dialogue can be the central starting point for an entire participatory research project where the participants can get to know each other. It addresses concerns regarding researcher privilege, and the sharing of power in research settings, allowing the co-construction of meaning between the researcher and participants, generating high-quality interactive data (Salmon 2007). I used a creative and participatory type of focus groups as I assumed it would support the participants' voice, while acknowledging the need for co-construction of knowledge through a supported dialogue.

After each session I wrote down field notes of what was observed and experienced during the sessions with the purpose of structuring the analysis. The focus group work contributed knowledge about how to conduct participatory research with people with early-stage dementia. In the overall evaluation more traditional focus groups with semi-structured interview questions were used (Appendix 6). The evaluation also contributed to the aim of the study.

4.5.5 VIDEO RECORDING AND TRANSCRIPTION

Video recordings were made of the semi-structured interviews and focus groups in order to capture both direct quotes from the student participants and relevant non-verbal signals. Video recording is often used for observations because it captures situations as they happen in real time and provides the opportunity to watch the situation repeatedly afterwards. It can provide information about non-verbal behaviour and about the context, meaning that some of the conditions and circumstances of the situation can be captured as well (Bjørner 2015a). The use of video recordings minimised the risk of misinterpretation of the participants' thoughts and views. Videos can be used to reflect on the research process, essential for developing new inclusive methodologies because it can record both successes and failures (Cook 2003, Knight 2005), which was relevant for the development of a participatory research model. Unfortunately, studies using video recordings to observe people with dementia have not included them in the research process (Aggarwal, Vass et al. 2003, Cook 2003, Skovdahl, Kihlgren et al. 2003). However, video observations are useful when involving older people with dementia in participatory research processes (Cook 2003, Knight 2005) and then used carefully, they are a powerful research tool, which can both add to the understanding of dementia and include people with dementia in the research process (Cook 2003).

The video recordings of the interviews were transcribed by a student familiar with research at University College of Northern Denmark. I checked every transcription to ensure that no misunderstandings had occurred during transcription. The video recordings of the focus groups were examined and I transcribed significant video sequences for further analysis, also including relevant non-verbal signals. No copies

of the transcriptions were shown to the student participants for approval because it would be difficult for them to read, reminding them of the progression of dementia. The quotes reproduced in the thesis were translated without correcting the language used, illustrating the participants' language problems but at the same time being truthful to their way of explaining themselves. The proof reading was conducted with assistance from University of Northampton, which was bound by confidentiality.

4.6. ANALYSIS

Two different analytical methods were chosen in the study on a pragmatic basis relevant for the scope of the study. The hermeneutic phenomenological lifeworld perspective with the four lifeworld existentials: spatiality, corporeality, temporality and relationality was used to analyse the interview material as it opened up the participants' lifeworld perspectives (Appendix 7). This analytical approach allowed the lived world to be explored as it was experienced by the participants, offering the researcher knowledge about the participants' lifeworld perspectives relevant for conducting the participatory research project. The lifeworld existentials were used as a coding and analytical framework to gain a deeper insight into the abstract components of the participants' lifeworld perspectives and to manage the tension between remaining close to the particular experiences of the participants while at the same time retaining enough critical distance to appreciate the differences and similarities that emerged. This was supposed to bring different elements into focus at different times in order to achieve and support a holistic understanding of lived experience (Rich et al. 2013). The use of the four existentials was not aimed to impose a set of predetermined themes or categories upon the interview material but rather provide guidance in the understanding of the phenomenon under investigation, allowing an inductive and bottom-up approach. It was important to stay true to the interpretive nature of interpretive inquiry and to support methodological trustworthiness (Plazas et al. 2016).

A thematic analysis was used to analyse the material collected from the focus groups, as it is a useful method in participatory research with participants as collaborators. The results of a thematic analysis are generally also accessible to public (Braun, Clarke 2006). Thematic analysis is the most useful analysis method in capturing the complexities of meaning within textual data. It is also the most commonly used method of analysis in qualitative research (Guest et al. 2012). Thematic analysis focuses on identifying, analysing and reporting both implicit and explicit themes and patterns that emerge around living and behaviour important to the description of the phenomenon (Braun, Clarke 2006, Fereday, Muir-Cochrane 2006, Guest et al. 2012) (Appendix 8). It is a form of pattern recognition within the data, where emerging themes become the categories for analysis. It is about recognising important moments with qualitative richness of the phenomenon relevant for interpretation. It describes patterns across qualitative data without being theoretically bounded and is relevant for interpreting subjective viewpoints within focus group discussions (Braun, Clarke

2006, Fereday, Muir-Cochrane 2006). The thematic analysis was used within the study to reveal the motivations, expectations, opinions, experiences and needs of the focus groups when collaborating in a participatory research project. It focused on knowledge relevant for developing a participatory research model.

Different from a phenomenological analysis, a thematic analysis can build theoretical models and solutions to real world problems. It is relevant to use with larger data sets as it can highlight similarities and differences across the data, it can generate unanticipated insights and study topics other than individual experiences (Braun, Clarke 2006, Guest et al. 2012). Whereas a phenomenological analysis is suitable in analysing subjective human experience and meaning. It is relevant to use with smaller data sets as it is a more deeply analysis (ibid). This indicates the reason why I chose to use two different analytical approaches within the study as the purpose of the analysis of the interviews was to capture the participants' lifeworld perspectives with focus on understanding the participants' everyday experiences of life. Whereas the analysis of the focus groups was to identifying themes relevant for developing, a participatory research model based upon the focus groups' work and collaboration, showing both similarities and differences across the data. Here a thematic analysis is relevant as it is suitable for participatory research and for model development.

It can be argued that thematic analysis and Grounded theory is very similar to each other and when Grounded theory is used in a way that is essentially Grounded theory "lite" - as a set of procedures for coding data it is very much akin to thematic analysis. Such analyses do however not fully subscribe to the theoretical commitments of a "full-fat" Grounded theory, which requires analysis to be directed towards theory development (Holloway, Todres 2003).

4.6.1 THE LIFEWORLD INSPIRED ANALYSIS

Van Manen describes six analytical "*steps*" within an analytical process but sees the analysis as a process of recovering structures of meanings that are embodied and dramatised in human experience represented in a text. To analyse the thematic meanings of a phenomenon is a complex and creative process of insightful invention, discovery and disclosure. Grasping and formulating a thematic understanding is therefore not a rule-bound process but a free act of seeing meaning (Van Manen 2014).

In the beginning of an analysis the thematic aspects in the lifeworld descriptions are discovered by asking "*What is going on here?*" and "*What is the essence?*". The researcher reads the text several times searching for themes (Van Manen 1997, Van Manen 1984). By examining the text different thematic formulations are attempted, followed by constructing a list of themes (Van Manen 1997). Next the thematic statements are isolated by finding the statements and phrases that express something about the theme (Van Manen 1984). A way to isolate thematic aspects of a phenomenon in a text is to use the selective approach. Here it is asked: "*What*

statements seem particularly revealing about the phenomenon or experience?''. Sentences or part-sentences that seem to thematise the experience under investigation is found (Van Manen 2014, Van Manen 1997). Then commonalities between the themes and finding the statements and phrases that capture the experience are identified. Some beginning emerging themes may recur as commonalities in the descriptions, and these themes are captured by noting appropriate phrases or singular statements in the experience described (Van Manen 1997).

Composing linguistic transformations by composing phenomenological paragraphs in a hermeneutic process is the next step. As the themes are found the work begins by capturing the thematic statements in more phenomenological sensitive paragraphs. Notes and paragraphs are written on the basis of reading the texts and other research activities. Composing linguistic transformations are a creative hermeneutic process (Van Manen 1997, Van Manen 1984). The next step is cleaning the thematic descriptions by grasping the essence in the phenomenological description. The source of all the analysis is the experiential lifeworld of human beings. It transcends the experiential world in an act of reflective existence (Van Manen 1997). Determining essential themes from incidental themes is the last analytical step. Here collaborative discussions with others can help in generating deeper insight and understanding. In determining the essential of a theme it is necessary to discover aspects or quality of a theme that make a phenomenon what it is and without which the phenomenon could not be what it is. Here the method of free imaginative variation is used to verify whether a theme belongs to a phenomenon (Van Manen 1997, Van Manen 1984).

These analytical steps and the four defined life existentials in the methodology chapter (Van Manen 1997) were the analytical approach towards the interviews in the study. The lifeworld existentials offered a method through which to navigate and manage the interview material. They offered a counterbalance to data immersion and, in particular, my familiarity and closeness with the data (Rich et al. 2013).

The analysis started with all twelve interview transcripts being uploaded into NVivo. NVivo is a software programme that facilitates organising, analysing and finding insights in unstructured qualitative data like interviews and videos. It allows marking themes across the uploaded data (QSR International 2016). In the beginning of the analysis the transcripts were read several times, focusing on getting an overview over the material by asking *“What is going on here?”* and *“What is the essence?”*. Notes and comments were written in annotations within NVivo when something interesting and surprising were identified in each transcript and across the transcripts. This gave an overview of the material.

Hereafter the transcripts were read several times and each transcript was coded using the four life existentials (spatiality, corporeality, temporality and relationality). The lifeworld existentials were used as a coding framework through which to begin to explore and organise the data. One lifeworld existential was chosen at a time and used

as a lens through which to examine all transcripts, one after the other. This process allowed all of the interviews and existentials to be approached on an equal footing, not privileging one over the other but granting them all the same importance (Rich et al. 2013). This showed some existentials were more relevant than others. Each existential was coded with a unique colour and node across all transcripts. The earlier annotations supported the coding and further annotations were written within NVivo. Following this process, an open coding process was performed within the lifeworld existentials. This was characterised as a renewed coding of each transcript – it was a “recoding” or in-depth coding. This focused on identifying the themes emerging from the data related to each existential. This ensured a bottom-up perspective. A list of themes was derived for each existential by using unique coloured child nodes and annotations based on the first overall coding. Then the themes were isolated, selected and consolidated. The statements and phrases which revealed something about the themes were found and written down, illustrating the essence and content of each theme.

Differences in perspectives were also captured to reduce the possibility of positive over-interpretation regarding consensus about the themes in the analysis. Different opinions regarding the themes were noted. This was done outside NVivo where nodes assumed in NVivo were used to locate statements that captured the fundamental meaning of the identified themes. Hereafter the meaning of the different themes was interpreted based upon the four lifeworld existentials. During the process discussions with the advisory group took place and no major differences were identified between the researcher’s and the advisory groups’ understanding of the themes. In the final stage all the analysed material was looked through to ensure that there was coherence and connection between what was interpreted and what the material said.

In table 7 the coding and the analysis of one existential, relationality, is illustrated with the in-depth coding “*The role of the family*” and “*Social relations and activities*” that emerged after coding the existential. The in-depth coding informed the theme “*We still live an active and social life regardless of difficulties*”.

Table 7: Example of the analysis process

Lived relations/re-lationality	The role of the family	Notes	Social relations and activities	Notes	Theme
<p>Interviewer: <i>“So you have good help in your wife?”</i></p> <p>Bent: <i>“Definitely”</i></p> <p>...</p> <p>Bent: <i>Also in my children”</i></p>	<p>Interviewer : <i>“So you have good help in your wife?”</i></p> <p>Bent: <i>“Definitely”</i></p> <p>...</p> <p>Bent: <i>Also in my children”</i></p>	<p>Bent talks positively about his family and the help he receives from his wife and children. No frustration seems to be present. He is aware of his need of help.</p>			<p><i>“We still live an active and social life regardless of difficulties”</i></p>
<p>Bent: <i>“Well it is, that we, we come together”</i></p> <p>...</p> <p>Bent: <i>“... that it's great. We can talk with all people ...”</i></p>			<p>Bent: <i>“Well it is, that we, we come together”</i></p> <p>...</p> <p>Bent: <i>“... that it's great. We can talk with all people ...”</i></p>	<p>Bent appreciates to be social and talk with people with dementia - They are sociable.</p>	<p><i>“We still live an active and social life regardless of difficulties”</i></p>

Bent: "... <i>one must be careful - you do not sit down and then say to yourself: "Now it's good enough that over there..."</i>			Bent: "... <i>one must be careful - you do not sit down and then say to yourself: "Now it's good enough that over there..."</i>	Bent explains the impor- tance of being active and not give up	<i>"We still live an active and social life regardless of difficulties"</i>
--	--	--	--	--	--

The three other existentials were coded in the same way as illustrated in table 7, which led to identifying in total five essential themes within the analysis. See table 8 for the identified themes.

Table 8: The identified themes

Themes	Characteristics
<i>“We live a social and active life regardless of difficulties”</i>	Describing how they try to live a social and active life despite the dementia
<i>“We try to look at the bright side of life with dementia”</i>	Describing how they try to get something positive out of life
<i>“It takes time to adapt, at the same time we are losing time”</i>	Describing their struggles with overweighing time
<i>“We can still learn but it is challenging”</i>	Describing their struggles with learning after getting dementia
<i>“We try to remember but keep forgetting”</i>	Describing their struggles with their short-term memory

4.6.2 THEMATIC ANALYSIS

In the study a thematic analysis inspired by Braun and Clarke were used to analyse the focus group transcripts. The thematic analysis is a foundational qualitative analysis method (Clarke, Braun 2013) which is widely-used. Unfortunately, there is no clear agreement about what a thematic analysis is and how it is conducted (Tuckett 2005). Braun and Clarke (2013) argue that it is an analytical method without adherence to any particular theory or framework (Guest, MacQueen et al. 2012), which means it can be used across a range of epistemologies from essentialist to constructivist and across a range of research questions. It is a flexible method for identifying, analysing and reporting themes within data (Rasi, Künzler-Heule et al. 2014). Interpreting various aspects of the research topic. It is appropriate for research questions around people’s experiences and understandings and can be applied to produce data-driven or theory-driven analysis (Braun, Clarke 2006, Clarke, Braun 2013, Taylor, Ussher 2001).

Thematic analysis is not wed to any pre-existing theoretical framework and can be used within different theoretical frameworks (Braun, Clarke 2006). It is driven by the analytical question and the flexibility of the method allows determining themes in different ways as long as consistency is applied. It is possible to use the analysis for rich thematic description of the entire data to get a sense of any predominant themes but it can also be used to provide a more detailed and nuanced account of a group of themes within the data. This might relate to a specific area of interest within the data

(a semantic approach) (Braun, Clarke 2006). The themes can be identified in one of two primary ways – inductive or deductive (theoretical). An inductive approach means the identified themes are strongly linked to the data themselves by coding the data without trying to fit it into a pre-existing coding framework or analytical preconceptions. In the deductive thematic analysis, the analysis is driven by a theoretical or analytical interest in the area and is thus more explicitly analyst-driven, meaning data is coded for quite specific research questions. It provides a more detailed analysis of some aspect of the data (Braun, Clarke 2006).

The themes can be identified at two levels – the semantic or the latent level. With a semantic approach the themes are identified within the explicit meaning. The researcher is not looking for anything beyond what a participant has said (Braun, Clarke 2006, Frith, Gleeson 2004). At the latent level one identifies the underlying ideas, assumptions, conceptualisations, and ideologies that are theorised as shaping the data. The development of the themes themselves involves interpretation and the analysis is already theorised. It tends to come from a constructionist paradigm and in this form thematic analysis overlaps with some forms of discourse analysis (Braun, Clarke 2006).

Thematic analysis can be conducted within both realist and constructionist paradigms. In a realist approach motivations, experiences, meanings and realities of the participants can be theorised straightforwardly because a simple largely unidirectional relationship is assumed between meaning, experience and language. This is in contrast to a constructionist perspective where meaning and experience are socially produced and reproduced rather than inherent within individuals. Therefore thematic analysis conducted within a constructionist framework cannot focus on motivation or individual psychologies but seeks to theorise the socio-cultural contexts and structural conditions that enable the individual accounts (Braun, Clarke 2006). The overall research question drives the project and it can be very broad, supplemented with narrower questions. These narrow questions may be part of a broader overarching research question. If they are, then the analysis of these narrow questions can provide answers to the overall research question. Thematic analysis involves searching across data to find repeated patterns of meaning. The exact form and product of a thematic analysis varies. Those who consider specific aspects, latent themes and are constructionist tend to cluster together, while those who consider meanings, embrace the whole data set, semantic themes and are realist orientated often cluster together (Braun, Clarke 2006).

In the study the analysis was related to a specific area of interest, which meant a selective analysis of essential episodes was conducted. It meant a detailed analysis of some aspect of the data was coded. The approach was inductive with deductive elements because the themes emerged and were discovered from data (a bottom-up and data centred approach) but at the same time I was driven by an analytical interest in the area looking at specific episodes that said something about the training, the

research environment, the support mechanisms and the learning and understanding gained through the research process with the aim of developing the participatory research model. The level of analysis involved a progression from identifying the themes on a semantic level to interpret the themes on a latent level where the significance of the patterns and their broader meanings and implications were found. The focus was on motivations, expectations, opinions, experiences and needs of the participants. The episodes were not selected using a quantitative saturation principle where the selection continues until no new or relevant information emerges but after identifying the episodes that allowed an in-depth analysis. The analysis of a small set of video observations can be considered a limitation (Høiseth, Keitsch et al. 2014) but in the study it was regarded as an advantage because the main criterion for the selection was not to represent typical examples but to maximise what could be learned to inform the participatory research model. According to Morse (1995) a crucial principle for understanding the process of saturation is that the richness of data is derived from detailed description not the number of times something is stated.

The analysis was conducted within a participatory methodological paradigm possible with thematic analysis. Apparently participatory research, other forms of co-operative research and social constructivism resemble each other. They share the same critique that conventional research often justifies the position and interest of the powerful (Lincoln 2007). Within the social constructivist orientation it is assumed that individuals construct their own realities and meanings from their culturally available language and subjective experience to make sense of their daily lives (Braun, Clarke 2006). This correlates with the participatory methodological framework used to look at the way the interaction and collaboration was constructed within the participatory research project. This was analysed both in a straightforward way but also in relation to the meaning being produced and reproduced socially within the groups.

According to Braun and Clarke, the researcher familiarises with data in the first phase by reading the data repeatedly searching for meanings and patterns. This provides the basis of the analysis, where notes and ideas of initial analytical observations are written down (Braun, Clarke 2006, Clarke, Braun 2013). In phase two the initial codes are generated inspired by the initial list of ideas from phase 1. The codes identify what is interesting and refer to the most basic segment of the raw data that can be assessed in a meaningful way regarding a particular phenomenon. The coding organises the data into meaningful groups (Tuckett 2005) guided by the research question. The phase ends by collating all the codes and relevant data extracts (Clarke, Braun 2013).

Moving on to phase three the researcher looks for themes in the list of codes. Here the analysis is re-focused at a broader level of themes, sorting the different codes into potential themes to form overall themes. A collection of candidate themes and sub-themes are identified (Braun, Clarke 2006). The phase ends by collating all the coded data relevant to each theme (Clarke, Braun 2013). In phase four the themes are reviewed and refined. During this phase some themes are recognised as not being

themes while others might collapse into each other or be broken down into separate themes (Braun, Clarke 2006). When the refinements do not add something substantial new to the analysis it is time to stop. The themes should tell a convincing and compelling story about the data and begin to define the nature of each individual theme and the relationship between them (Clarke, Braun 2013). The next phase is about defining and naming the themes. The essence of each theme is identified and the aspect of the data each theme captures is determined. Collected data extracts for each theme are re-visited and organised into a coherent and internally consistent account with accompanying narrative. It is vital to identify what is interesting about them and why (Braun, Clarke 2006). For each theme a detailed analysis is conducted. In the end of this phase themes and sub-themes are defined clearly and named (Clarke, Braun 2013). In phase six the final text is produced based on the themes and involves the final analysis and write-up. Here the focus is to relate the story of the data in a way that convinces the reader of the merit and validity of the analysis (Braun, Clarke 2006).

The beginning of the analysis process started with focusing on the whole. This meant all materials including video recordings of the focus group sessions and the field notes taken immediately after each session were seen and read several times in their entirety to get an overview of the material. The aim was to familiarise and capture a first understanding of the material, searching for meanings and patterns (Braun, Clarke 2006). In total the video material included 10-11 video sessions for each project group and the length of each video recording ranges from 1½ to 2 hours. Condensed notes were written about what was going on in each session and comments were written where something of interest appeared for further analysis. The aim was to understand certain episodes, the complexity of human relations and how these revealed information relevant about the motivations, expectations, opinions, experiences and needs of the project groups relevant for developing the participatory research model. The notes and field notes with comments were coded in hand with different colours. The field notes, the condensed notes and comments gave an overview of which episodes were relevant for further analysis. Selected video sections were identified and analysed separately after several viewings were completed. A video section was chosen when judged to be relevant to the aim of the study. The episodes selected were related to the research process conducted, which meant the themes were explored within phase 3 where the participatory research project was established, conducted and disseminated.

In the analysis chapter the analysis also includes a description of the process of the training and research project together with the analysed themes. It provides a general overview (the broad narrative) together with an in-depth presentation of central themes (the detailed narrative). The themes are described in relation to the sessions where they were most pertinent, ensuring that the research model captured the whole research process. The chosen Monday and Tuesday groups' video data episodes were analysed together showing both similarities and differences between the two groups.

The selected video sections were uploaded in NVivo and transcribed with both verbal and non-verbal signals. Afterwards, the transcripts were coded. Comments were written in annotations and an in-depth coding of the material was completed, focusing on emerging themes. It re-focused the analysis at a broader level of themes sorting the different codes into potential themes to form overall themes. A list of themes (overall themes and sub-themes) was made by using nodes, child nodes and annotations which captured the extracts of data coded. Each code had a unique colour and node used across all transcripts. The statements and phrases which told something about the themes were then written up, illustrating the content of each theme. Here nodes and child nodes resumes were taken out of NVivo from a selective approach by locating the statements that captured the fundamental meaning of the identified themes. Next the themes were reviewed and refined and the essence of each theme was determined. Hereafter the meaning of each theme was interpreted. In this process, discussions about the themes with the advisory group were also conducted. No major differences were identified between the researcher's and the advisory groups' interpretations. In the final text the themes identified in the project phases formed different paragraphs.

In table 9 the analysis of the theme, *"Others don't have a clue, let's change it"* is illustrated. The theme emerged from collapsing the initial potential themes *"Get knowledge"*, *"Make a difference"*, *"Seeking and spreading information about dementia"* and *"Self-development"* coded in the *"Introduction to project work and establishment of the project group"* session.

Table 9: Example of the analysis process

Initial potential themes	Comments	Theme
Get knowledge Bent: <i>"We th... I personally think that it is only good that you find out something"</i>	Bent is positive towards a knowledge production about dementia and it seems to be his motivation for participating in the participatory research project	<i>"Others don't have a clue, let's change it"</i> Explaining a motivation for getting more knowledge about dementia

<p>Make a difference</p> <p>Elsa: <i>"There are really many who have no idea what it is we're talking about ... you get sad that people have no idea, nor will familiarise themselves with it, even though you are relatives and are close together and so on, so they are, to put it bluntly so so stupid"</i></p>	<p>Elsa is very motivated for participating in the participatory research project because she has experienced that people and relatives around her do not know anything about dementia. She wants to change the ignorance. She gets sad when she is met with ignorance or arrogance</p>	<p><i>"Others don't have a clue, let's change it"</i></p> <p>Explaining a motivation for changing the existing culture of ignorance and arrogance about dementia</p>
<p>Seeking and spreading information about dementia</p> <p>Kurt: <i>"And what it is named and what it is you do not remember and things like that. That I think is very interesting and particularly interesting because when we know it, it is something we can tell others about it"</i></p>	<p>Kurt thinks it is possible for them to gain more knowledge about dementia by participating in the participatory research project. This will help them understand the illness better with the purpose of informing others about dementia so they can learn</p>	<p><i>"Others don't have a clue, let's change it"</i></p> <p>Explaining a motivation for getting more knowledge about dementia with the purpose of informing others about dementia</p>
<p>Self-development</p> <p>Emma: <i>"You will probably such a thing because you think you can use it for something that can do good and happiness and even develop oneself ...more"</i></p>	<p>Emma talks about the possibility of learning and self-development for her own sake by participating in the participatory research project. She sees that as a possibility for life with dementia</p>	<p><i>"Others don't have a clue, let's change it"</i></p> <p>Explaining a motivation for getting more knowledge for own learning and self-development</p>

Six themes emerged from sub-themes within the analysis of the research process and they were named after essences within each theme. The themes were written within each project phase section. This is illustrated in table 10.

Table 10: The identified themes and its organisation

Project phase section	Theme within this section	Characteristic
Introduction to project work and establishment of the project group	<i>“Others don’t have a clue, let’s change it”</i>	Describing the student participants’ motivation towards the participatory research project
The data preparation sessions	<i>“You may be our conductor”</i>	Describing the student participants’ need of support in the research project
The data collection and analysis sessions	<i>“We are still the same even though we are not the same”</i>	Describing the experiences of dementia and how it influences daily life
The data collection and analysis sessions	<i>“To be with the likeminded is liberating”</i>	Describing their positive and supportive relationship
The prepare dissemination, evaluation and dissemination sessions	<i>“Why does it have to be so negative?”</i>	Describing their relaxed and humoristic attitude towards others and the dementia
The prepare dissemination, evaluation dissemination sessions	<i>“It is nice that some will collaborate with us”</i>	Describing their gratitude towards the researcher for including them in meaningful research activities

4.7. CONCLUSION

To summarise, this chapter outlines how the aim of the study was achieved, illustrating a project within a project. The overall aim, which was to develop a

participatory research project model, was informed by a participatory research project with people with early-stage dementia and an in-depth literature review. The study was organised in five phases, illustrating a whole participatory research process. For the participatory research project, two teacher advocates were recruited to ensure the student participants would not be harmed in the study. Also a pilot participant was recruited along with twelve student and two teacher participants. An advisory group was established to ensure the study was participatory. The data collection methods used in the study were participant observations, interviews and focus groups with the use of video recordings to allow verbal and non-verbal signals to be captured. The methods contributed to knowledge about the individual person, memory and learning (participant observations and interviews) and with the interaction and collaboration within a participatory research process (focus groups). The analysis of the interviews was inspired by Van Manen's hermeneutic phenomenological lifeworld analysis and four life existentials. The analysis of the focus groups was inspired by Braun and Clark's thematic analysis.

The following chapter describes the ethical considerations that are essential when conducting a participatory research project with people with early-stage dementia.

CHAPTER 5. ETHICS

5.1. INTRODUCTION

Chapter 4 outlined the chosen methods in the study, illustrating how knowledge was gained through the project.

The ethical issues associated with working with people with dementia in research are varied and wide-ranging. This chapter, whilst discussing the intricacies of these issues, provides evidence that with careful consideration, consultation and planning, people with dementia are able to be involved. At the beginning of the chapter the ethics around involving people with dementia in research is outlined with the purpose of showing the ethical considerations that exist when planning research with this group. Thereafter ethical actions about how to inform the group, assess the ability to give informed consent and gain an ethical justifiable informed consent from people with early-stage dementia are discussed. Finally, moral sensitivity all throughout the research process is described as a way of conducting research in collaboration with people with dementia to ensure that the group is not burdened unnecessarily.

5.2. ETHICS AND DEMENTIA RESEARCH

5.2.1 ESTABLISHING THE RESEARCH PROJECT

Normally, risk and avoiding harm is a part of the ethical considerations in research (Beauchamp, Childress 2013). It is important to be aware that involvement in research can stress participants mentally and socially. However, it can be difficult to forecast the harm or risk in a qualitative study, which requires a high level of attentiveness in practice (Heggstad, Nortvedt et al. 2012). Beuscher and Grando (2009) describe three key obstacles to qualitative dementia research: Determining capacity to provide informed consent, engaging in effective communication and ensuring credibility of data (Beuscher, Grando 2009). These present challenges in conducting research in dementia as the illness threatens the rationality and independence of a person. Consequently, it challenges the way we normally see research interaction and collaboration in the Western World where we generally anticipate it to be based on rational autonomous individuals (Whitehouse 2000). If a researcher wants to involve people with dementia it must be accepted that the collaboration can take different forms from normal qualitative research collaborations. At the same time it is essential to ensure the participants' dignity in these forms of collaboration (Hellström, Nolan et al. 2007). In the study, I was aware of the challenges the dementia caused based upon the observations and interviews conducted. This knowledge was useful when planning the training and participatory research project as it made me aware of the need of modifying the project to a supported peer-research project (See Chapter 4),

which was different from a traditional qualitative study. It is important to be aware of what type of project that is realistic to conduct when involving people with dementia and plan in accordingly.

When including people with early-stage dementia ethical challenges may be encountered from planning to dissemination and many are not possible to foresee. A lot depends on how the participants react to the research process and researcher (Heggestad, Nortvedt et al. 2012). Unpredictable ethical challenges can arise e.g. interviewees may tell sensitive or inappropriate personal details to a researcher in an interview or the researcher may become aware of inappropriate carer and partner behaviour (Carmody, Traynor et al. 2015). This can challenge the research tremendously. Another issue is that whilst it might be hard to achieve public involvement the task becomes even more daunting when attempting to engage people with dementia (Martin, Augusto et al. 2013). In addition, the stigma associated with dementia can increase the challenges, a problem which can be unintentionally heightened by the terminology used by researchers (Bull, Lesley Boaz et al. 2014). In the study, it was possible to engage the participants with early-stage dementia relatively un-problematically because I used convenience sampling (See Chapter 4) and recruited from VUK where the participants already knew each other. I anticipated, it was relevant to identify a place where the potential participants already attended and used a convenience sampling to ensure enough people were recruited.

One could argue that people with early-stage dementia should not be involved in research where there is potential for harm. However, studies show that inclusion of people with dementia provides beneficial, even therapeutic, effects (Bartlett, Martin 2002, Clarke, Keady 2002) as feeling valued and as being taken seriously as capable persons boosts self-esteem (Hellström, Nolan et al. 2007). Evidence also suggests that benefits from participation in research can outweigh the drawbacks (Thornton 2006). Berghans and Ter Meulen (1995) argue that a distinction between therapeutic and non-therapeutic research can be a way to decide whether it is ethical to involve people with dementia in research or not. Therapeutic research may benefit while non-therapeutic research has no direct benefit for the person. As a result, non-therapeutic research involving people with dementia is argued to be immoral as it does not benefit them (Bartlett, Martin 2002, Berghmans, Meulen 1995). On the other hand, people with dementia continue to be marginalised if they are never involved in research (Heggestad, Nortvedt et al. 2012). I assume the consequence can be that they continue to have a silent voice with an unvoiced agenda. Thus, it can be argued that research with persons with dementia which do not harm them and is not against their interest can be justified even if they are unable to give consent. This view is supported by Agarwal et al. (1996) who argue that providing research is acting in peoples' interests and if a study has no side-effects then, unless a person has actively expressed a desire not to participate, it is unlikely to violate their fundamental rights (Agarwal, Ferran et al. 1996). Howe (2012) argues that a general rule is as follows - the greater the risk,

the stronger a person's capacity to consent should be, meaning informed consent is less important if there are no risks associated with the research.

Contradicting this view, Bartlett and Martin (2002) argue that harm is indeed caused if researchers intervene in others' lives without their knowledge, intruding their privacy and that certain conditions have to be met before non-therapeutic research with people with dementia is justified. See box 7 for justification of non-therapeutic research involving people with dementia.

Box 7: Justification for non-therapeutic research

- The research cannot be conducted with a less vulnerable population
- The research must be scientifically sound and promising with a reasonable expectation of benefit for future persons with dementia
- The research must imply no more than minimal burdens and risks for the participant
- The informed consent by a legal representative of the person must be given if the person is not able to do it
- Researchers should be sensitive to verbal and non-verbal signals showing symptoms of distress resulting from the research

(Bartlett, Martin 2002, p. 53-54)

Furthermore, it is also relevant to determine in advance what constitutes a refusal by a participant to ensure a participant is not overheard (Howe 2012). In the study, the five conditions were understood as important guidelines but it was also seen as important to involve people with dementia in research in general so they are not only involved in research when it cannot be done by others. Similarly, the consent to participate in research has first to be sought from the person wherever possible as many people with dementia are capable of expressing their desire to participate in research and engaging in consent discussions (Cubit 2010). They should therefore be asked for some sort of consent, even if proxy consent is used, to show respect for the person being recruited. This study was characterised as being a non-therapeutic research project as it did not include any therapeutic gains for the participants. It was regarded as being very low risk because it included collaboration between the researcher and the participants about their lifeworld perspectives chosen by them. For that reason, I judged it was necessary to involve people with early-stage dementia in the research, because they were the experts of living with the illness. A participatory research model based upon the lifeworld perspectives of people with early-stage dementia could not be explored from the perspective of others; those who live with dementia pose a unique expertise that enhances deliberations, provides insights and

valuable contributions (Thornton 2006). I anticipated that the knowledge gained through the study would benefit people with dementia who want to participate in research activities, showing the ways in which this is possible. As a researcher, I saw it as an ethical duty to enable them to be active contributors in the research project, while acknowledging that protection against distress was needed. I reviewed the risks of harming the group and considered whether it could be planned so that it engaged the participants to ensure more knowledge about dementia was gained from the perspective of those living with the condition.

The main challenge of research is how to engage people with dementia and minimise the risks for them when taking part (Martin, Augusto et al. 2013). One way to respond to this is by taking a person-centered approach which acknowledges that people with dementia have rights for their experiences to be explored through research (Downs 1997) (See Chapter 2). Robinson who has dementia emphasises the point:

“What a hugely missed opportunity it would be if people with Alzheimer’s were excluded from the very thing that could be used to gain a fuller understanding of their disease” (Robinson 2002, p. 104)

This shows that people with dementia see they have something to contribute and this is acknowledged in the person-centered approach. The approach also reflects the participatory methodological framework in the study which also highlights the importance of listening to the participants as experts of living with dementia (see Chapter 3). For that reason, it was natural to include the person-centered approach in the planning of the research process based upon the knowledge gained through the observations and interviews. If research with people with dementia is not conducted because of ethical challenges no new knowledge about how dementia is experienced by those living with it will be gained. This can increase their vulnerability and may be unethical and a threat to their dignity, being a form of dis-respect (Heggestad, Nortvedt et al. 2012). However, more knowledge about dementia may reduce the stigma associated with the condition and lead to more openness around it. It is therefore important that the researcher sees research ethics as a continuing concern when dealing with people with dementia (Heggestad, Nortvedt et al. 2012). In the study, the person-centred approach was not just planned to be used in the consent process but also in the project work to ensure they were respected, their points were heard and that they were supported in an appropriate way.

Four ethical principles can be helpful when conducting research with people with dementia. The principles are respect for autonomy, beneficence, non-maleficence and justice (Beauchamp, Childress 2013). The respect for the autonomy includes the right for an individual to make his or her own choice. The individual is seen as a rational agent making informed and voluntary decisions. They have the capacity to act intentionally, with understanding, and without controlling influences that would mitigate against a free and voluntary act. This principle is the basis for informed consent (Beauchamp, Childress 2013). Beneficence is the principle of acting with the

best interest of the other in mind, including taking positive steps to prevent and remove harm. These duties are viewed as rational and self-evident and are widely accepted as the goal of medicine. Non-maleficence is the principle that “*above all, do no harm*”, as stated in the Hippocratic Oath. It requires that we do not intentionally create harm or injury to others. In common language, it is negligent if one imposes a careless or unreasonable risk of harm upon another. Justice is a concept that emphasises fairness and equality among individuals. It implies the fair distribution of goods and requires that we look at the role of entitlement (Beauchamp, Childress 2013).

Relating to these four principles it was important in the study that the participants with dementia could make their own choices around participating and were enabled to give informed consent. I saw it as my duty to prevent any harm for the participants engaged in the research by minimising the risks to a minimum. Justice ensured that each participant had a due and the benefits and risks were balanced in the study. To have their due every effort was made to ensure that their voices were sought and included. The study was planned in accordance with these four principles to ensure it was ethically justified. However, more research is needed on how to solve ethical research questions in practice if researchers want to show the participants with dementia respect for their autonomy and privacy (Heggestad, Nortvedt et al. 2012). Until now the published dementia research literature often lacks clarity regarding ethical issues such as informed consent and data collection procedures (Bartlett, Martin 2002). This is set against a backdrop of extensive theoretical debate about the ethical issues of obtaining informed consent from people with dementia, offering little in terms of practical guidance for researchers (Cubit 2010). This study contributes practical considerations about the consent process based upon the knowledge gained through the research process.

5.3. ETHICS AND CONSENT

5.3.1 INFORMING PARTICIPANTS

Helping the individual to understand research information as fully as possible and checking whether the person understands the information are prerequisites for obtaining informed consent. Important conditions for obtaining consent are sufficient time and information compatible with cognitive capacity. In general, people with impaired cognitive functions have poor information recall of important issues related to research (Meulenbroek, Vernooij-Dassen et al. 2010), which means it can be a task to explain what the research is about to potential participants with cognitive challenges. Further, the cognitive impairment is often accompanied by visual, auditory and language deficits and constraints making acquiring understanding and adequately weighing the information provided difficult (Meulenbroek, Vernooij-Dassen et al. 2010). It is important that the information is presented as clearly as

possible and is given interpersonally because it puts the potential participants at ease probably because it increases their level of understanding (Howe 2012).

Many researchers have used visual, auditory and hearing aids such as pictures, vignettes, storybooks and audio- and videotapes; however, these aids can distract rather than being an aid for people with dementia. The use of multimedia and enhanced consent forms has also limited success (Meulenbroek, Vernooij-Dassen et al. 2010). On the other hand, Howe (2012) argues that visual diagrams, pictures and information presented in an interactive way can be relevant when used in conjunction with person-to-person interaction. Meulenbroek et al. (2010) also argue that educational sessions, videos or drawings can enhance decision-making capacity. Awareness of or experiences with the research methods also improves competency to consent (Meulenbroek, Vernooij-Dassen et al. 2010). In the design of the materials, forms and procedures it is important to consider effective strategies to improve the understanding of informed consent information. The information can be given verbally or in writing. A good relationship with the participants may enhance understanding and it is important to have enough time for informing so the participants understand the pros and cons of participating in the research project. It can also be helpful to allow family and friends to support the person to understand the information given. Language is important as well so that the person can retain the information long enough to make a decision. Here visual prompts or cues such as leaflets, notebooks, photographs or videos can be beneficial. To use a conversational, rather than an interview tone, can also support understanding (Murray 2013).

In the design of the information leaflet and consent form it was important to consider effective strategies to improve the understanding of the information about the study. Participant information leaflets and forms to consent were designed for the teacher advocates, the pilot participant and the teacher and student participants. A separate information leaflet was also designed for the students' relatives. To counteract the fact that the student participants' capacity to consent might be limited because of their cognitive impairment, the written information leaflet and the consent form were written in an accessible style, and reviewed by a class of students with early-stage dementia at VUK. The written information was designed to match the reading ability and comprehension of the participants and feedback was requested on these elements. To test the information material and consent form with the group wanting to engage in the research was a way to ensure that the materials were easy to understand. The information leaflet outlined the research, aim, methods and what was being required of the participants, and that their identity would be confidential and anonymous, together with contact details of the researcher (Appendix 9). It was explained that it was possible to first decide to take part, and secondly to withdraw at any time without any repercussions (World Medical Association 2013). Information regarding the research, confidentiality and the ability to withdraw at any time was repeated several times during the research process to ensure that the participants knew they had the ability to withdraw from the project (World Medical Association, 2013).

Each participant was informed separately about the study, and the information leaflet and consent form was introduced. Thereafter, the participants had the opportunity to decide whether to be involved in the research or not, and it was explained that non-participation would not influence on their attendance at the school; for the teachers, that it would not impact on their employment. Potential student participants were given a week to reflect on the information before a second visit was made to the school; the rationale was that participants opted in to rather than out of the project to reduce any pressure that they might feel to participate. The teacher advocates supported this process, ensuring that the student participant understood the information and voluntarily gave informed consent. They followed up on the information given when necessary when they spent time with the student participants, having opportunities to talk face-to-face to the participants as part of their normal teaching. Furthermore, they conducted a *Mini-Mental State Examination* test (MMSE-test) and a teacher advocates' feedback on the MMSE scores before consent was gained (See Gaining consent section). I found it was relevant to ensure that the participants had enough time to consider participation and had opportunities to discuss it with others who had insight in to the project to help make a decision.

In some earlier research involving people with dementia, it was argued not to focus on the diagnosis when informing about a study if the participants did not mention it themselves. The fear of mentioning the diagnosis built on an assumption that this harmed the participants because of the stigma associated with it (Hansen, Hughes et al. 2008). An important issue then became whether a person was informed or not and whether the person was aware of the diagnosis (Heggstad, Nortvedt et al. 2012). This was not the case in the study. Not to inform the participants that the study was about their lifeworld perspectives of living with dementia was considered unethical because one of the main principles in research ethics is to give full information about the research. If a researcher does not provide full information it may be interpreted as deception. By deception one violates both the principle of autonomy and the principle of telling the truth. Deception demonstrates a degree of disrespect toward the participants and may undermine the trust that serves as a basis for all human interaction. It may also be seen as an abuse of power. Telling the truth is one of the most fundamental principles in the ethics of duty (Heggstad, Nortvedt et al. 2012). I therefore talked openly about the fact that the participants were included in the research because of their dementia which did not surprise them because they had received the diagnosis of dementia and it was not possible to attend VUK without one (VUK 2013). As a researcher, I found it was important to pay attention to whether the participants were aware of their dementia or not. I was aware that I had to manage the situation if some expressed that they were not fully informed about their diagnosis. However, it never became an issue in the study.

5.3.2 GAINING CONSENT

A cornerstone in research ethics is to obtain voluntary informed consent (Bartlett, Martin 2002) based on a full understanding of the research (Heggestad, Nortvedt et al. 2012). This is stated in both in “*The declaration of Helsinki*” (World Medical Association 2013) and “*The Nuremberg Code*” (The Nuremberg Code 1949). The informed consent process includes three stages; receiving information, understanding the information and giving a response voluntarily (Hellström, Nolan et al. 2007, World Medical Association 2013). This means a participant with dementia has to be fully informed and has the capacity to understand the implications of taking part in a study. Considerations have to be made regarding capacity (Hellström, Nolan et al. 2007) because consent can only be informed when a person has cognitive ability to understand the information presented and to consider the implications of a decision to participate or not (Cubit 2010).

Alzheimer Europe’s policy standard on research ethics in dementia research includes informed consent issues, challenging the researcher who has to meet the current legal and ethical standards and at the same time ask a person with dementia about informed consent (Meulenbroek, Vernooij-Dassen et al. 2010). Unfortunately, when it comes to research with people with dementia there is no sharply defined consent requirements (Howe 2012), which is problematic as one of the most challenging issues when involving people with dementia is obtaining an informed consent in a moral and ethical way. To be moral and ethical includes the respect of human rights and dignity (Cubit 2010). Even though ethical guidelines exist, and may be useful in the consent process, they introduce various terms which may be interpreted and implemented differently (Meulenbroek, Vernooij-Dassen et al. 2010). Today, no consensus exists regarding how to recruit and obtain consent for people with dementia.

Vulnerability includes the risk of exploitation and impaired ability to understand information. Research involving vulnerable groups should therefore only be undertaken when careful consideration has been given to the potential risks and benefits to a person (Cubit 2010) because it is important that the rights of vulnerable groups are protected (Bartlett, Martin 2002). In the “*European legal informed consent framework*” and the “*Guidelines for Good Clinical Practice*” it is stated that mentally incompetent individuals should not be included in research, with the exception of research that is necessary to promote the health of the population represented, and which cannot be performed on legally competent persons (Meulenbroek, Vernooij-Dassen et al. 2010). In the UK “*The Mental Capacity Act*” states that people are deemed capable unless there is evidence to the contrary. If there are any doubts an assessment needs to be made of the person’s ability to: understand what decision needs to be made and why, understand the likely consequences of making the decision, understand, retain, use and weigh up the information and to communicate this (Murray 2013).

A two-stage test of capacity can be completed when the capacity to make a decision has to be decided. Stage one asks: *“Does the person have an impairment of, or a disturbance in their mind or brain?”*. Stage two asks: *“Does the impairment or disturbance mean that the person cannot make a decision when needed to?”*. Here it is determined if the person understands the information given, retains the information long enough to make a decision, weighs up the information available to make a decision and finally communicates the decision made (Murray 2013). Consequently, the consent process becomes longer, which also was the case in the study. Here the recruitment period lasted seven months even though a convenience sampling was used. A long recruitment period can be case when engaging people with dementia.

As a consequence of the complexity in gaining consent from people with dementia, they are often excluded from research (Hubbard, Downs et al. 2003), even though a diagnosis of dementia does not necessarily indicate incapacity to give consent. McKillop (2004), who has dementia and has participated in several research projects, argues that it is important to ask persons with dementia themselves, and give them a choice instead of the carers (McKillop 2004). In previous research, carers were used as a proxy on behalf of their relatives who had dementia (Clarke, Keady 2002, Hellström, Nolan et al. 2007). This approach is outdated and not in line with a person-centered approach, limiting the autonomy, the dignity and the individuality of a person with dementia (Murray 2013). It can result in others acting in a way to maximise what they think is best for the person as opposed to expressing what they believe the person wants (Howe 2012). In addition multiple layers of protection have surrounded people with dementia, where family caregivers feel that they protect the person with dementia from situations that might be upsetting, avoiding threats to their self-image (Fisk, Wigley 2000). Building trust with the person with dementia and the family caregiver is therefore essential in the consent process (Bull, Lesley Boaz et al. 2014). It means the informed consent process is about both establishing rights and privacy for the participants and about establishing mutual trust between the researcher and the participants. Otherwise systems of protection can reduce rather than increase opportunities to have a voice in research (Burns, Hyde et al. 2014), which can erode the person’s autonomy, and contribute towards a process of infantilisation (Hellström, Nolan et al. 2007). It illustrates a paternalistic attitude, which disempowers people, who have made their own decisions throughout their lives (Bartlett, Martin 2002). To claim beforehand that a person is not competent because of a diagnosis is discriminating and the person deserves a fair evaluation of his or her competences (Heggstad, Nortvedt et al. 2012, Meulenbroek, Vernooij-Dassen et al. 2010), being regarded as competent person until demonstrated otherwise (Clarke, Keady 2002, Hellström, Nolan et al. 2007).

In the study, the proxy consent was not used as it was seen as unethical not to gain consent from those participating in the research because in the early-stage of dementia, the cognitive impairment causes only slight deterioration of performance (Videncenter for demens 2013). To give the participants the opportunity to give

consent instead of using proxy informants ensured that the autonomy and integrity of the participants was maintained. I focused on designing the information leaflet and consent form in a way understandable for the group. To avoid any conflicts of protection, the relatives were also informed about the study. They were seen as supporters in the consent process because the participants had time to discuss the participation with relatives at home before giving consent. As a researcher I considered ways in which people with dementia could give consent to avoid using proxy consent as standard when involving them in research.

Another issue to be aware of is that existing ethical procedures and protocols can replicate and reinforce rather than offer alternatives to ideas of people with dementia as passive subjects of research, who are assumed dependent and vulnerable (Burns, Hyde et al. 2014). Ethical processes, procedures and protocols while ultimately protecting research participants' rights, can simultaneously prevent these voices from becoming heard within research and exclude participation. It can result in constraining the voice and the development of more egalitarian relations (Burns, Hyde et al. 2014). However, guidelines are necessary when involving people with dementia in research so they not are excluded per se or included in research inappropriately. It is about balancing the procedures and protocols with the precise group of participants the researcher is recruiting.

In the study, some participants found the consent process rigid and questioned why it was necessary with so many ethical precautions. This indicated that the ethical considerations were experienced by some as patronising. Nevertheless, the abilities of comprehension, making judgments, reasoning and remembering may become increasingly impaired during the progression of dementia. The ability to understand and consider the consequences of involvement in research will decline and thereby capacity to informed consent may be affected. An assessment may therefore be necessary (Cubit 2010, Hubbard, Downs et al. 2003). I considered it ethical for the participants in the study to give informed consent based upon the result of an assessment conducted beforehand, revealing mental capacity to consent. Capacity is a legal term that is linked to understanding information, making choices and communicating these. A person's capacity to consent is where one reflects on the participants' ability to understand the nature of the research, the consequences of their participation and judge if a reasoned choice is made (Cubit 2010).

However, there is no standard for assessing capacity and only limited empirical evidence on assessment of capacity to consent exists. Thus most research groups have limited experience with the development of informed consent procedures, but the topic is increasingly discussed because dementia research is expanding (Meulenbroek, Vernooij-Dassen et al. 2010). It can be difficult to determine a person with dementia's capacity to provide informed consent (Cubit 2010) because it depends both on the cognitive capacity of the individual but also on the design of the study, both of which can challenge the ability to consent. People with mild to moderate dementia have been

shown not to understand proposed medical treatments suggesting that some with dementia have problems with the capacity of understanding especially when the dementia is more severe (Cubit 2010, Howe 2012). Conversely, research has shown that people with early-stage dementia can give informed consent e.g. a longitudinal study showed that 92% of people with mild dementia could give consent (Karlawish, Kim et al. 2008). This shows that people in the early-stages can give informed consent; however, understanding declines in the moderate stage of dementia (Karlawish, Kim et al. 2008). Thus there is a great need for valid, reliable and efficient instruments and procedures to assess capacity to consent when involving people with early-stage dementia (Cubit 2010).

Different ways to assess capacity in terms of levels of memory and orientation are used in research to help determine whether these have an effect on the decision-making. The MMSE-test is the most widely utilised screening tool for dementia (Lacy, Kaemmerer et al. 2015) and is often used to assess capacity to consent, though limitations of MMSE are documented (Fisk, Wigley 2000, Howe 2012) (Appendix 10). One problem with the test is the high false-negative rates where studies have shown that people with Alzheimer's disease can perform perfectly in the test. It seems to be particularly insensitive to subtle cognitive deficits and is not a valid screening tool for early-stage Alzheimer's disease or mild cognitive impairment. There is also evidence that MMSE scores are mediated by age and educational attainment. Consequently, a lack of clarity remains as to what score may indicate impairment and for whom. More robust assessments especially for delayed recall are needed (Lacy, Kaemmerer et al. 2015). Furthermore, the MMSE does not capture the full picture of a person's competence to give consent (Heggestad, Nortvedt et al. 2012) as a person with dementia can go in and out of lucidity and confusion, which means the results may vary from one day to another. Another important perspective is that people who take the test can find it humiliating and experience it as threat to their dignity (Heggestad, Nortvedt et al. 2012). This can have a negative impact on how they see themselves. To experience a decline in a score can be difficult to handle, reminding them of the progression of the illness. The UK's National Institute for Clinical Excellence also states it is not clear to the extent to which the MMSE is accompanied by real-life functional changes that are meaningful to persons (NICE 2001), which indicates that the MMSE-test is not a full proof test when assessing the ability to give informed consent.

In the MMSE test, people who get a score of 27 or above (out of 30) are considered normal. If the score is between 10-26 it is defined as mild to moderate dementia, a score between 10-20 is defined moderate dementia, and a score less than 10 is defined as severe dementia (Alzheimer's Society 2012). However, it is important to be aware that a person's capacity is not only about understanding but also about appreciating what they are consenting to. It may differ greatly from how a person performs in the test. In one report some patients who scored 26 or more did not have sufficient

capacity to participate in research determined in a separate clinical interview. In contrast, two persons who scored 19 had the capacity (Warner, McCarney et al. 2008).

Another screening tool is the “*MacArthur Competence Assessment Tool for Clinical Research*” (MacCAT-CR), which is often described as the gold standard of measuring capacity to consent (Howe 2012, Walaszek 2011). The instrument is based on discussing the research study over a course of 15-20 minutes, where information is gathered about the potential participant’s understanding, appreciation, reasoning and ability to express a choice (Hellström, Nolan et al. 2007, Walaszek 2011). The central idea of the instrument can be applied in most consent procedures but the implementation of the whole instrument is resource consuming and requires specific training (Howe 2012, Meulenbroek, Vernooij-Dassen et al. 2010). At the same time it also risks, as the MMSE-test, not capturing the day to day variation (Hellström, Nolan et al. 2007). A third well known screening tool is “*The Behavioural Assessment Scale of Later Life*” (BASOLL). It assesses the level of self-care, memory, orientation and perceived challenging behaviour of people with dementia with the purpose to assess the capacity to provide informed consent (Bartlett, Martin, 2002). All these tools rely on an indirect assessment where another person makes an assessment and from this determines whether the person with dementia is capable in giving consent. This takes the power away from the person to make their own decisions. At the same time it is important to be aware that cognitive tests do not necessarily give any indication of the abilities to talk about life, experiences and needs (Hellström, Nolan et al. 2007), which are relevant topics in qualitative research (Carmody, Traynor et al. 2015).

Another way to assess the capacity to consent is to have a person to person interview with the participant prior to the study (Howe 2012) or involve a professional who knows the person with dementia as it captures a more holistic evaluation of the capacity to consent. It requires comprehensive knowledge about the person over time (Heggstad, Nortvedt et al. 2012, Hellström, Nolan et al. 2007). A judgement can explore people’s awareness of the procedure they have been through, adjustment and level of acceptance of their memory loss, retained verbal fluency, level of concentration and competence and ability to give informed consent (Keady, Williams et al. 2005). The evaluation of the results from a test and a judgement can result in a valid answer to the question of whether an individual is competent to consent (Meulenbroek, Vernooij-Dassen et al. 2010). When evaluating the capacity of consent it is essential to discuss the study with the potential participants more than once since some may only understand after discussing it several times. The person assessing the capacity of consent must also try to ascertain whether or not the person is repeating what those around him or her say, which can be seen in some cases with people with Alzheimer’s disease (Howe 2012). The problem with assessments is that on one hand the judgement on capacity to consent is done in general but it can only judge the ability for a specific situation (Meulenbroek, Vernooij-Dassen et al. 2010) and it only assesses hypothetical vignettes (Meulenbroek, Vernooij-Dassen et al. 2010).

Consequently, some participants who can give consent risk being assessed as incompetent and hence disempowered. As the capacity to make decisions may vary it is important to be sensitive to what the participants understand and to renegotiate the consent constantly (Heggstad, Nortvedt et al. 2012).

In the study, it was acknowledged that some would not benefit from being included in the research project, and protection was needed in giving an informed consent, but at the same time they were regarded competent until demonstrated otherwise. Therefore, both an MMSE-test and a teacher advocates' feedback on the MMSE scores were used to demonstrate whether they were able to give a voluntarily informed written consent. The MMSE-test was used despite the fact that its use has been criticised. Its use should protect the participants by contributing knowledge about their ability to consent and to read, write, understand, interpret and solve a task which were all competences needed in the research project. The test was therefore not so much targeted at placing the participants on a dementia scale (early, middle or late) but to assess their ability to be involved in the participatory project being developed. I anticipated it would give an overall picture of the person's cognitive ability, and at the same time, the participants were familiar with the test, since it is used in Denmark (Sundhedsstyrelsen 2015b) and at VUK. Thus I assumed that the test would not be a threat to the participants' self-image because the teacher advocates could conduct the test as they were trained in its use.

To supplement the test a teacher advocates' feedback on the MMSE scores was also done as it allowed daily variations to be identified. The teacher advocates' knowledge about each participant ensured all participants' competences were seen so that a low test result did not exclude any relevant participants. The test and the teacher advocates' feedback on the MMSE scores were conducted by the teacher advocates before the consent was gained to ensure the participants were able to participate. Ideally, an assessment is conducted by someone independent of the study personnel (Howe 2012), which was the case in the study because it was the advocates who tested and evaluated the participants. The other two tests mentioned above were not used because they were not known to the teacher advocates or the participants. It would have taken time to train the advocates to conduct the tests and it would have stressed the participants unnecessarily to take a test unfamiliar to them. I therefore considered what instruments there were appropriate towards the recruited group. Different considerations had to be made before a procedure was identified. A balanced choice between relevant tests and ethical considerations was made.

It was possible to conduct the MMSE-test on all participants, except three. Here, the teacher advocate decided to stop the test because the participants became stressed, upset and angry with themselves, for not being able to answer the questions. This showed that the test did not capture the day to day variations. Even though the tests were not completed, the teacher advocate supported the participants' choice to

participate, because they recognised that the test had not shown normal competences of these individuals. Normally, they performed better in their usual teaching environment than in the test, showing that the setting and the test influenced their performance even though they were familiar with the test. It became obvious that the MMSE-test could not be used for deciding whether a participant could consent or not, because the results did not reflect the person's competences. It was taken into account that the persons' ability to act and respond could vary within the same day, which meant a one-time test was inappropriate to get a realistic picture of the participants' competences and challenges. Interestingly, two participants performed surprisingly well in the test. It was assumed that the test suited the participants because both had competences in teaching, communication and conducting tests as a former teacher and a teaching nurse. This showed that the results might be mediated by the participants' educational attainment and experiences. The student participants' MMSE-scores showed that most participants had an early-stage dementia, and were able to consent. This is illustrated in table 11.

Table 11: MMSE-score of student participants

Recruited student participant	MMSE-score	Reflection over the score in relation to the teacher advocates' feedback on MMSE scores
Johan	29	This person's score was in line with the teacher advocates' feedback as he could overview the tasks he worked with at VUK. He had only minor memory problems.
Ernst	30	This person's score was in line with the teacher advocates' feedback as he only had minor memory problems related to finding correct words.
Victor	25	This person had problems with his short-term memory. The score was in line with the teacher advocates' feedback.
Emma	24	This person performed surprisingly well compared with the teacher advocates' feedback. The test suited earlier working qualifications and experiences as a teaching nurse.
Elsa	%	The teacher advocates' feedback revealed this person could normally explain date and year for her birthday, which was not possible in the test. She got emotional and the test was not completed.
Bent	14	The score was lower than anticipated by the teacher advocates. Normally he managed to socialise and communicate with other students at VUK. He became talk-active and humoristic covering up memory problems in the test.
Henrik	22	This person's score was in line with the teacher advocates' feedback. He was newly diagnosed with Alzheimer's disease and was able to overview the tasks he worked with at VUK.

Jette	29	This person performed surprisingly well. It was evaluated that the test suited earlier working qualifications and experiences as a teacher.
Wilhelm	%	The teacher advocates' feedback revealed this person could normally explain date and year for his birthday, which was not possible in the test, making him stressed and angry with himself. The test was not completed.
Peter	%	This person had vascular dementia, resulting in problems with verbal formulation. He got emotional, and the test was not completed. The teacher advocates' feedback stated that with support he could formulate himself in the project.
Ove	26	This person's score was in line with the teacher advocates' feedback as his challenge was the short-term memory and loss of initiative.
Kurt	30	The score was in line with the teacher advocates' feedback as he was newly diagnosed and only had minor short-term memory problems. He was able to overview and solved the tasks given at VUK.

If the study had only relied on the MMSE-test the participants who had not completed the test and Bent who scored 14 would have been excluded. However, the teacher advocates' feedback on the MMSE scores supported that all participants were included in the project as having dementia in the early-stage. If the test and the teacher advocates' feedback on the MMSE scores had shown that a potential participant did not have the level of necessary mental capacity to consent the participant would have been excluded. This was possible because the assessment and feedback was conducted in the period between informing the participants and gaining consent. The process of assessing the competences was relevant before gaining consent to avoid excluding participants after giving consent.

5.3.3 CONSENT AS AN ONGOING PROCESS AND A ONE-TIME SITUATION

A one-off attainment of consent can be inadequate for a person with early-stage dementia, placing the person in a less powerful position than the person seeking the consent. A continual, ongoing process can be better (Dewing 2007, Hubbard, Downs et al. 2003, Reid 2001) as it gives the opportunity to determine a person's capacity to understand and give consent during a study (Howe 2012) together with controlling the willingness to be involved (Hubbard, Downs et al. 2003). This is relevant because their cognitive capacity may decline during a research period (Howe 2012). The consent process involves asking participants for verbal consent at each stage of data collection, reminding them that they can withdraw. Terms used to describe ongoing processes towards consent include process consent, ongoing negotiated consent and narrative-based approach to consent (Dewing 2007, Hubbard, Downs et al. 2003, Reid 2001). Unfortunately, a consensus does not exist regarding the application of concepts such as assent and dissent in dementia research or which procedures researchers should use (Black, Rabins et al. 2010, Carmody, Traynor et al. 2015).

However, the method of Dewing (2007) regarding adopting process consent is often used in qualitative research. The method focuses on how persons with dementia normally give consent for other activities, and uses this to inform decision making around consent monitoring (Martin, Augusto et al. 2013). This flexible, inclusionary approach ensures that ethical principles as veracity, justice, beneficence and respect are adhered (Murray 2013). It requires the researcher to be explicit and transparent about how consent is maintained throughout the research process (Dewing 2007, McKeown 2010). The five elements presented by Dewing (2007) informed the consent process in the study. The five elements are illustrated in box 8.

Box 8: Attaining consent

Box 1: The Process Consent Method

Background and preparation

Establishing the basis for capacity

Initial consent

Ongoing consent monitoring

Feedback and support

(Dewing, 2007, p. 15)

Regarding *Background and preparation*, it must be transparent how access to people with dementia is negotiated. In the preparation, knowledge about the potential participant's biography and signs of wellbeing are important, so these can be assessed in research. This requires an investment in time because it has to be done without appearing forceful. A period focusing on *Establishing the basis for capacity* is the next step. Here timing is important and pre meetings may be helpful to get to know the people and to assess their abilities (Hubbard, Downs et al. 2003). When gaining the *Initial consent*, it is important to verbally explain the research at a level so that the person with dementia understands. In this case the best tool is skilled communication (Hellström, Nolan et al. 2007, Hubbard, Downs et al. 2003, McKeown 2010). The *Ongoing consent monitoring* is characterised by a continual assessment of the person's choice to continue in the project. The significance of non-verbal behaviours and verbal utterances in assessing not only whether to continue to participate but how or when to intervene is important (Dewing 2007, Hellström, Nolan et al. 2007, Hubbard, Downs et al. 2003, McKeown 2010). The method of process consent can be adopted at each research contact to ensure willingness to participate and understanding of the aim of the project (Keady, Williams et al. 2005). Finally, *Feedback and support* throughout the project is essential to record evidence to demonstrate that consent is continually monitored (Dewing 2007, Hellström, Nolan et al. 2007, Hubbard, Downs et al. 2003, McKeown 2010).

A limitation of the process consent method can be the skill and experience of the researcher in interacting and understanding people with dementia from a person-centered approach (Dewar 2005). The researcher needs to commit to the ethics of participation as well as flexibility, patience, imagination, ingenuity and reflexivity (Dewar 2005). The ongoing consent can be relevant in qualitative projects because all potential ethical dilemmas cannot be anticipated from the outset but there is an issue about whether consent needs to be re-negotiated on every research contact. Clarification is needed on the issues of consent remaining valid throughout a study

and this is important if the use of advanced directives is to be explored for those in the early-stage of dementia (Bartlett, Martin 2002).

In the study I anticipated that a renewed verbal consent in each working session was relevant to ensure the participants' continual participation because the progression of dementia could challenge this. The two elements *Background and preparation* and *Establishing the basis for capacity* were realised by participating in classes at VUK before recruitment. Hereafter the *Initial consent* was gained. This was the only consent gained for the teacher advocates and teacher participants. For the student participants the initial consent was gained in collaboration with the teacher advocates, where the students wanted one present. The consent form was inspired by the Alzheimer Europe's suggestion for consent, with boxes to tick off with a "yes" or "no" about understanding the project, and what participation in the project involved (Alzheimer Europe 2012) (Appendix 11). An initial consent to participate in the study was first gained and a renewed written consent was gained when starting the participatory research project with the participants. This was done in collaboration with the teacher advocates. All consented. The participants were then asked if they wanted a teacher advocate to join their project work and no one did. Instead one of the teacher participants was included in the Monday group after the participants' acceptance so Helen could learn from the process to lead similar future projects. She did not take part in the research project but supported the participants together with me. This was helpful because of her knowledge about each participant.

Furthermore, an ongoing verbal consent was gained for each working session, which was video recorded (Pipon Young 2012) with regard to the *Ongoing consent monitoring*, the student participants were informed continually that they could freely participate in or withdraw from the research at any time without prejudice. Verbal consent was used because people with dementia can lose their ability to read and write and signatures can raise feelings of anxiety and insecurity (resembling semi-legal practices) especially if written consent is required often (Bartlett, Martin 2002, Burns, Hyde et al. 2014). However, it transpired that a renewed verbal consent was considered unnecessary from the participants' point of view. They found themselves capable in judging whether they wanted to continue or not without being asked every time they met me. The verbal consent was found unnecessary. In the verbal consent non-verbal and behavioural cues to ensure that the person has given consent to participate can be useful (Hellström, Nolan et al. 2007). In the study, I observed the participants' non-verbal language when asking for a renewed verbal consent. The participants were relaxed and comfortable but indicated irritation when being asked again for consent. It is therefore important that the ongoing consent is used wisely as it can challenge the participants' patience and be experienced as patronising.

Feedback and support was given from both the teacher advocates and I throughout the project. The teacher advocates revisited the participants' capacity throughout the study to ensure the participants were able to continue. The teacher advocates'

contribution supported their ongoing involvement, through advising on daily fluctuations in capacity, along with observation of more general decline. Through the project the teacher advocates and I collaborated closely to ensure the participants could continue in the project.

5.4. ETHICS AND THE RESEARCH PROCESS

5.4.1 MORAL SENSITIVITY IN THE RESEARCH PROCESS

Previous research on people with dementia has often focused on the process of giving consent and the assessment of the participants' ability to give consent. However, a few studies have focused on other ethical challenges than the procedural ones and it is important to think ethics throughout the research process (Heggestad, Nortvedt et al. 2012). Focussing on ethics in the beginning is no guarantee for being able to solve all ethical problems occurring during the research process. Thus it is important to protect the participants and prevent risk and harm. Moral sensitivity can be a way to act ethically in practice (Heggestad, Nortvedt et al. 2012). It includes an attention to the moral values involved in the situation, acknowledging what principles are involved as well as awareness of one's own role in the situation. It is an important pre-condition for behaving and judging morally, as moral sensitivity is important for moral attentiveness and a full-fledged understanding of moral situations. The concept of moral sensitivity takes both emotions and reasoning in a situation seriously. One needs to be touched both emotionally and cognitively (Heggestad, Nortvedt et al. 2012) to have a positive and beneficial relation with the participants. This means the relational and contextual protection of the participants becomes a part of the research process. So, instead of avoiding research including vulnerable groups, it is relevant to focus on moral sensitivity and how researchers can develop this sensitivity (Heggestad, Nortvedt et al. 2012). The active moral sensitive involvement of people with dementia in research rests on values of transparency, honesty and openness (McKeown, 2010). Moral sensitivity is shown by listening to the participants' opinions and understandings throughout the research (Heggestad, Nortvedt et al. 2012).

To act in a morally sensitive manner the researcher can find inspiration from Løgstrup (1905–1981) who was a Danish philosopher and theologian. He combined elements of phenomenology, ethics and theology. He argued trust is not of our own making; it is given. Our life is so constituted that it cannot be lived except as one person lays him or herself open to another person and puts him or herself into that person's hands either by showing or claiming trust. By our very attitude we help shape the person's world. By our attitude to the other person we help to determine the scope and hue of his or her world; we can make it large or small, bright or drab, rich or dull, threatening or secure. We help to shape the world not by theories and views but by our attitude. Herein lies the unarticulated anonymous demand that we take care of the life which trust has placed in our hands (Løgstrup 1997).

In the study, I was aware that my attitude and actions influenced the participants and that I had to take care of the trust shown to me to support the participants so that the participation in the participatory research project was positive and safe. This awareness included being morally sensitive and acting trustfully and to put the relationship with and the well-being of the participants higher than the research. For example, two participants, Wilhelm (from the Monday group) and Jette (from the Tuesday group), decided to withdraw from the project because they felt it was difficult to participate in the way they wanted. It was agreed with the participants and the teacher advocates that they withdraw with the possibility to join again if they wished. Both were moving to nursing homes in the same period, which created a lot of distress for them. Their withdrawal showed that participatory research might not be relevant for all people with early-stage dementia, which is important to acknowledge. The Monday and Tuesday groups were informed that Jette and Wilhelm withdrew and the groups expressed an understanding for this, but nobody else wished to withdraw. I was aware that when involving people with dementia in research, I had to be prepared of a high withdrawal rate because of the progression of dementia. Withdrawal has to be handled with sensitivity towards both the person withdrawing and those remaining in a research project. I therefore recruited so it was possible to continue the project regardless of the risk of withdrawal.

The relationship between the participants and the researcher is characterised as asymmetric because the researcher is the one who has power. It is important to be aware of this power imbalance and respect the participants' autonomy and reactions. This imbalance exists because of different status and factors such as age and disability. Consequently, the researcher should focus on how he or she uses the power in favour of the participants. This can be challenging when the participants have limited verbal capacity and have challenges with expressing them clearly (Heggestad, Nortvedt et al. 2012). For that reason, it is important to build up a relationship with the participants so the researcher is not a stranger but is familiar with the way the participants express themselves. To have knowledge about the group the researcher is working with can make the researcher more sensitive to what happens in the relationship (Heggestad, Nortvedt et al. 2012). It is also positive to have knowledge about engaging people with dementia in non-research activities and collaborating with persons who know people with dementia (Nomura 2009, Whitehouse 2000).

Another important aspect is to be aware of the differences of the contribution by each participant. Reasons can be multiple and include the personalities of the participants, differing levels of cognitive ability and the researcher's position within the group. It raises dilemmas about what level of collaboration is acceptable and what strategies can be employed to facilitate equal collaboration (Pipon Young 2012). By adapting research approaches people with dementia can be empowered to participate in all levels of research activities (Murray 2013). Future research will therefore benefit from identifying what is the appropriate level of collaboration when conducting research with people experiencing cognitive impairments (Pipon Young 2012).

In the study, the power relations between me as the researcher and the participants were something I was aware of throughout the study. A way to shift the power dynamic of an interaction and give people with dementia power is to allow them to have the role of an expert on their own life (Müller 2009, Nomura 2009). In this study, every effort was made to situate the participants as experts of their lives. The participatory approach enabled them to take action and to speak out about the lifeworld perspectives they wanted. At the same time, I arranged that I could not participate in the decision making about, for instance, the research questions and data collection methods to allow the participants decide what the project was about and how it was going to be investigated. In this way, I tried strengthening the relation with the participants in collaboration with the teacher advocates. It also meant adapting the research process and the research methods to secure their continuous participation in the project depending on how much they were able to contribute from one session to another. Here the right amount and type of work was essential together with creating continuity in liaison with the person-centered approach. In the sessions small informal breaks were allowed and participants who needed more breaks could come and go during the sessions. Furthermore, it was discussed how they could have a bad day which meant they did not contribute to the work on other occasions. This showed how I adjusted the project work according to the daily variations the participants experienced, allowing them to be a part of the project work. As a researcher I needed to be flexible in the collaboration with the participants to ensure a positive relation and collaboration together with a constructive research process.

5.5. CONCLUSION

To summarise, this chapter outlines the ethical considerations the researcher has to be aware of when planning engagement with people with dementia in research. The project has to be planned so it is possible to recruit this vulnerable group. Furthermore, it is important to plan the research so even non-therapeutic research becomes relevant when having dementia. It is also argued in the chapter that consent should be gained from the participants whenever it is possible instead of using proxy consent. Here it is important to inform the participants in a way understandable for them, together with choosing an appropriate consent form. When involving people with dementia it can be relevant to assess their mental capacity to consent before involving them. This can be achieved by both using a cognitive test and a teacher advocates' feedback on the MMSE scores to ensure all competences are appreciated since only to rely on a test can be problematical. A way to ensure the participants' continual involvement can be by using ongoing consent but this has to be used wisely otherwise it can be experienced as patronising because some people with early-stage dementia remember that they have given consent earlier. Finally, it is important to act in a morally sensitive manner to ensure the participants are not harmed. This includes building up trust and putting the relationship higher than the project results and using the power in favour of the participants.

The following chapter focuses on the analysis of the interviews conducted with each participant informing the planning of the training and the participatory research project.

CHAPTER 6. THE LIFEWORLD PERSPECTIVES OF THE STUDENT PARTICIPANTS PRIOR TO THE PARTICIPATORY RESEARCH PROJECT

6.1. INTRODUCTION

Chapter 5 described the ethical considerations and challenges regarding collaboration with people with early-stage dementia in research with the purpose to succeed with involving the group in research.

This chapter presents the results of a hermeneutic phenomenological lifeworld-inspired analysis of the individual semi-structured interviews conducted with the student participants. The analysis was structured and coded by Van Manen's four life existentials. It reveals how the participants experience life and learning with dementia compared with before being diagnosed with the illness.

6.2. ANALYSES OF INTERVIEWS

Five themes emerged based upon the coding framework inspired of the four life existentials. The themes reveal lifeworld perspectives of the participants based upon a holistic lifeworld framework of Van Manen, ensuring all aspects of lived experience are seen. .

6.2.1 "WE LIVE A SOCIAL AND ACTIVE LIFE REGARDLESS OF DIFFICULTIES"

The first theme that emerged related primarily to the relationality existential (lived relation). It showed how important relationships were for the participants.

The participants thought it was important to be socially engaged and they enjoyed being together with family, friends and others with dementia. Emma said:

"For then I try to find all the benefits there are with it, and then e-enjoy them with others at similar level or with my children"

She focused on being together with others which was associated with positive feelings and enjoyment. It was positive to be busy and have a good time rather than have nothing to do. Furthermore, it was seen as important to be orientated towards the society because as Ernst said, it helped communication with other people. The participants prioritised their lived relations. However, it could be difficult to sustain the relationships because dementia affected them in various ways, complicating natural relationships. Their experience was that they were no longer equal with others and Jette worried it might come to a point where it was no longer possible for her to socialise as now. She was aware her temporal landscape (her lived time/temporality) changed because of the dementia progression over time with a negative consequence on her lived relations.

Most enjoyed the activities and hobbies they always had appreciated and continued with these for as long as possible. It was important not to give up because of age or dementia as Bent explained:

*"T-thus, you must be careful - you do not sit down then and say to yourself:
'Now it's good enough, this over there'"*

He did not want to end up accepting being passive. Yet some activities were difficult to continue with because of the dementia e.g. bicycling, cooking, working and swimming. Wilhelm said he had given up hunting because of security reasons as in his experience his brain could no longer be trusted, which meant his lived body/brain (corporality) did not act reasonably any longer. The loss of activities could lead to isolation, decreasing the lived space (spatiality) further, which was a negative experience. Some tried to cope with the situation by, for example, attending services or getting a visiting friend. Henrik also tried to start a bicycling club but it was difficult because other people hesitated when they heard he had dementia, which made it difficult for him to sustain his lived relations. For that reason, dementia influenced his quality of life negatively as it was difficult to continue his hobby.

Close family was the primary social supportive relation for all, except for Johan, with close relation to children and grandchildren. Bent told how grateful he was for his family. He found quality in life through the family such as grandchildren brought joy and laughter into his life and forced him to stay active. For those living alone children and children-in-law were the primary support with professionals also being helpful. Living alone was experienced as being a little lonely because the family could not interact as much as they wished but as Elsa explained she knew her family could not do more than they did. This showed how the family relation was also under pressure for especially those living alone. Challenges also existed towards family. In Johan's experience it was too stressful to live as a family, which made him move away from his wife to his own apartment to get peace around him, demonstrating that even the closest lived relations risk being compromised because of the dementia. Ove also described how he experienced conflicts with his wife because of his memory problems and loss of initiative.

Others described how old roles were lost because the spouse or family took over. Some took over completely, which could lead to a feeling of being redundant resulting in a negative relation. Contractively, Henrik explained how his wife had taken over, for which he was grateful although it was difficult to accept as he did most of the decision-making previously. This changed their relationship so it was no longer an equal relationship between spouses. A few talked even more positively about receiving help when experiencing difficulties. This was especially the case for Emma because it enriched her lived relations and rescued her from feeling unsafe.

Another way to socialise was to attend the school VUK, which allowed them to get out of the house. This expanded their lived space. The school supported their lived relation by giving them an opportunity to develop new relationships with people with dementia. These relationships seemed more equal than those they shared with family because they could talk openly about their situation and how they coped with it. Elsa explained:

“So I think we talk a lot about things, and I think we're trying somehow to find something that can benefit ... about some of the things we discuss. And I think that's good”

They supported each other by sharing experiences and advices but also enjoyed a good time with laughter. Difficulties of course also existed. Henrik said:

“... There are some people who like ... marring a little (laughs) ... I can overlook it a little in a period but then, it should not be for long periods. Because then I think it becomes ... it becomes difficult ...”

He had difficulties sometimes in containing others' behaviour with dementia because he got annoyed. It could be in relation to others' repetitive behaviour, constant talking or lack of understanding. This challenged the lived relation with likeminded people.

Participation in the participatory research project was also partly driven by a social motivation. They found the social part and the possibility of helping others with dementia in the participatory research project positive, which was more important than understanding the project in detail. They wanted to contribute regardless of their dementia. Also the relation to me seemed more important than understanding the project. Most mentioned me as friendly, decent and trustworthy and they hoped the project would be conducted in the same nice atmosphere as the interview. They said that they looked forward to helping with the PhD project. Only Johan talked about insecurity about the research process but even for him the positive relation towards me was more important than understanding the process in detail. He thought the process would be managed at the time and he trusted that I as a researcher would make it clearer as the work started.

6.2.2 “WE TRY TO LOOK AT THE BRIGHT SIDE OF LIFE WITH DEMENTIA”

This theme also related to the relationality but not as closely as the previous theme. It showed how the participants tried to be positive and how this influenced their lived relations.

The participants talked about dementia, its symptoms and progression and it seemed important to be open and honest about their situation. VUK was experienced in making it easy to talk about dementia which was especially positive for those who felt embarrassment about their condition. Emma explained:

“... That you can say: 'I have, I have Alzheimer's disease', right? But then, we can certainly talk and things like that. If you think I say, make some nonsense, and then tell it to me. So, then you are on the way, and then there is not anything, 'Hu, they, just do not find out ...'”

Emma believed it was easier to tell the truth because it relaxed the stress of trying to hide the dementia. Likewise it made it easier to get help. Otherwise life with dementia could become hard, difficult and lonely. To be open about dementia might strengthen the lived relations by raising awareness of dementia amongst others.

The reality of living with dementia was difficult to cope with and some did not think too much about their situation as they otherwise felt sad because of the problems they experienced. Not to think was viewed by some as a way to protect oneself a defence mechanism. Henrik had experienced how dementia had changed his expectations towards life, meaning that his focus was now on the present as the future had become uncertain. The lived time was now focused on the immediate life. A few tried to cope by going for walks to think while others drew or painted. Through drawing Emma had found an effective way to remove negative thoughts about dementia which helped her stay positive. Many talked about trying to have a positive attitude towards life even though it was difficult. Victor clarified:

“It is my wish yes. That, to get as good a life t-t-together with, with my illness and, and, and ... For I can have much joy of my life, and so that others also can understand that I also may well be ... comfortable and happy and joyous”

Victor had wishes for his life with dementia, focusing on quality of life for which he had to argue as it was different from how dementia was normally seen. To come to terms with life with dementia also depended on a person's personality. Some commented they always had been optimistic by nature which helped them in the process. Having a positive attitude involved focussing on remaining resources, which was difficult for some when experiencing, for instance, memory and language problems. It was about trying to be positive although the lifeworld was changing.

Humour was also used to cope with the situation both ordinary jokes and jokes related to life with dementia. Emma joked:

"Yes. And the medicine I get, it's also for someone with Alzheimer's disease. So then it is at home. Although it is allowed to move (laughs). No, now - it is allowed to stay" (smile in her voice)

At VUK the humour created a relaxed atmosphere. Johan described how it made it possible for the students to tease and help each other. This made their socialisation informal and non-frightening. Johan explained:

"The whole thing should not be so straight and so ... and there must also be room for mistakes. And one must also, of course, self could take them. Otherwise, there's nothing about it"

The humour was an important response to all the correctness and seemed to make it easier to make mistakes and laugh about them if a person was open towards it. It relieved the stress in the lived relations that otherwise could be experienced.

Humour was also used when they experienced language problems. It could be related to missing words, forgetting what they talked about, could not answer a question or when they believed they talked nonsense. In the interview Jette laughed when she realised she had said something wrong. It seemed like the laughter made it less embarrassing when she could not find the right words. In general, the humour was a coping mechanism that made it easier to talk about and handle the difficulties they experienced when living every day with dementia. However, it had to be used carefully. Jette explained:

"... I just could not ... f-f-find out how I should ... And Karen ended up, that I thought it was annoying, that she just laughed of it all" (laughs) ... "We take it up enough to discussion sometime"

For Jette, it was not pleasant that Karen laughed when she suddenly could not manage her Calendar. She thought she would confront Karen with this because it had been a negative experience and it was something she did not want to experience again in her lived relation with Karen. Here the humour was experienced as insulting in comparison with the problems she experienced due to the dementia.

6.2.3 "IT TAKES TIME TO ADAPT, AT THE SAME TIME WE ARE LOSING TIME"

Temporality (lived time) was identified as an important existential talked about by the participants and a theme around time was identified.

The participants explained how it took time to get used to, and come to terms with, dementia. Shortly, after the diagnosis, the participants felt like they were alone in facing the diagnosis. Johan emphasised:

"... Mja, but it was probably like many others - I thought I was the only one in the whole world"

This was a time associated with painfulness and loneliness because it was difficult to accept it was impossible to beat the illness. To be diagnosed with dementia was described as getting a conviction. It was a process, which took time, to learn how to live with dementia. Wilhelm explained:

"... That I ... was told what it was. Well it was horrible, right? But, uh ... so then about a year probably went, right? And now I feel also as good ..."

In his experience time helped in accepting dementia as it was really difficult to accept it in the beginning. All described this process of accepting as difficult and demanding.

When living with early-stage dementia the lived time changed from before the diagnosis. It became difficult to hold on to time and talk about it. For instance, it could be difficult to remember their birthday and year together with their age. Many also had difficulties in saying when they were diagnosed and with what type of dementia. Johan said:

"... I think it was in '04. That's why I asked if we should so..." (points towards his bag with papers). "... Because I have yes, I have yes - it it it is what with, with, with time ... is something very strange ..."

Johan had brought papers³ with him so it was possible to talk about exact objective time periods because the time had become strange for him. The objective time seemed no longer logical. A way for him to try to keep order of time was to put important papers in a folder he could bring with him. Even those who were newly diagnosed had difficulties in explaining when they got their diagnosis. However, a few could describe in detail how time was around and after the diagnosis, how they got in touch with VUK and when they began to attend the school, naming the months and years and different professionals they had met in the process.

Another way they experienced that time had changed was that it sometimes was difficult to respond immediately when communicating with other people. It could be

³ The papers refer to the fifth existential materiality. However, the interviews were not coded with special focus on this existential.

demanding and time was needed to be sure what the situation required and what to answer. Johan explained:

"You gotta take a phone when it rings and you have to respond to what is being asked for, when standing with the phone in the handset. And it is sometimes, that I can use just half an hour to think me about"

He found it was better to use emails than a telephone⁴ because they gave him time to respond. The participants also got tired if they communicated for a longer period when it became difficult to find the right words. They were only able to concentrate for a certain amount of time. Furthermore, the time of the day also influenced their ability to communicate because often they experienced greater challenges later in the day because they got tired. The lived time was experienced differently during the course of the day.

All tried to structure the objective time and most of them used a Calendar. It could be an electronic Calendar or in paper form⁵. Many found it useful to get a sense of objective time. It helped them to remember appointments, birthdays, hobbies and other activities. Ove explained his need for a Calendar:

*"I, I suffer somewhat to remember many times. Whether it's Monday or Tuesday or Wednesday or Thursday and Friday and things like that, right?
... Yes. And I must say; it, it helps me a lot"*

It was no longer possible for Ove to distinguish between different days, which made it difficult to overview daily activities. The objective time with different week days had become difficult. Some had all daily activities written in the Calendar while others only had appointments with friends and family in it as they thought they still could overview time without having reminders in the Calendar. For Ernst, his short-term memory was not so challenged so he did not write any activities in a Calendar as he remembered his appointments.

For some it was mostly the spouse or other family members who managed the Calendar, writing down the participant's activities, to try to give an overview over objective time. Some started the morning by checking the Calendar to get an overview of the day and week. They saw this as helpful and a security so they did not need to use too much energy to try to overview time. Some tried to remember the daily activities before checking the Calendar. Emma explained:

⁴ Also the computer, emails and the telephone are connected to the materiality existential.

⁵ A paper or electronic Calendar also relates to the fifth existential materiality.

"What was right, it was that I should?' And then I just try, and then I go to, 'Yeah!' (great empathy) ... Because then I can still ... train that I remember it. So I cannot do more myself"

For Emma this was a way to train her memory, stay active and take responsibility for her own life. It gave her a satisfaction when it was possible to remember her activities. Then she was not 'totally cracked' as she described. Even though the Calendar was a useful tool, it could now and then be difficult to use and understand. Jette said:

"Yesterday I could not manage it. It was all wrong. The s-, that's something ... irrational something, pretty much"

Jette experienced how dementia affected her ability to use her Calendar, meaning the Calendar some days became incomprehensible. To attend different services was also a way to structure one's life so the time did not just disappear without doing anything.

6.2.4 "WE CAN STILL LEARN BUT IT IS CHALLENGING"

The corporeality (lived body) existential was also identified in the analysis as the participants experienced changing learning abilities because of dementia.

Most participants explained they had no problems with learning before they got dementia. Elsa said:

"No, it it I do not think, I never, that I have had problems learning something new"

They had been curious, industrious to learn new things but it was difficult to explain exactly how they had learned in the past. It seemed it happened without any great awareness, although they had found reading, illustrations, discussions, doing it in practice and asking others useful. Also preparation, taking notes and writing keywords had been useful techniques. Emma and Jette had teaching experience themselves from their working life being a teaching nurse and a teacher respectively.

The participants were aware their memory and ability to learn had decreased after getting dementia. Ernst emphasised:

"Well, y-y-you have to think more than you should in the past ... I may become a little slower to grasp or understand or learn. And, and, and remember those new things"

It had become more difficult to understand, learn and remember and more energy was needed if he wanted to get a grip of things. On the other hand, it was not experienced as impossible. Sometimes, the participants needed help to understand, learn and remember new things but at the same time they did not think there were many demands in their daily life, which made it difficult to explain their specific learning

difficulties. To be familiar with a learning environment because of one's former working life was also argued as being a reason for not having any major problems with learning at the moment. However, there was awareness that early diagnosis and medicine helped even though not all benefitted from medical treatment.

Some mentioned they had learned new things after the diagnosis e.g. Johan talked about how he had learned to do Sudoku and use an iPad and Jette talked about how she had re-learned to knit. All thought they learned at VUK. In the learning process repetition was a key. Johan explained:

"It's repetition, repetition and repetition, and so at some point, so it's like then it goes maybe a tiny bit better. So you say, 'Pyhh ...'" (Laughs)

It was possible to learn new things but it took a big effort and long time. Other learning techniques used were writing notes, asking others, trying to remember before checking books and using associated words. Some also talked about reading books and newspapers, making puzzles and crosswords to train the brain and stay active. To have access to new learning possibilities was associated with positive feelings because it was nice to solve and learn new things. Henrik liked to be challenged regardless if it was associated with obstacles. However, a learning process could be long and hard and some gave up if it was too demanding and confusing. For Victor it meant he had stopped challenging himself and only did what he was 100 percentage sure he could manage. This showed how the participants reacted differently towards learning challenges.

(Sighs) "Well it's the only thing with, with, with remembering things - it is, but then I-I-I do nor any thing that I do not juust ... I will say 100-100 percent sure that I can ..."

The learning environment at VUK was experienced positively. Most thought the learning was properly adjusted to their learning challenges although the training could be challenging because it required concentration and thinking. The participants had to both concentrate on understanding and on solving the tasks, which called for lots of concentration. Fortunately, it was possible to get support from the teachers. They were seen as nice and helpful and open to inputs from the participants so that the teaching matched their interests and competences. Nevertheless, they had difficulties in explaining what learning activities they worked with at VUK because of their short-term memory problems. Wilhelm said directly he could not remember what he worked with but he did recall some of the activities later in the interview. A few explained in detail what they did at VUK. Johan explained:

"Yes, but right it is that one brain gymnastic department in at Keld, where we actually are using the upper part and massaging it with discussions and talks and with newspapers and assignments and everything"

He explained the different activities and their purpose, which was to use and challenge the brain. The lessons followed a certain structure that was reconcilable for many. In general, the lessons with cognitive stimulation were experienced as interesting but some advocated for more creative activities such as drawing and painting. Jette also missed talking more about dementia and the problems associated with it.

Most had no prior expectations about being involved in the participatory research project. They voiced no expectations that they would learn easier or remember better after the project. No improvement towards the lived body was highlighted. Ernst focused on how research was needed to develop more knowledge about dementia; he wanted to contribute to it. The only concern the participants had was if they had anything to contribute, questioning their own competences. Kurt exemplified it by characterising him and the other participants as “*semi-finished*” people, showing that he did not see them as whole persons any longer. The lived body was no longer complete.

To support their learning and memory in the project, briefing and using a summary folder was mentioned as relevant. Emma said:

*“... Written up that says ... what we have begun with to talk about, right?
... If you nevertheless still become - and possible even weaker to remember,
we could just go back to it. It's such one, one, a help product, right?”*

She was aware of their short-term memory problems and therefore found a summary folder relevant as a supportive strategy. To use texts, pictures and video recordings were also mentioned as strategies but it was important not to use too much text. Yet it was difficult for many of them to know how they wanted the training and thought it would be easier to make suggestions during the process. However, a general suggestion was to be aware of the language used because it was difficult to understand technical and foreign words. Moreover, it was important not to rush through the training and repetition was again mentioned. However, it had to be used properly, otherwise the training would become boring. Regarding the teaching environment they did not have any particular expectations. They thought the classrooms at VUK worked as long there were not too many disturbing elements.

6.2.5 “WE TRY TO REMEMBER BUT KEEP FORGETTING”

The corporeality existential was also identified in relation to their experienced memory problems as the memory did not function as it did before dementia became a part of life.

Noticing memory problems was the first significant issue that most of the participants discussed experiencing before their diagnosis. Elsa told:

"... Yes, how I found out it? I think that it, I think that it was my lack of and ability to remember and for-, keep track of. I think that it was therein"

She discovered she could no longer remember and keep track of things as she used to, which was a painful discovery. Her lived body no longer succeeded in managing her everyday life unconsciously and she became aware of her impairments. Memory problems affected the participants differently in their daily life. Bent reflected on how some things were not possible to remember at a given time but with focus they would come; he did not feel his own memory problems were too challenging.

"Well, uh, that there are some things that I do not remember, but then gradually, so uh, it comes up. Right?"

Victor's experiences differed; his short term memory was impaired, illustrating the diversity of experiences within this group. Victor explained how he could talk about past experiences as long as it was not associated with the recent past. Remembering things from the recent past took a great deal of energy and even then these memories could be impossible to recall. Some noted that recent major life changes were at times easier to remember, for example moving to a nursing home or having a son sleeping at home for security reasons. These situations indicated significant experiences, which were easily remembered. Nonetheless, it was easier for them to describe episodes from their childhood and younger adult life, for instance, about their childhood home, school and sports activities. Most could explain these with empathy. Many could also describe details about their adult life focusing on their interests, hobbies and work but the descriptions differed in details. Peter had difficulties in explaining his job.

"Mja - t-t-t mh ... But, uh ... Yes ... I- ... Mh ... All those who called me, uh ... and I juust had to come over and show there ... And so on, so forth. So ... So ... And ... and there were many - many different ... I was visiting"

For some the memory problems also included difficulties in remembering exact words, expressions, and the names of persons, places and towns. This made it challenging to describe things when they could remember them. Occasionally, they also used words or sayings which did not fit the context. It made them feel insecure as they had to think about the right pronunciation or find other words that described the missing word. This could result in problems when communicating because it became difficult for others to understand what they said. One way to manage the communication problem was to prepare themselves before meeting others. Jette said:

"... If now I go to my children, or they come to me ... so I will of course, so I will of course just have gone through it ..." (draws air in deeply). "I could be so much wrong ..."

She was aware of her problem with remembering the names of her children and compensated for it by going through the names before meeting them, practicing the

names. It seemed to be important for her not to get it wrong and it worked for her to use associated words to recall names. In contrast Victor avoided using names. Other participants noted that it had become difficult to remember the number, names and ages of their grandchildren; two could almost not remember the grandchildren. As the memory influences the way people carry themselves, their gestures, words and language, all participants had to reinterpret who they once were and who they were now. Not being able to remember led to a less positive picture of themselves than before dementia became a part of their life. The lived body was no longer as reliable as it was before.

Another problem in conversations was they occasionally only picked up few words in a sentence or forgot what they were asked and what they were answering. Johan experienced this in the interview where he forgot what I had asked and what he was answering but chose to laugh about it, asking me to repeat the question. During the interviews others misunderstood some of the questions and some found it difficult to answer questions where they were not clearly focussed on one topic. Johan asked:

"What, what do you eh, do you ask about now? What was it you said? Yes, but I was thinking more about - what was it you ..." (laughs) (laughs). "It was right there, yes. I lost the thread"

Furthermore, some repeated themselves in the interviews by telling the same stories, for instance, Bent repeated frequently he had attended a secondary school, been an auditor and that he had two daughters. In general, many of the participants were aware of these challenges and some asked for directions and support during the process. Some also stopped talking, taking an opportunity to try to return to the main point being discussed. Henrik explained:

"So I have to interrupt uh ... what I want to say really. No ... it runs a little out of hand, then, once in a while"

He was aware he had problems with sticking to the point and interrupted himself when he discovered it. He wanted the lived body to act reasonably.

Memory problems also influenced the ability to overview activities and keep orientated to the details. The different actions in an activity were difficult to remember. Consequently, they did not always succeed with these, which included daily activities suddenly becoming difficult. Both Henrik and Johan experienced that they suddenly could not find their way through well-known terrain and Elsa told how she forgot to buy things when she went into town.

"So sometimes so - well, so I cannot exactly figure out the very last thing, of what I have to and so on. And then, and then I have to go home"

Their strategy was to go back to where they remembered they started to try to orientate themselves again. For Elsa it meant going home when she could not remember what to buy. This was useful to cope with the impaired memory as the body then remembered. To manage a difficult situation was seen as a positive learning situation although it was difficult to accept a normal daily activity suddenly became difficult to manage because the lived body no longer fared "routinely". The strategies used towards handling the memory problems were mentioned as those they discovered when facing challenges.

Most of the participants wrote down important things they wanted to remember which was a helpful strategy but at times they forgot to read the notes⁶ either they or their relatives wrote down. Ove told how it was complicated to use this strategy:

"Yes. I do. So I do, but I, I, I'm bad to forget it. But, uh ... uh, yes - otherwise then we have a note lying at home ... in the kitchen, right?"

He used notes but experienced that he forgot these even though he knew they were in the kitchen so that the impaired memory challenged the use of this strategy. The strategy was also challenged because the ability to write was decreasing for some. The lived body was experienced as losing its competences.

A few participants used notes in a very structured and systematic way. They always had paper in their pocket to write down important things. Johan then wrote his notes in his Calendar in the computer at home. The others did not talk about using a computer in this way. Instead many had given up using a computer because it was difficult to keep up with the new versions even though they had earlier used computers at home or at work. The same was the case with mobile phones and iPads because it was difficult to learn and remember how to use new technologies. A way Johan and a few others compensated was to use old mobile phones and old desktop computers which the lived body still was able to remember to use.

6.3. CONCLUSION

To summarise, this chapter outlines the results of the analysis, inspired by Van Manen's four life existentials, of the conducted interviews describing five different themes. The themes illustrated some of the tensions the participants experienced in life with dementia. They tried to live a social and active life with family and friends but it was challenged by dementia. Furthermore, they tried to stay positive but it was hurtful to think about and experience the challenges dementia caused. The experience of time also created tension because it took time to adjust to a life with dementia but at the same time they lost time as it was difficult to hold on to. Finally, they experienced their abilities to learn and remember decreasing after getting dementia,

⁶ To write notes refers to the fifth existential materiality.

which created tension because they wanted to learn and remember. Different strategies were used to try to compensate for the challenges, which showed they tried to cope with their difficulties in life with dementia.

6.3.1 KNOWLEDGE GAINED FOR THE TRAINING AND PARTICIPATORY RESEARCH PROJECT

The knowledge gained from the analysis above was used in the planning of the training and the participatory research project. The analysis revealed the role the participants presumably wanted to have in the project as they described themselves as social and active. They were motivated towards helping others with dementia and me although they were vulnerable themselves. Furthermore, it was essential that trusted relations were established in the project. This had a higher priority than understanding the project in detail. This raised my awareness of the importance of establishing trust for succeeding with the project. The analysis also revealed I had to support both their openness about dementia and their need to protect themselves. Furthermore, humour could be used carefully to ease difficult situations.

Another important aspect was the fact that the participants were only able to concentrate for a certain amount of time and it was easier for them to concentrate and communicate in the beginning of a day. With this knowledge in mind, I planned the project in late mornings. The analysis also showed it was possible to learn new things when living with dementia, if supportive strategies were used. Most also found it interesting to learn new things. This supported my presumption that people with early-stage dementia could be involved in research if their needs were met. The different strategies mentioned such as repetition, patience, note taking and using a folder including pictures and small texts were planned and used to support their memory. Moreover, to learn research terminology or to use computers or iPads was considered to be too challenging.

It became obvious that the participants besides having memory problems also had attention problems, which was addressed by using a certain structure throughout the project to support the participants. However, the analysis also revealed that it was difficult for them to recall recent past learning because of their impaired short-term memory. For that reason, I did not expect the participants to remember the training for a long period and I did not want to give any impression the participants would remember better after the project to avoid any unrealistic expectations.

The following chapter describes the analysis of the focus groups conducted with the participants carried out in accordance with the knowledge gained from the interviews.

CHAPTER 7. THE PARTICIPATORY RESEARCH PROCESS IN COLLABORATION WITH THE STUDENT PARTICIPANTS

7.1. INTRODUCTION

Chapter 6 presented the results of the analysis of the interviews conducted with each participant with the purpose to gain relevant knowledge about them, relevant for planning the training in research skills and the participatory research project.

This chapter presents the results of a thematic analysis of the focus groups. A general overview of the participatory research process is presented together with an in-depth description of six central themes, described within the sessions in which they were present the most. Pictures are included in the analysis to visualise the work process in the project. A complete version of the pictures is in appendix 12.

7.2. ANALYSIS OF THE FOCUS GROUPS

7.2.1 INTRODUCTION AND ESTABLISHMENT OF THE PROJECT GROUPS

In the introduction, the participants were presented with a folder with session papers including a work plan, where they ticked off each session to visualise progression through the process. See picture 1 illustrating the folder and work plan.

Picture1: Folder and work plan



Title of the folder: Insight into the life with an early-stage dementia

Session nr.	Dato	Indhold	form	Udført
1	23.-24. februar 2015	Nyt samtykke. Introduktion til projektet. Projektsamarbejde med fordeling af roller og ansvar	Introduktion og drøftelser og aftaler	
2	2-3. marts 2015	Hvad er et projekt og et projektpørgsmål? Formulering af et projektpørgsmål.	Præsentation og øvelser	
3	9-10. marts 2015	Finde deltagere og metoder til at indsamle og analysere fund.	Præsentation og øvelser	
4	16-17. marts 2015	Øve valgte metoder og bruge metoderne i projektet	Øvelser og projektarbejde	
5	23-24. marts 2015	Lave projekt	Projektarbejde	
6	27.-28. april 2015	Lave projekt	Projektarbejde	
7	4-5. maj 2015	Lave projekt	Projektarbejde	
8	18-19. maj 2015	Hvordan præsentere resultaterne?	Præsentation	
9	1-2. juni 2015	Præsentation af resultater	Projektarbejde	
10	8-9. juni 2015	Præsentation af resultater	Projektarbejde	
11	15-18. juni 2015	Evaluering af hele projektet	Gruppe interview	

Der er et mandags- og et tirsdagshold (derfor to datoer). Diane Schack Thoft har i samarbejdet med VUK dannet holdene. Man deltager kun på et af holdene og arbejder kun med projektet, når man normalt er på VUK (enten mandag eller tirsdag). Der er ingen hjemmearbejde eller yderligere behov for at komme på VUK for at deltage i projektet.

Plan for the training and project work. Each session is described in Chapter 7. Furthermore, a structure for the work was presented. This structure was anticipated to help the participants to follow and remember as much as possible. See box 9 illustrating the structure.

Box 9: Structure of the work

- Overall resume of last session supplemented with pictures
- Presentation of the aim of the session
- Presentation and introduction of the content
- Work with the content
- Repetition of the session in headlines
- Resume of results gained
- Verbal evaluation

In the beginning of each session, the last session's work was repeated with a verbal resume supported by pictures and text in the session papers. Thereafter new content was introduced and they worked and finished this content within a session.

In the first session the aim of the project and gaining a mutual understanding of it, together with discussing the group collaboration, was the focus. I presented the project and followed by a brainstorming time, supported by questions in the session papers. I wrote these on big post-its to visualise them. Both groups needed help to formulate their competences and challenges towards the project. They were observed as being a bit reserved when talking about their challenges, mentioning language and memory problems and problems of understanding. Also my role as the researcher was defined. Both groups wanted me to keep the structure and timeline in the project. They also brainstormed different project ideas in the session. This led to the theme "*Others don't have a clue, let's change it*".

7.2.2 "OTHERS DON'T HAVE A CLUE, LET'S CHANGE IT"

All were motivated about contributing their knowledge about dementia to inform society and help others with dementia who did not have the same opportunities as they had. The overall theme "*Others don't have a clue, let's change it*" was consolidated

from collapsing the coded initial potential themes “*Make a difference*”, “*Get knowledge*”, “*Self-development*” and “*Seeking and spreading information about dementia*”. Two sub-themes were identified within the theme “*Contribute knowledge about dementia*” and “*Increase the knowledge about dementia*”, which form the headlines within the presented theme.

Contribute knowledge about dementia

The participants wanted to inform society about dementia because many did not know enough about the condition. This included society, family and friends. They wanted to make a difference. Elsa explained:

“There are really many who have no idea what we're talking about ... It is with that you get sad that people have no idea, nor will familiarise themselves with it even if we are relatives and are close together and so on they are, to put it bluntly so so stupid” (talks with anger in her voice)

She and others found that many did not know what dementia meant and what it was like to live with it, including her relatives. The ignorance and the non-willingness to understand were described as hurtful. The quote showed Elsa could criticise others' behaviour. Indirectly, she argued it was not her having dementia which was the problem but it was those who did not have it. They were the stupid ones when they did not know about or did not want to learn about dementia. This turned the picture around about who were the stupid ones.

Both groups were upset about society's attitude towards dementia because of a negative stereotype of people with dementia based upon TV programmes and movies. Emma told how some hide dementia because of this picture, although she did not appreciate it as dementia was an illness you should talk about. Emma and Elsa mentioned the importance of the project as they experienced they were not seen as competent any longer, illustrating the stereotypic picture of dementia. Emma told:

“You surely will something like that, because you think you can use it for something that can give benefit and happiness and even develop oneself some more ... do not feel put aside with a dementia but feel that you can begin that I can do that then, and I can use for something ... you you get on the team in a way ... yes even though you may feel more and more outside because you could not be picked up or otherwise ... “

Emma hoped the project would bring something positive towards life with dementia by being a part of a team. Hopefully, it would fight the stigma and the isolation experienced with dementia. She associated the project with positive feelings, showing she found pride in it. To be a part of the project work was associated with the possibility of self-development. At the same time she described how people with dementia otherwise could feel excluded, left behind and overlooked. This left an impression of people with dementia not having a voice in society as seen from the

researcher's perspective. Most participants saw possibilities in the project, especially around gaining quality in life and knowledge about dementia. In the brainstorming of possible project ideas they focused on the experience of dementia together with the need to tell what could be done in life with dementia based upon their experiences with VUK.

Increase the knowledge about dementia

Both groups wanted to contribute knowledge about dementia as living with dementia had become a part of their identity. However, some hoped to gain more knowledge about dementia by participating in the project although they were informed they might not gain personally from their participation. This especially included those newly diagnosed. Those who had lived with dementia for a longer period were more relaxed about their knowledge-base. Johan thought that people talked about dementia dependent on how far they were in the process of accepting it. All those who wanted more knowledge could explain the symptoms of dementia, showing they already had some knowledge. Kurt told:

"...and what is said, and what it is you do not remember and things like that. I think this is very interesting and particularly interesting because when we know it, it is something we can tell others about ... Yes it is the meaning of it (the researcher writes on the board) and it will of course come in the end of the project we come to progress but I think it's interesting"

Kurt explained there were different types of dementia and memory problems by mentioning how it was named and what you could not remember. For him it was important to seek more knowledge so they could inform others about dementia in order to help. Not many supported this idea. Instead, Johan argued it was important to spread knowledge about dementia based upon their experiences which most participants agreed with. However, Kurt remained focused on searching for information about dementia in books, through the internet and by asking the researcher.

Another reason why they wanted to be involved was they wanted to help the researcher. To contribute to a PhD project was important and they wanted the results to be useful for both society and the PhD. Both groups had high ambitions and the Tuesday group even talked about creating internationally relevant results. This put pressure on me as a researcher and it could be questioned if they were realistic, being novices in research. However, they were driven by awareness of the knowledge and attitude in society which they wanted changed so others could have the same opportunities as them, showing a type of activism.

7.2.3 PREPARATION FOR DATA COLLECTION

In the next sessions (sessions 2-4) the participants were trained in the data collection. Session 2 focused on what characterised research and research ideas. Here they discussed what research meant, prompted by pictures and drawings. See picture 2 illustrating the visual prompts the participants used.

Picture 2: Pictures and drawings



Pictures and drawings used for discussing what research was

Their suggestions were written on big post-its. Then they were informed about what characterised a project idea supported by the session papers. Then the participants chose the research idea they wanted to work with based upon ideas from the interviews and the brainstorming conducted in session 1. There were ten ideas brought up by the participants. See table 12 for the project ideas.

Table 12: Possible project ideas

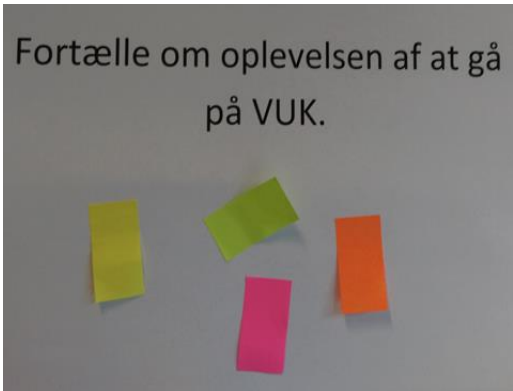
Project ideas generated by the interviews and the brainstorming activity
Describe the most common dementia types
Tell about the experiences/problems you can have with dementia
To raise awareness and understanding of what dementia is
Why does it have to be so negative to live with dementia? The humour and the positive attitude's meaning
Tell about how you can live well with dementia. To stay active and be social
Tell about the experience of attending VUK
Tell about the changes of roles that can happen in a family when you get dementia
Tell about the losses you can experience in life with dementia
Ways to remember and learn in life with dementia
Practical advice when being together with and talking with a person with dementia

The participants voted using post-its to identify the research idea. I did not take part in order to ensure it was the participants' decision. See picture 3 for illustration of the voting process of the Monday group.

Picture 3: The Monday groups' voting



The possible research topics. See table 12 for translation of each topic

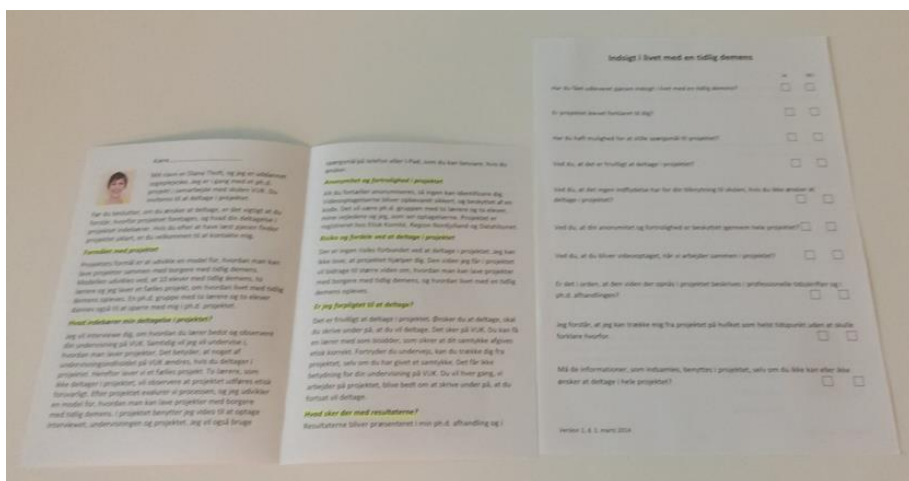


Chosen research topic: Tell about the experience about attending VUK

The Monday group voted several times and the ideas which had less post-its were excluded ending up with the project idea “*Tell about the experience of attending VUK*” while the Tuesday group wanted to work with “*Tell about the experiences/problems you can have with dementia*”. Then a research question was formulated. The Monday group formulated the research question: “*How do we experience attending VUK?*” and the Tuesday group formulated the question: “*How is it experienced to live with dementia?*”. The groups wanted research questions that “*educated*” society about dementia and about relevant services, showing congruence with their motivation. Finally, a brainstorming activity on how to work with the research questions was undertaken.

The next session was about inclusion criteria, research ethics and data collection methods. With support the participants found they could be the informants because they fulfilled their formulated inclusion criteria. When discussing the ethics of the research, I used the information leaflet and consent form from the PhD study as the participants had seen and commented upon them before. See picture 4 for illustration of the information leaflet and the consent form.

Picture 4: The information leaflet and the consent form



Information leaflet and consent form from the PhD project for discussing research ethics. See appendix G and K for translation

The important elements were highlighted so they could focus on important sentences, which made it concrete although it still was challenging. The groups agreed if their projects were conducted in line with the leaflet and consent, their projects would be ethical. Afterwards, they were introduced to qualitative and quantitative research and it was explained qualitative methods were relevant in their projects because of their focus on experiences. Hereafter, they were presented with four qualitative data collection methods: Interview with cue cards, story with a gap, storytelling with pictures and a diary. All methods were shown visually. See picture 5 illustrating the methods the participants chose from.

Picture 5: Possible data collection methods



The different data collection methods introduced to the student participants: Story with a gap, interview with question cards, storytelling with pictures and diary

The visualisation helped the participants stay focused when choosing the research methods using the same voting system for the research idea. Both groups decided to work with interviews with question cards because it was most structured, helping both the interviewer and interviewee to stay focused.

The last session introduced the interview and the groups formulated 5-7 question cards. Thereafter, the cards were prioritised with numbers to create a logical structure. Finally, the participants practised the interview in pairs. In general, the participants needed support to complete the tasks described in these sessions. This led to the theme *"You may be our conductor"* describing my role in the project.

7.2.4 “YOU MAY BE OUR CONDUCTOR”

The participants were aware their dementia influenced the project and they described the researcher’s role as the conductor to ensure the quality of their project. The overall theme “*You may be our conductor*” was consolidated from collapsing the coded initial potential themes “*Structure*”, “*Repetition*”, “*Language problems*”, “*Different types of questions*”, “*Visual prompts*”, “*Suggestions*”, “*Power*”, “*Give and take control*”, “*Motivation*”, “*No mistake attitude*”, “*Repetitive behaviour*” and “*Adjustment*”. Five sub-themes were identified within the theme “*Structure and repetition*”, “*An understandable language*”, “*Questions and suggestions*”, “*The power relation*” and “*Acknowledge and adjust to keep focus*”, which form the headlines within the presented theme.

Structure and repetition

During the sessions both groups had difficulties in focusing, for example, in managing the work plan and session papers, regardless of the structure used. Support was therefore essential to explain the steps of the work. Also mentioning paragraph and page numbers when moving from one paragraph or page to another was needed. I explained:

"Yes well. As I have written under point 6, page 6 for I also have another check I would like to do with you. Point 6 here" (points to Henrik)." *Yes, we have chosen this project idea up here and this project question"* (points towards the board)

I both mentioned paragraph, page numbers and pointed where they were, observing, supporting and conducting the project at the same time. I used the text in the session papers and pointed towards the board to enable the participants to follow me, using repetition to help them recall their research idea. This was useful as more participants recalled things from earlier sessions when using repetition. Also the overall structure became familiar for them as it was repeated. Some even pointed out when the researcher changed things from the way it was done earlier.

Peter: *"Yes, but you have not done anything"* (points to the board and looks at the researcher)

Me: *"No, but I will come to that"* (looks at Peter) *"I promise that I'll do something ... I have some new material for you today"* (gives session papers to Peter)

Peter: *"Yes"*

Me: *"So that's what we need to look at today"* (gives session papers to Elsa, Ernst and Bent)

Peter: *"It looks like the one we got ..."*

Peter commented that I had not put up post-its as I had done earlier, recognising that things were different from the way I had started previously. He also recognised the structure of the session paper, mentioning it looked like the papers they received earlier. It showed the participants learned and remembered things regardless of their short-term memory problems.

An understandable language

In the project the participants were not taught research terminology, instead the everyday language was used as it was anticipated research terminology was challenging to understand and remember. For instance consent was explained as a voluntary contract and anonymity as being allowed to talk about a project but without anyone being recognised. When I used unfamiliar or foreign words it was also commented on by the participants. For example, Ernst commented that I used the word brainstorm without explaining it. It showed how he wanted the language to be understandable.

In both groups language problems were seen. It could be problems with understanding words, remembering what to say and/or expressing certain words. Especially foreign words with more than two syllables were difficult to pronounce. I supported with explanations, suggested words and gave verbal and visual clues. This also included drawings; for example, I explained to Kurt the difference between dementia and Alzheimer's disease by drawing an umbrella, talking about dementia being the overall term (the umbrella) for different types of dementia (the rods of the umbrella). After this illustration he distinguished between dementia and Alzheimer's disease and it helped Henrik to understand Parkinson's disease was a type of dementia. He thought he had a flash of understanding when seeing the drawing as he earlier had seen the symptoms of Parkinson's disease as bad behaviour but now understood it was another variant of dementia to the one he had.

Questions and suggestions

To use different types of questions was useful as it gave the participants a framework to talk from. Repeated and reformulated questions were used when they were unable to answer, becoming more and more specific until they could respond. The questions also varied in how open and closed they were. Often, it was easier for them to answer a question if a context was included, meaning the question was directed. It was more difficult to reply to open, analytical and reflective questions. However, the Tuesday group succeeded in answering an open question about inclusion criteria whereas the Monday group needed specific questions about sex, gender etc. It showed the groups had different analytical reserves, which made me use different levels of questions. Questions were also used to guide the participants and in response to what they said to ensure a correct understanding.

Bent: *"It is research certainly"* (holds a picture)

Me: *"Yes it is research. What is going on? Where is it going on?"* (Sits down beside Bent and leans towards Bent)

Peter: *"I do not know. Is it something that is going on"* (points towards the samples at the picture)

Me: *"Yes that is some samples something like that, right?"* (Leans back)

Bent: *"It's probably something going on at the hospital something like that"*

Bent understood the meaning of the picture but no details were mentioned which made me ask two questions in a row which might be inappropriate but it made Peter answer the first question verbally and non-verbally even though he was unsure. I supported him with words. This helped Ben to answer the second question, maybe prompted by the word 'sample' suggested by me. This showed how a picture together with questions and suggestions prompted them to come up with relevant suggestions about research. The picture here functioned as a visual prompt. Often I also summarised what they had said relevant to the project and asked if this was all right to use. In this way their voice was included based upon the researcher's analysis, interpretation and reflection.

The power relation

At times, it could be questioned if I was too directive in the project as my questions were more or less rhetorical:

"Is it not something like what we experience by attending here at the school? Is it not pretty well done? I think actually it is"

Here the participants were assumed to agree with me, showing I was satisfied with the work. This showed I could overview the work by evaluating, having a powerful position. Although positive, it illustrated how I used my power to lead the project. I connected the sessions with explanations so the participants did not have to do so. This was also done in the end of the sessions where I described what to do next time based upon present work. Consequently, I worked with the past, present and future within the sessions, illustrating a progression in the project. It meant no pressure on the participants because they were always informed, using my overview to support. This was also the case when formulating the research question. Here I came with suggestions, using my research knowledge but at the same time asked their opinion to reach agreement before a decision was made.

Me: *"... And I could imagine that our project question could be this and now you may tell whether you agree or not. That is, how it is to attend the school VUK. Could it be that? How we experience attending the school. Could it be our project question?"*

Emma: *"Like it, like it a lot"*

Peter: *"Yes. That's why I'm sitting here, right?"* (Laughs and looks at Ernst. Ernst laughs and Peter chats his arm)

The quote showed how I ensured the participants were given control in tasks difficult for them to solve. The Monday group accepted the formulated research question and so did the Tuesday group after discussing the formulation. After formulating the questions both groups began to answer them instead of discussing the relevance of them as I asked. This showed they found the research question manageable and relevant but also that it was difficult for them to be critical. The same happened when formulating the question cards. Here I had to interpret the participants' comments and formulate them as interview questions to give them most possible influence in this task. Here I balanced between taking control and giving control to the participants.

The participants were aware of my power in the collaboration, mentioning I only presented some data collection methods, but for Kurt it was natural as I was the conductor. I restricted the possibilities to make it manageable for the participants, setting a framework from which they could choose. In both groups a few commented on the advantages and disadvantages of each method. Some struggled with deciding because of loss of initiative and concentration problems. Here I supported by going through each method with them. This helped them to choose but it required time. Overall, time was important, so nothing was rushed through.

Acknowledge and adjust to keep focus

During the sessions I acknowledged and recognised the participants' comments and suggestions by using positive feedback. For example, emphasising that they were the best to answer the chosen research questions because of their personal experiences with dementia. They were motivated; they concentrated and worked hard and never refused to work. At times they even asked for introduction of tasks before I had done so, showing their motivation. The training was inspired by errorless learning where I acknowledged the participants' contributions although these did not answer directly the posed questions. Here I tried to connect the contribution to the project from a 'no mistake' approach. Some needed more support to raise their voice, which made me ask those who could keep focus for a long time to wait until those with more impaired short-term memory and latency had expressed themselves. Repetitive behaviour also had to be managed, for example, Emma repeated the same story about her mother:

"Then I got her home to live with me and when I sometimes came in and she sat in the living room and walked around so she clapped her hands together and then she said" Nooo you have found me"" (Emma claps her hands together and talks with exacted voice)

This story was repeated throughout the sessions with almost the same words. Mostly, the participants were allowed to repeat their stories as they were almost impossible to

distract. Occasionally, it disturbed the group which made me restrict the length of the stories. To get the group back on track I related their stories to what the group was working on. Some were aware they got side-tracked and apologised when they realised it. In the end of each session their work was summarised to help them see what they had contributed and I expressed satisfaction with the progress.

Also adjustments were made to keep focus. For example, when practicing the interviews some participants only came up with short answers. To get more in-depth answers I adjusted the training asking permission to support with supplementary questions. This was accepted and I supported those who struggled. This helped all to succeed with conducting the interviews. After practicing, it was agreed that I would support those in the interviews who needed it, which had not been planned at the beginning. Another adjustment was the planned breaks so the participants would not get exhausted. However, Ove explained they did not want these breaks because they would forget what they worked with, although it was observed they appreciated the small informal breaks that occurred which allowed chatting. After an informal break, I summarised their work and presented what they had to work with before beginning again. I also adjusted the way the folder was used because it was difficult for many to organise, so instead of asking them to do it I asked for the papers and folder in the end of the session and then I organised them. Those who managed to organise the folder continued to do so before handing it to me.

7.2.5 DATA COLLECTION AND ANALYSIS

The data collection and analysis covered session 5-8/9. In these sessions personal experiences with dementia were revealed, leading to the theme *"We are still the same even though we are not the same"*. Also their special relationship was exposed around how they supported each other. This led to the theme *"To be with the likeminded is liberating"*.

Session 5 focused on conducting the interviews with question cards. First the techniques in an interview were presented supported by the session papers. Afterwards the interviews were conducted in pairs and video recorded. All participants conducted the interviews, although some had support because they struggled with the order of the cards or to ask or answer questions. However, all understood the structure of the interview and used the question cards to ask questions. Indeed some in the Tuesday group gave very in-depth answers without any support. They also adjusted the interview if a question already had been answered or found something interesting to expand, showing a great overview.

In session 6-8/9 transcripts from the interviews were analysed. I transcribed the interviews and condensed these to anonymous narratives for each group. It was challenging to analyse and interpret the transcripts and some got confused when they could not see who had said what. Each person highlighted essential sentences

supported by an analytical question relevant to their research question. It captured the participants' opinions as the highlighting kept it visible for them. Both groups needed repeated instruction in the analysis which helped them become more confident in highlighting. I wrote the highlighted sentences on post-its and placed them on a board to cluster them in themes. Here some participants took the lead because they saw the connections between the post-its. They pointed out overlaps and discussed the suggestions that were made. This was also the case when the groups afterwards formulated headlines for each theme. See picture 6 for illustration of the Tuesday group's themes based upon the sentences written on post-its.

Picture 6: The Tuesday group's themes



A theme from the data analysis with the headline: The social community is also important

Laugh and talk seriously together

Nice to talk about what you can do

To talk helps

You always have to take new standpoints

It is best that it is me who is telling about dementia

A talk with the GP

Dare to step forward and talk openly about dementia

Activities are good + nice – High school – VUK – Other things

So you have a good life and a good community

Good company and to get an overview



A theme from the data analysis with the headline: Consequences and impact of the dementia

Acknowledge that you can need help

Acknowledge that you have difficulties in remembering and this can be negative

It is negative with the short-term memory

I take it as it comes. I am happy and satisfied

Not able always to find what I need to use

Aggressive

Person names are difficult to remember

I need to get as much as possible out of it

The present is important

I feel better now and is not nervous

Happy that it progresses slowly

Take it easy and enjoy things

The family breaks a little

My experience with dementia has not been negative

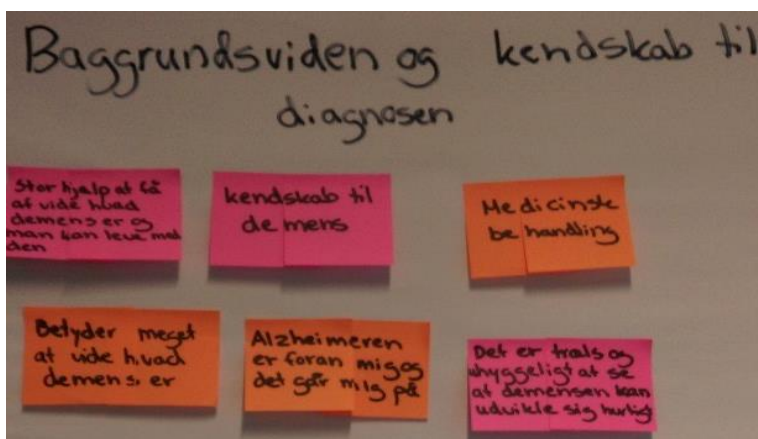
You have to be at the top but it is not possible all the time

Life has not stopped and is not broken

Different perceptions about dementia

I have it well with the dementia

It is difficult to get into gear – insecurity in the traffic – no driving



A theme from the data analysis with the headline: Background knowledge and knowledge about the diagnosis

Great help to get knowledge about what dementia is and that you can live with it

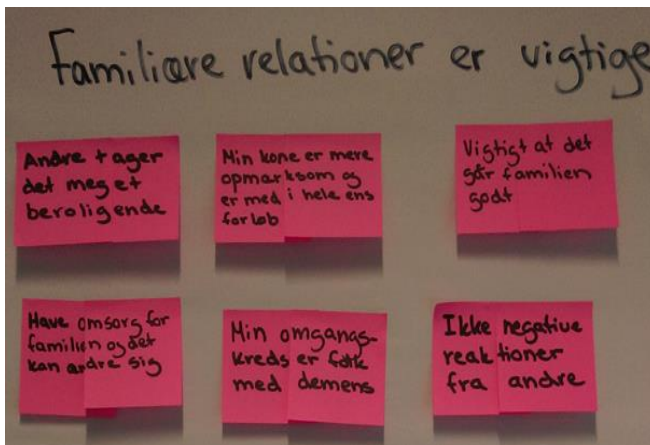
Knowledge about dementia

Medical treatment

Means a lot to know what dementia is

The Alzheimer is in front of me and it bothers me

It is negative and awful to see that the dementia can progress quickly



A theme from the data analysis with the headline: The family relations are still important

Others take it very calming

My wife has more attention and is with me in my process

Important that it goes the family well

To care for the family and it can change

My social circle is people with dementia

No negative reactions from others

Finally, the themes were interpreted from the perspective of living with dementia and quotes were found for each theme by using same highlighting procedure as for the

identification of the themes. I then wrote the interpreted themes with quotes into a coherent text.

In this process the Monday group needed more support than the Tuesday group. For that reason the group's analysis seemed superficial compared with the Tuesday group whose process took longer because of productive group discussions. Consequently, the Tuesday group did the data collection and analysis within session 5-9 whereas the Monday group did it within session 5-8. The analysis was time consuming although they worked with concentration. A progression in dementia challenged the work for several and the analysis was therefore adjusted to their abilities. For some it changed from one session to another or even within a session.

7.2.6 "WE ARE STILL THE SAME EVEN THOUGH WE ARE NOT THE SAME"

All were aware of their dementia and how it influenced them but at the same time they thought they were the same person as before dementia, although they were changed. The overall theme *"We are still the same even though we are not the same"* was consolidated from collapsing the coded initial potential themes *"Knowledge about dementia"*, *"Positive towards dementia"*, *"Negative towards dementia"*, *"Learning"*, *"Memory and language problems"*, *"Losses"*, *"Coping strategies"*, *"Insecurity"*, *"Openness about dementia"*, *"To socialise"*, *"Fight the dementia"* and *"Enjoy the moment"*. Three sub-themes were identified within the theme *"Dementia is experienced differently"*, *"Dementia changes life"* and *"Get the best out of life"*, which form the headlines within the presented theme.

Dementia is experienced differently

All knew what dementia was and several talked about how they had known family members, friends or neighbours with dementia. Many described different symptoms of dementia. Emma described her experiences with her grandmother and mother having dementia:

"... Because incredibly sweet but her dementia did, yes so that she could not figure things out but never aggressive in a negative way. It was when she got scared and could not figure it out. In this way, I think that my dementia, I am fully familiar with it because I have experienced what happened to her and have so sweet a mother who was yes demented. It is not life's most terrible thing that has happen that's how I feel it and I feel good to have it"

She found her mother sweet but forgetful, explaining how the personality could be positive even though competences were lost. Her experiences made her think dementia was not the worst thing in life. She mirrored her own life with dementia in the life of her mother, using her experiences in her present life situation. She saw herself being the same person as before she got dementia but with losses of

competences. This was a positive way to see herself. The quote showed she could share her experiences with dementia in a logical structured way. She described dementia, explained the aggressiveness and concluded positively about dementia in a logical, well-organised way. She illustrated the competences a person with early-stage dementia still had, learning from former life experiences to accept a life with dementia. In Emma's group they talked much about aggressiveness and Johan defined aggressiveness in two ways:

"...But there are two ways to be aggressive. There is the violent aggressiveness" (moves forward on his chair and looks at me) ... "As some have because of the disease, where they change personality. However, there is also the one with the world getting smaller. The psycho psycho psycho just the emotional world is getting smaller" (Looks in front of him and towards me. Plays with the pen. When he cannot say psycho he closes his eyes and puts the head to the left and when saying emotional he puts the arms out to the sides). "Where you now become very very quickly irritated and say so, however, shut up, I understand right?" (Articulates with both hands)

Aggressiveness could be physical because of personality changes caused by the dementia and it could be psychological as the emotional world diminished in life with dementia. For that reason, a person got easily irritated. The group agreed with this, showing a great insight and knowledge about dementia.

Several talked more negatively about dementia, seeing it as irritating and frustrating. Some experienced good and bad days while others did not feel any variations. The bad days occasionally resulted in self-isolation. Henrik was unsure about the possibility of living well with dementia.

Henrik: *"There is a sentence that says I'm fine with having dementia. I will say that it's not me who has..."* (reads from the paper and looks at me and points towards himself)

...

Kurt: *"Yes, yes it is the few who say they feel good being sick"* (looks at Henrik)

Henrik: *"Yes yes"* (Looks at Kurt)

...

Emma: *"Or conversely I am sick but I feel good about it"* (looks at Kurt)

Kurt: *"Yes precisely"* (looks at Emma and points towards her)

Henrik: *"No it is never real"* (looks towards Kurt and then Emma)

Emma: *"Yes, it is really the one you cannot change it. You resign yourself and in that way it becomes true. You cannot get it off. You cannot get rid of it. It is there and you have said to yourself, but then I'll live with it. And then it seems to help. So, you've made it up with yourself, I cannot get rid of ... "* (looks intense at Henrik when explaining and uses hands to gesticulate. She ends pointing towards Henrik)

Henrik: *"I'll think about it"* (looks in front of him)

Henrik initiated a discussion around the possibility of living well with dementia, thinking this was not realistic for him, which Kurt supported with the comment that he thought most people would agree with that. However, Emma argued for the opportunity of living well with dementia in which Kurt could see the reasoning. Yet Henrik still thought it was unrealistic. Thereafter, Emma tried to convince Henrik by explaining her point of view. It seemed important for her he understood that the acceptance of dementia made it easier, focusing on positive coping. To make her point clear she looked intensely at Henrik and pointed. This made Henrik less certain and it appeared he was moved a little in his way of thinking about dementia. A form of negotiation about how dementia influenced each person appeared to take part in the group. The quote showed they performed as dialogical actors and discussed subjects of interest. The groups prompted discussions and disagreements between the participants as they learned from each other about dementia.

Dementia changes life

All participants thought they had changed because of dementia except Kurt who did not feel any changes. He was still happy and satisfied with life. Only his wife had become more aware of his memory, indicating she experienced his memory problems which did not seem to bother Kurt. In contrary Henrik's experience was that dementia had destroyed his former life by memory, language and attention problems. He felt changed, describing how the Alzheimer's disease was in front of him.

"I cannot always find what I need. I have such an impression that the Alzheimer is in front of me. It bothers me. I almost do not know what to say"

This metaphor gave an impression of him trying to catch up with a fast running illness, not being in control of his life any longer. Sometimes he felt like disappearing in his own life which led to a feeling of missing life. The progression of dementia was often related to how long they had lived with it but there was also fast and slow developing dementia. Especially, the Tuesday group talked about how hard it was to see when a dementia progressed fast.

In the peer-interviews conducted in the focus groups all talked about their memory problems, experiencing their memory was not as it used to be. Kurt told how he got irritated struggling to find his glasses and keys, which made Johan comment on the importance of learning routines so it was possible to find things again. This showed how strategies were used towards the challenges they experienced. Johan's advice also showed they supported each other. In general, the memory problems caused unhappiness. Often their memory problems also made it difficult to recall certain words or names.

Kurt: *"so so what is it now called? What is it now called?"* (Looks to the left side and then towards Victor) *..." So then you stop. Then you look a little..."* (looks from left to right and back to Victor). *"Well, well. So you find out another way to say it"* (draws a path on the table)

Victor: *"Well of course but otherwise you say I cannot remember"* (takes up his pen and points with it and puts his other hand in front of him to show it is not important)

Kurt and Victor experienced difficulties in finding the words when communicating with others, which occasionally made Kurt stop during a conversation. Kurt and Victor also discussed how to cope with this, using different strategies. It showed their flexibility and creativity, adjusting to their language problems. Victor seemed more relaxed about it than Kurt who wanted to make his point clear by finding ways to do it regardless of the memory problems. The quote showed the peer-interview was more a conversation between equals than a formal interview, exchanging similar experiences. Also more extensive language problems were seen in both groups which led to misunderstandings and *"talking nonsense"*. They were aware they sometimes said something wrong or something they should not have said. Peter compensated for his language problems with non-verbal signals, using gesticulations and drawings which gave others visual clues. He still communicated although he struggled.

The participants also experienced loss of independence. Henrik related that he had stopped driving and bicycling which was hurtful. He almost felt like dying when he gave up driving. Victor also mentioned how he only cycled the same route, which limited his mobility. It showed they were conscious about their loss of competences and acted reasonably about it. They tried to *"control"* the lack of control they experienced. Kurt, who was the only one driving, commented that the discussion about driving had made him think because he did not want to take any risks. Johan explained it was necessary to accept things had to be given up:

"It has turned upside down everything but then one can get used to it ... Whether you're sick or not you should always take new stands. There is never something that is stationary ... so there are some things you cannot do anymore but you can some other things. Or so you must learn it. Or you may get others to do it for you. To get some solutions"

Dementia changed life completely but life would always change because nothing was stationary. This description of life showed how Johan's experiences formed his opinions about life. He found it was possible to adjust, accept and cope with dementia as you got use to changes. Johan's and Henrik's descriptions showed how they experienced and coped with dementia differently. Johan accepted things had to be given up, focusing on adjusting to the changes by developing strategies. This could include accepting the situation, focusing on manageable things, learning how to do things or asking for help. This illustrated different coping strategies. All were aware of their need of help and most asked for help when necessary. For Emma it was important to be open about dementia because it increased her chances of getting help. She accepted help was needed to live well with dementia and experienced a possibility of growth when receiving help. However, help was not needed for everything, especially when living with early-stage dementia.

Furthermore, the participants talked about how insecurity and confusion became a part of life. Time was difficult for many to overview and it was difficult to remember when to do what. This was also seen in the project. Henrik especially got confused about the anonymised transcript which made me and other participants explain that because everyone had contributed to the text he could not recognise all sentences. This showed Henrik was aware of what matched his life but got confused when reading the answers of others. Other participants recognised their sentences in the transcript and still agreed with them without being confused, showing they had the same opinion on a subject over time.

Get the best out of life

The participants found it was important to talk about dementia and Victor informed his network about what dementia was and meant to him:

"For my part, I am glad that it goes as slowly as it does. It is many years since I got my diagnosis and it goes fortunately slowly. The short-term memory is what it is wrong with. It is the most affected ... I've never hidden it and the surroundings have accepted it. It is a very good thing. I am talkative"

He explained how his dementia progressed slowly and it was mostly his short-term memory that was affected, showing a big insight into dementia. Dementia was not something he was happy about but he was relaxed because it progressed slowly. This might explain why some experienced dementia less negatively than others. He also described how his network accepted the illness due to his openness. He had not experienced any stigma as he was a decent communicator, indicating it could be difficult for people who were less talkative. For Kurt, being open about dementia put him in charge of what to say instead of only answering questions, which gave him some control.

All except Johan talked about how important it was for them to socialise with friends and family. Johan explained:

"Now, I may admit that my peers are people who happen to have dementia. The rest I pretty much kept me slightly from. I know that. It's damn inconvenience of going all the time and tell how you feel. We know how we feel. It's very different"

Johan's social life had changed remarkably after getting dementia as he excluded people without dementia as it was too exhausting to explain. He found it easier to socialise with people with dementia because they shared a common life situation. Johan had made a choice and opted out from what he experienced as not suitable. The others talked about how the family was Alpha and Omega. They were interested in the wellbeing of the family and wanted to support their family even though the progression of dementia challenged this and would make it impossible sometime in the future.

Most also talked about how they fought dementia. They tried to pull themselves together, focus on the positive things and take medicine. To take medicine was described as trying to curb the brain drain. At the same time they all knew dementia would progress, affecting their life negatively. Regardless of this they tried to get the best out of life by focusing on the moment and enjoying things they liked. Of course it took time to come to terms with the situation and one's personality also influenced the process. Johan described how the experience of dementia had changed over the time he had lived with it. In the beginning, he tried to gain control by searching for knowledge about what to do but he had realised there was no right way with dementia. Now he focused on the moment as he had no influence on tomorrow. It was about living in the moment and getting something positive out of it. Victor also took life as it came which always had been his life motto. He still lived like this even after getting dementia, seeing life in the same perspective with or without dementia. The participants still tried to live a fruitful life as they would have done without facing dementia.

7.2.7 "TO BE WITH THE LIKEMINDED IS LIBERATING"

The participants talked about their positive relationship as they were likeminded. They relaxed in each other's company and supported each other through all the challenges that existed. The overall theme *"To be with the likeminded is liberating"* was consolidated from collapsing the coded initial potential themes *"Friendship and relationship"*, *"Positive talks"*, *"Peer learning"*, *"Attending VUK"*, *"Patience"*, *"Support/peer support"*, *"Protection"* and *"Challenges"*. Four sub-themes were identified within the theme *"A special friendship"*, *"To be patient"*, *"Support and protection"* and *"Challenges in the relationship"*, which form the headlines within the presented theme.

A special friendship

Both groups had a close friendship, welcoming each other when entering the project room. They helped each other to settle and were happy with each other's company, appreciating having friends with dementia. In the Monday group they talked much about their friendship and that it was one of the most positive things about attending VUK. Bent told:

"It's the camaraderie. I think at least. I think you get some buddies who you can talk to. I think at least. That's what something worth"

He thought the camaraderie was important because they could talk together. This was very precious to him. Others also talked about how the teachers and students were nice to talk with without getting into "trouble", meaning they did not have to think about how they talked or behaved. They were in good company at VUK. They could relate and understand each other because they all knew about life with dementia, which made them relaxed without being afraid of stepping outside normality. They talked about their activities at VUK and more personal things, being interested in each other and asking question. After bank holidays they 'smalltalked' much about their experiences with family and friends. All engaged in these talks. Also more serious things were talked about in both groups. Kurt told about his experiences with dementia:

"I saw it with Eva there. William's wife like that was so far along. Yes, and it was my mother in law actually also. "But who are you? What do you want here? "" (looks around the group and gesticulates with the hands) ... " So it's not so funny" (looks ahead of him and hands put together in front of him)

Kurt described dementia as a negative progressive illness from the two cases he had experienced. He gave examples of questions that were hurtful to be asked as they indicated no recognition and no welcome when visiting. Many had similar experiences they shared. They gained from these talks as it was characterised as a peer-learning, getting inputs they could relate to their own lives. They also prompted each other when they talked and I observed their reservation about talking about dementia decreased during the sessions and especially within the interviews when they were very honest about their situation. They also shared critical voices because they felt it remained within the group. They seemed to appreciate having a private confidential room where they shared peer experiences. This was not described in relation to family and friends, possibly because they did not always share thoughts and feelings around dementia with those close to them.

In general it was experienced as positive to meet and talk with other people with dementia. It was positive to get out of the house and attend VUK. They wanted to avoid being isolated at home, enjoying getting out. Ove explained he attended VUK to avoid the risk of getting inactive at home. For him it was important to get new

inputs to take home and talk about, contributing something to family life. He showed initiative in preventing being mentally and physically isolated by staying social and active regardless of dementia. Others also mentioned it helped memory to get new inputs from people.

Furthermore, the participants were interested in me and the PhD project as it gave them an opportunity to collaborate as a group. Victor stopped attending VUK during the project but continued in the project because he enjoyed the work and being a part of the project group. The relationship with me also developed during the project so that they began asking personal questions about my working life and children. Johan even expressed concerns about me succeeding with the project in time, illustrating his engagement with me.

To be patient

Most of the time, the participants socialised regardless of various eccentricities due to dementia and adapted without asking questions about why some acted in a particular way. They were patient and tolerant and when one spoke, the rest of the group paid attention to what was said. It gave everyone a voice, showing dialectic between an individual voice and group voice within the groups. This was also the case when one repeated him or herself. They did not interrupt although small comments afterwards indicated some remembered the story from earlier occasions. They were also patient and supportive when someone struggled with telling.

Ove: *"You were in Copenhagen this weekend. Were you not?"* (Takes the glass and looks at Peter)

Peter: *"In the weekend. We went damn all the way around"* (looks at Ove and me and shows the way around with the left hand)

Me: *"So you came out fine and ..."* (looks at Peter)

Peter: *"on the walls like that ..."* (draws a big circle with his hand in the air)

Ove: *"Yes, I also think that you told me that last week that now you went to Copenhagen"* (drinks the water and puts the glass down and looks at Peter)

Ove helped Peter to say he had been in Copenhagen so Peter could tell his story although he missed words. With Ove's help the group knew Peter was talking about Copenhagen. No one interrupted Peter when he told about the walk he had taken. Also during the analysis, patience was demonstrated by those who managed to highlight the transcript quickly. They stayed quiet and moved on in the text instead of disturbing those who needed longer time. Often those with most resources also allowed others to speak first. For example, Johan and Ernst mentioned how they observed that I

supported those who struggled most to raise their voice in the group and they found it okay that they then had to be silent. They stayed in the background until their contribution was needed to progress the work. It showed their insight and wish to include all in the project, illustrating that inclusion in the project was not only about me including the participants, but also about the participants including each other.

Support and protection

In both groups those with most resources helped others without being encouraged to, showing empathy and peer-support towards each other. This was also seen in the interviews where some participants used their pre-understanding to come up with supportive suggestions and repeated questions when necessary. Some even specified the question so it was easier to answer. Ernst was concerned about interviewing Peter as he was afraid he could not understand him because of his language problems. When conducting the peer-interview he supported Peter by suggesting words, names and by correcting Peter's answers.

Ernst: *"You are not sorry to come here?"*

Peter: *"Yes, yes"*

Ernst: *"No, you're damn not regret coming here. You are happy to come here at the school?"*

Peter: *"Yes with someone like you"*

Ernst: *"Yes it provides us unity. Is it okay?"* (Looks at Peter)

Peter: *"Yes"* (looks at Ernst and laughs)

Ernst corrected Peter and rephrased his question as he thought Peter misunderstood the question. I observed Ernst used irony in his first question, which perhaps confused Peter. Peter agreed with Ernst and Ernst explained the reason for correcting the answer and asked if it was ok with Peter. It showed Ernst did not want to decide Peter's answer. During the peer-interview Ernst gave Peter positive feedback although he supported Peter hugely by using his pre-understandings about him to help pre-configure his answers. This illustrated how the participants took and gave control in their collaboration which was also a characteristic for the collaboration between the participants and me. Support was also around practical things, for example, sorting the session papers, explaining things and correcting inaccuracies.

At times the support worked as a form of protection. This was seen when Johan interviewed Henrik who struggled with answering the interview questions. Here Johan joked to ease the situation.

Johan: *"It's also something awkward she makes us do"* (laughs and claps Henrik's arm and puts the hand on his hand)

Henrik: *"Yes"* (looks at Johan, laughs and looks at me)

Johan: *"Yes it's not an easy task this here ..."* (laughs). *"Well it is basically very out of our normal daily lives both on the one and the other way"* (looks at me). *"That's why it sometimes seems a little bit heavy. Never mind, never mind ..."* (looks at Henrik). *"It is not us who have an exam when it comes to the crunch. It is she who..."* (points towards me and laughs)

Johan justified how demanding the interview was for Henrik because it was different to their normal activities and Henrik agreed. Johan joked they did not have to worry because it was not them who had to pass an exam. Here Johan tried to make Henrik relax by using humour and positive non-verbal signals such as clapping Henrik on the hand and arm. He protected Henrik in a situation that was difficult but without connecting it to dementia. Henrik responded positively towards this and laughed. It showed how Johan was competent in reading and handling a difficult situation. This kind of protection was seen in both groups. Interestingly, the support also included me. For example, Henrik helped me by putting his hand on Emma's arm to let her know I was trying to get Emma's attention during the analysis work. A few participants in both groups also pointed out when I made mistakes, forgot paragraphs or duplicated quotes in the analysis. They also interrupted if I moved on too fast, helping keeping focus in the project.

Challenges in the relationship

Although the relation between the participants was positive and supportive challenges also existed. Some found others' behaviour disturbing or irritating, for instance, when Kurt had a mobile phone ringing during the project work. Also Elsa got irritated towards the men in her group because they disturbed her so it was difficult to concentrate. Their talking was too noisy. Also Emma and Henrik in the Tuesday group were easily disturbed if too much talk was going on. Elsa did not appreciate some of the tone in the group especially between Ove and Ernst. Often Ove and Ernst teased each other. Nevertheless, they discussed and disagreed in a friendly atmosphere. Both groups had discussions related to the project, for example, about interpretations of their work. Especially it was those participants with the best preserved language who discussed in the groups as it was more difficult for those with language problems to get their viewpoints across in a discussion.

7.2.8 PREPARE DISSEMINATION

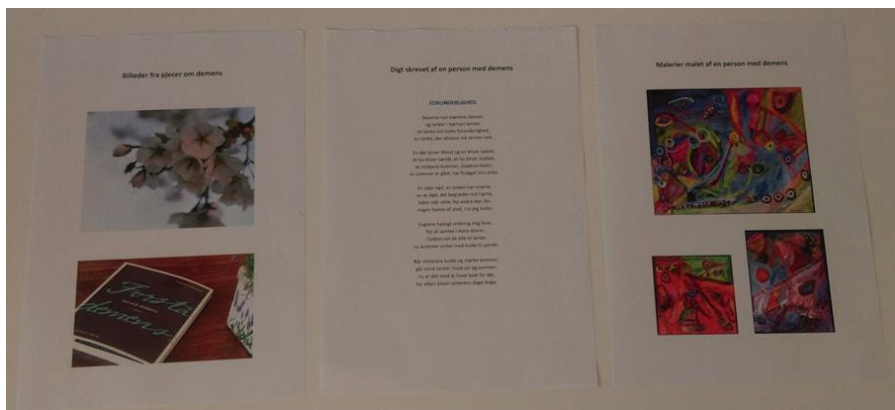
In session 9/10 the dissemination was prepared. Here the participants' positive attitude and humour were present. It was important for them to focus on the positive things revealing a theme named *"Why does it have to be so negative?"*.

In the session I asked for renewed written consent for presenting their results in a local newspaper and a television report. This was talked about in several former sessions

and in this session a renewed written consent was gained. Some immediately consented while others discussed it with relatives first. In two cases the participants wanted a teacher advocate with them when consenting. As Bent said it was nice to have someone with him although it was not necessary. All wanted to participate in the public dissemination except two but no one withdrew from the project. In general the participants questioned the need to ask for renewed consent and it became something they joked about.

In the session both groups corrected the written analysis and interpretation I had conducted based upon their contributions. The researcher read the analysis and the participants commented on what they wanted changed. Only small corrections were made and then they were presented with three different creative ways to supplement the analysis. It was: poems, paintings or pictures. See picture 7 for the visual presentation of the methods.

Picture 7: Possible creative methods



Examples of creative methods to supplement the analysis: Pictures, poems and paintings

Both groups wanted to supplement their analysis and they voted to choose a method. Both decided to add pictures and they brainstormed what pictures they wanted. Their suggestions were drawn by me on big post-its, which created fun because of its poor quality. It was decided that I would find matching pictures to the drawings to present in the next session.

7.2.9 “WHY DOES IT HAVE TO BE SO NEGATIVE?”

The participants enjoyed a good laugh and talked about the importance of not focusing on negative things. However, humour also had undesirable consequences. The overall theme “*Why does it have to be so negative?*” was consolidated from collapsing the

coded initial potential themes "*Humour is positive*", "*Joking for fun*", "*Joking for coping*", "*Exclusion*" and "*Critique*". Three sub-themes were identified within the theme "*Humour is positive*", "*Humour used towards dementia*" and "*Humorous tensions*", which form the headlines within the presented theme.

Humour is positive

In both groups much humour was used, often initiated by those with most resources, although all participated in the humour. They used humour in different ways, for example, by turning the meaning of words around, by using dialect or telling old stories. In the Monday group a story about one village in the region was repeated often by Bent. There was a saying about the village that you had to drive fast through the village otherwise you would lose your hubcaps and they liked to fight. All knew and recalled the story and linked it to their project, saying they started a fight if disagreeing. The joke linked them together as a group as they all understood. They recalled jokes from their youth and used them in the present situation. The joking was especially used among participants who knew each other well and less towards newer students. They often teased each other in a humorous way.

The project work was also joked about. For example, Kurt joked about not being satisfied with the result of the voting regarding the creative methods used to supplement the analysis.

Kurt: "*Uh the purpose of teaching today has been getting Johan and me down*" (looks down, points with a pen towards the papers and points towards Johan and then looks at me)

Me: "*Nooo it has not*" (Looks down and laughs)

Kurt: "*Well do not you think so?*" (Looks at me, laughs and looks around in the group)

Emma: (Laughs) "*Oh you poor thing*" (Looks at Kurt and laughs)

Victor: "*I suppose the purpose. You have that ... [...]*" (looks at Kurt and then down in his papers he sits with in his hands and smiles)

Emma: "*I'm coming to pick you up*" (looks at Kurt)

Kurt: "*Do you?*" (Looks at Emma and laughs)

Kurt initiated a joke about the result of the group's voting, pointing out it had suppressed him and Johan. He remembered this in the end of the session. The group found the comment funny and both Emma and Victor followed up on Kurt's joke. Victor confirmed it had been the purpose to tease Kurt while Emma pitied Kurt and said she would pick him up as you would say to a child. Victor and Emma used both irony and Emma also used grown-up versus child humour. The participants initiated

the joke without any interaction from me other than denying the allegation. To have fun was appreciated and understood on a high level.

They also joked about how hard they had to work in the project. Ove and Bent questioned how much I could decide as the conductor and joked about refusing to work. In reality they did not but it was funny to tease my position in the project, knowing I depended on their contributions. Here the participants possessed power because they could withdraw whereas my power related to giving or limiting their voice in the project. The jokes also showed the existing trust between the participants and me where they were comfortable about joking me about my mistakes and memory problems. They joked I was becoming one of them. Normally, I did not joke but I followed up when the participants initiated it. Often I supported the one being teased to balance the situation. When I initiated jokes, it was about myself, for example, about my drawing skills. This made the power relationship less dominant, although I was the one ending the joking to get back to the project, as I was the one leading the work.

Humour used towards dementia

Jokes were also used about dementia and the challenges they faced, laughing at their mistakes and memory problems. Bent often joked in situations where he or others struggled, which frequently meant they lost focus. Also Ove used humour to take the pressure out of difficult tasks, for example, when Helen helped him arrange his session papers as he had placed them in the folder too early.

Ove: *"You are damn clever"* (looks at Helen)

Helen: *"Yes I am precisely"* (organises his papers)

Ove: *"It will say that you are my secretary?"* (looks at Helen)

Helen: *"Yes"* (puts the papers in front of him and smiles)

Ove: (looks around and laughs)

Ove joked about the papers, which helped the situation not to become awkward for him, although Helen took over. Helen followed up the joke, indicating it was no big deal for her to help. The joke Ove used indicated he was powerful with his own secretary. He was in charge, turning the power situation around and making fun of the help he received.

Both groups also joked about their difficulties in following the structure in the sessions. For instance, when Bent and Victor did not manage to follow the structure in the analysis, because they had jumped between pages, they joked it was because they were enthusiastic and hard workers. Here the group was described as slow instead of them failing. Ernst also joked about me using red tape when having problems with

organising the session papers. Here it was my fault it was difficult to overview the papers. Also more general problems in life with dementia were joked about. Ove commented he occasionally became a bit hopeless showing he was aware of the challenges dementia caused. Also in the evaluation the Monday group joked a lot, ending up with few in-depth answers. Nevertheless, both groups were happy about the process and did not focus on the negative by not recalling the work conducted.

Humorous tensions

Overall the humour had positive effects but occasionally it also created tensions. This was especially seen in the Monday group. Often Elsa did not appreciate the humour Bent used or the noise the jokes created. Here the humour was experienced as disruptive and irritating which made it difficult to concentrate.

Elsa: (leans forward and looks intensely at me) *"You know what. I actually think that you have done very well because when I think of those (looks around towards the men) guys here?"* (Looks at me, laughs and claps Ernst on the shoulder)... (laughs and gets serious in voice) *"I will now admit that sometimes I have thought oh please just shut up"* (laughs)

Elsa's critique was raised in a humorous way by laughing and clapping Ernst as she explained how she got annoyed and had wished they sometimes had shut up. Her attention was withdrawn from the project caused by the humour used. She recalled the atmosphere in the project work, which she was not satisfied with all the time. The humour had excluded Elsa as she did not participate in it. For others the exclusion was more related to difficulties in following the funny situations due to the progression of dementia. This was seen in both groups. At times some looked down in the papers or stared out of the windows when others laughed. Then, when I focused on the work they continued to engage in the group. Here the humour excluded those with language problems and severe memory problems.

Humour was also used to give indirect critique. Many were critical towards the need of a renewed verbal consent in the project and joked about it. For example, Emma said 'no' to not participating in the project. Also Victor, Johan and Kurt joked about the consent.

Victor: *"Well, okay then"* (looks at me and laughs)

Johan: *"Otherwise we would not get in here right?"* (Leans forward to Victor, laughs and looks at me)

Kurt: *"Was it tomorrow, then we would ..."* (looks at me)

Victor, Kurt and Johan teased me when they said 'yes' today but tomorrow it would be a 'no'. Johan explained that the consent was unnecessary because they would just withdraw if they did not want to participate. He did not feel forced to do anything. It

demonstrated they did not see themselves as vulnerable. The consent became redundant and the need to take extra precautions was indirectly questioned. A continually renewed consent seemed “*unethical*” because it questioned their ability to decide and stay with a decision. They were “*negatively*” affected by this repeated consent. Consequently, some began to consent before I asked for it to get it over with, showing they remembered it was required.

7.2.10 THE EVALUATION

In session 10/11 the evaluation of the process was conducted focusing on the positive experiences of the project. The theme identified in the evaluation was “*It is nice some will collaborate with us*”.

In the session the participants were presented with the pictures I had found based upon the drawings from the previous session (See Appendix L phase 5 for illustration of the chosen pictures). Both groups accepted the pictures, which prompted their memory to come up with different stories. Afterwards, it was planned how to present their results to the fellow students at VUK and the journalist and photographers. It was agreed each participant presented one theme by giving a summarised description of the work, except Kurt who would read a poem he had written about the project. I would support if necessary. In the Monday group the participants highlighted the points they wanted to present. In the Tuesday group the preparation was less structured mainly because of time pressure. The points they wanted to present were only talked about as they thought the highlighting was unnecessary.

Before the presentation an overall evaluation of the project was conducted. A short video was shown about their work before the evaluation. In the Monday group especially Ove, Bent and Elsa had difficulties in concentrating on the video and in the Tuesday group Henrik, Emma and Victor lost attention as well. Johan commented that the video was not appropriate to present to others because it showed fragments of their work, which might also have made it difficult for the participants to follow the video. No one referred to it during the evaluation. Both groups evaluated the project with positive sometimes sporadic answers. They were easily distracted, meaning I had to keep the focus. The evaluation was also challenged as it was difficult for some to recall what they had worked on. However, it appeared using focus groups prompted their memory to come up with more answers by relating to other group members’ answers. It can be noted each session also included a small evaluation with three central questions about the work in the session. These were conducted in order to plan the next session and revealed that they could comment on how they experienced each session. All sessions were positively evaluated and no changes were suggested.

7.2.11 “IT IS NICE THAT SOME WILL COLLABORATE WITH US”

Both groups evaluated participation in the project as being positive and meaningful. They were happy the researcher wanted to collaborate with them. The overall theme “*It is nice that some will collaborate with us*” was consolidated from collapsing the coded initial potential themes “*Meaningful activities*”, “*Empowerment*”, “*Help others*”, “*Grateful*” and “*Organisation*”. Three sub-themes were identified within the theme “*A positive empowering experience*”, “*The purpose is important*” and “*The organisation is important*”, which form the headlines within the presented theme.

A positive empowering experience

The Tuesday group used words as 'exciting' and 'cosy' to describe their participation in the project. They enjoyed being together and the project had never been boring. Several talked about the importance of participating in meaningful activities which could include research projects.

Johan: *"And I think it really is a shame, eeh it can happen that there are any offers that do not fit into one's temperament and behaviour but then there may be some others and I think a way, it is probably better to get out of instead of going to vacuum and mow the lawn everyday"* (looks at me)

Victor: *"Well I think it is exciting and well and it is also nice to be one of the selected"* (looks at me)

Johan described how life could be monotonous and boring if the only activities were vacuuming or mowing the lawn at home. It was important to get new inputs by finding interesting services. He knew different things interested different people, indicating services had to relate to interests as he and Victor wanted to participate in meaningful activities. Victor described the positive in being selected and invited to participate in the project. He was important due to his knowledge about dementia and the project gave him a positive feeling, something he was proud of.

The project had given them more knowledge about dementia. For example, Johan had discovered there was no answer book about dementia since people were unique and because dementia affected people differently. He argued you learn about dementia by living with it but you cannot compare your experience to that of others. He gained insight by listening to how others talked about dementia. Kurt also talked about what he had learned. He felt empowered as the project had prepared him for a life with dementia, and felt more equipped. The work was rehabilitating because they felt more ready to live with dementia. Emma, Kurt and Victor also found talking with the likeminded supported them and gave them inputs as they gained knowledge from each other although they were affected by dementia differently. The project had been a learning situation towards their own illness, giving them a feeling of being empowered and rehabilitated for a future life with dementia.

The purpose is important

The groups found it was important that their results were relevant for society and also for the PhD. It was not enough they themselves were satisfied with them. Johan explained it was difficult to understand what I wanted at the beginning of the project but it was nice to see the results and get their message out. Both groups were satisfied and looked forward to informing society. They were happy I had contacted and collaborated with them.

Emma: *"And that's something that makes us there is sitting in the clamp right that we are very happy that there are some"* (looks me)

Kurt: *"Exactly yes"* (looks in front of him)

Emma: *"...that will work with it in a way so that we get something positive and it's true. It is my experience personally of this, right. It is a gift to get someone who will work with this stuff that can give us some input so we say yes to, and so we also have something to look forward to in this way. Yes"* (looks at me and leans back in the chair)

Emma and Kurt described how grateful they were that the researcher wanted to collaborate with them. Emma explained it was not normal to be involved in a research project when having dementia. She found the project had given them something to look forward to, learning from the inputs and it had been nice to be part of the project. This indicated that she found research activities meaningful even when having dementia.

The organisation is important

The participants appreciated the organisation of the project with groups of 5-6 persons because it was difficult to raise one's voice in a big group where it was possible to hide. Another positive was that they knew each other before starting the project so that they were comfortable to talk openly. If they had not known each other trust would have had to be established, indicating a project group had to trust each other before starting work. Time was also important so they were comfortable about raising and formulating their voice. Nothing was rushed through. The work had been conducted in a constructive and relaxed atmosphere with a supportive researcher. A further positive was that I structured the work and kept the focus so the project did not become a social club.

Victor: *"Of course we can well talk about how it has gone with AAB and stuff and discuss such things but here we stick to the topic"* (looks at me gesticulates with his hands).

Kurt: *"... although we sometimes make a little fun with it. You read up every single time. What should we do and what we did last time, etc. And we still need to be with you and all that comes"* (looks at me, points to the

papers and points forward). *"We are not starting from the beginning but but we'll just get (whistle and points with a finger) oh we are there and there and there. We can certainly follow you"* (looks at me and gesticulates with hands)

Johan: *"The summary"* (looks down in the papers)

Victor, Kurt and Johan found my focus on the work positive. Kurt described how repetition and structure helped them to follow and understand the work although they joked about it. Instead the structure gave a direction that was possible to follow. Also Johan recalled the way I worked by summarising and that I used resumes to support their memory. Victor said he found the way of working very much like going to school again and it was a nice break from daily life.

The folder was also evaluated positively as it gave structure and it was possible to go back if they could not remember the work they had done. They appreciated the combination of text and pictures in the session papers. The pictures gave a visual overview which also was the case with the post-its as they were possible to discard and correct during the project work, making it a flexible way to work. It was positive they were not asked to write during the work. They thought I had succeeded in leading the project and I could carry on in the same way in future projects. Nothing had to be changed, although Kurt would have appreciated more work in the project. This showed the differences in their resources as he managed to write a poem on his own about the project work.

7.2.12 DISSEMINATION

The Monday group presented their results at VUK with the support of me, introducing and presenting one theme. I also supported with questions to prompt more in-depth presentations. The highlighted sentences helped the participants to present the themes in a structured way. In the Tuesday group the less structured planning of the presentation made it difficult for some to present. I created structure for them within the presentation and asked several questions to get more in-depth presentations. For a few it became more a conversation than an individual presentation. Kurt managed to read his poem without any support (Appendix 13). Interestingly, the presentation prompted a student to tell his experiences with dementia. The end of the project was celebrated with cake and coffee and the groups were informed that they would get a folder with the results that they could take home the following week, when I would also say good-bye.

The meeting at VUK with the journalist and the photographers was planned so participants from both groups were present. The teacher advocates divided the students so that the participants who consented to be part of a public presentation met with the journalist while the others did other activities. This was done for protection. Beforehand I informed the journalist about the groups' projects so he could

communicate constructively with the participants. It resulted in two articles. One article from the Monday group about “*Gymnastic to the brain*” focusing on what it was like to attend VUK and another article from the Tuesday group about “*XXX forgets the forgetfulness*” focusing on living with dementia together with a short TV report arranged by the journalist and the photographers about their work. These are not included in the thesis for confidentiality because the participants here presented their project work with names and pictures. This was in accordance with the Danish Data Agency as long as the thesis ensures the participants’ anonymity.

7.3. CONCLUSION

To summarise, this chapter outlines the thematic analysis of the focus groups conducting the participatory research project. The analysis showed how motivated the participants were from the start about the participatory research project. They wanted to “*educate*” society about dementia to provide a more informed picture about dementia, by using their own experiences. However, the dementia challenged their participation in the project and therefore different types of support were needed throughout to ensure their voice was heard. The participants found themselves in a position where they felt they were the same but at the same time had changed and felt challenged in different ways because of the dementia. This could be difficult to manage and took time to come to terms with. It was therefore nice to be able to be together with others with dementia both at VUK and in the project group. Here they shared thoughts and feelings with likeminded people. They also supported and “*protected*” each other. Humour was likewise something they appreciated as it facilitated the socialisation with others and eased difficult situations, but it had to be used carefully not to hurt anyone. Finally, after the participatory project they still found it interesting and relevant to have been involved in and they appreciated the researcher wanted to collaborate with them. They found themselves empowered and rehabilitated after the project by learning from each other about dementia and found I as a researcher had led the project constructively.

The following chapter outlines the discussion of the thesis based upon the knowledge gained from the analysis of the focus groups, the interviews and existing literature with the purpose to develop a participatory research model.

CHAPTER 8. DISCUSSION

8.1. INTRODUCTION

The previous chapter presented the results of the analysis of the focus groups in the participatory research project with the purpose to reveal important aspects about conducting participatory research with people with early-stage dementia.

This chapter discusses the knowledge gained from the analysis of the focus groups, supplemented by knowledge from the analysis of the interviews, the literature review and other relevant literature. The chapter is structured around three essential questions relevant for developing a participatory research model involving people with early-stage dementia. The questions discussed are: *“How to plan and establish participatory research with people with early-stage dementia?”*; *“How to train and support people with early-stage dementia in participatory research?”* and *“How to interact and collaborate with people with early-stage dementia in participatory research?”*. Discussing and answering these questions supports the development of a participatory research model involving the lifeworld perspectives of people with early-stage dementia as the questions inform the reflections and guidances that are essential when conducting qualitative participatory research with people with early-stage dementia. It highlights the support mechanisms needed in the training, in the research project and in the evaluation when following a qualitative research process.

8.2. HOW TO PLAN AND ESTABLISH PARTICIPATORY RESEARCH WITH PEOPLE WITH EARLY-STAGE DEMENTIA?

Challenges exist when planning and establishing a participatory research project involving people with early-stage dementia due to the dementia itself and the lack of research experience of the participants. Furthermore, the literature review revealed that little knowledge exists about how to recruit and gain consent from people with dementia as the group often are protected by guidelines, frameworks and families and professionals (Burns, Hyde et al. 2014, Fisk, Wigley 2000). This can make it difficult to access people with dementia and identify the most appropriate ways of recruiting them.

8.2.1 THE RECRUITMENT PROCESS

The ethics chapter illustrates that existing guidelines and frameworks unexpectedly can support the dominant negative discourse of people with dementia as being too vulnerable to be included in research. This study however demonstrates that it is possible to recruit people with early-stage dementia for research but it is about

matching procedures and guidelines to the participants so the recruitment is both possible and ethical. It is important to be aware that some kind of protection is necessary when involving people with early-stage dementia in research as all of course do not benefit from being involved..

A way can be to access and recruit from an existing service for people with early-stage dementia. This can reduce the protection and the length of the recruitment period. However, it only gave access to a limited number of people with early-stage dementia in the study who all belonged to an active social group. Consequently, I engaged with energetic and active learners and the study therefore excluded people with dementia who are not as outgoing. Using another recruitment procedure might have avoided this self-selection of the participants. However, I can argue that to be social and active was essential for the participants, which was reflected in the theme from the interviews *"We live a social and active life regardless of difficulties"* and in the theme from the focus groups *"We are still the same even though we are not the same"*. This might characterise the majority of people living with dementia. This is supported by the literature review which argues that people with dementia try to be positive, focusing on things they are still able to do, keeping up meaningful activities and maintaining relationships (Clare et al. 2008, Dupuis & Gillies 2014, Papon Young 2012).

Nevertheless, the consequence of the recruitment procedure in the study can be similar to what Bartlett (2012) describes in the literature review around dementia activism where only some with dementia get a voice in research while others, perhaps more vulnerable people with dementia, remain stigmatised and marginalised. Roy (2012) supports this by describing how people with more advanced dementia and more severe cognitive impairments are often not involved in research. This can be seen as a limitation in the study whereas it is relevant in future research to also include more vulnerable groups of people with dementia by developing creative ways of recruiting to ensure variation in the participant population.

Another finding in the study is that the researcher has to be aware of the risk of withdrawal as dementia might progress during a research project. In the study, two participants withdrew as they experienced it as too challenging for them to be involved because of the progression of dementia and them moving to nursing homes. Consequently, the researcher has to plan already from the beginning how to deal with withdrawal. Based upon the knowledge gained from the study, a continuous recruitment to manage dropouts is not ideal when involving people with early-stage dementia in research as the participants found in the theme *"It is nice that some will collaborate with us"* which emerged from the focus groups. It was essential they knew and trusted each other before starting the project. This requirement cannot be met if participants are recruited continuously. It would also take an effort to include new participants into established research groups. A planned long recruitment period

where more people are recruited than needed can instead be useful so it is possible to continue the project regardless of withdrawals.

8.2.2 THE CONSENT

Another finding in the study was the importance of combining assessment methods when assessing the capability of the participants with early-stage dementia to give a voluntarily informed consent. In Chapter 5 it was revealed how for instance it can be problematic only to rely on one cognitive test such as the MMSE-test to assess potential participants' capability to consent as it can result in false positive and negative results as seen in the study. The problems identified in the study are in accordance with the existing critique of the test (Warner, McCarney et al. 2008) described in the ethics chapter. It illustrates the problem of only relying on a one-off assessment as a person's competences can vary day to day because of the dementia (Mckillop 2004). It is therefore recommended to use both a cognitive test and professional feedback when assessing the cognitive capability of people with dementia. In general I find that there is a need to investigate more methods to assess the ability to consent by people with dementia as most of the methods today face the challenge of not being able to give a true picture of the competences as they often are one-off assessments.

In the study, the teacher advocates' feedback on the MMSE scores supplemented the MMSE-test constructively by broadening the results from the test. However, this approach also has its limits as a professional can influence a participant depending on the professional's attitude towards the research project and the participant. This is also seen with the use of proxy consent; with the risk of others (the proxy) deciding what they think is most beneficial instead of what the participant actually wants as described in Chapter 5 (Howe 2012). A close dialogue between the researcher and the professional is therefore relevant during the consent period to avoid participants being included or excluded for the wrong reasons.

Dialogue is also very important with the participants and in the study it was established before consent was gained with the purpose of establishing a trusting relationship with the participants. This seemed to support the participants' decision about participating or not in the research project. Decision-making can otherwise be something people with dementia struggle with (Heggstad, Nortvedt et al. 2012). In the literature review, it was also stated that the researcher has to maintain a close relationship with the participants throughout the study. Negatively, it can be argued such a relationship can make it difficult to refuse to participate. This was not the case in the study where three participants declined to participate, defending their decision based upon honesty in the relationship.

In the study it seemed sensible to use the ongoing consent form presented by Dewing (Dewing 2007) as it continually measures the participants' willingness to be involved

in research. This form was outlined in Chapter 5. However, the participants questioned the purpose of the ongoing consent and mentioned in the theme from the focus groups “*Why does it have to be so negative?*”, that if they wanted to withdraw they would just refuse to attend the project room, which they knew they were entitled to do. Furthermore, the participants who dropped out had no problems in withdrawing without being supported by the ongoing consent procedure. It may therefore be emphasised that some people with early-stage dementia can judge if they want to be involved in research or not, without an ongoing consent. The consent procedure therefore has to be adjusted to the participants involved so it is fit for purpose but at the same time does not irritate or patronise them.

The study can be criticised for not succeeding with this as a renewed verbal consent was asked for in every session to ensure the participants felt they could withdraw from the project if they wished. Based upon the knowledge gained from the study, it is vital not to use a continually renewed consent as a standard procedure when gaining consent from people with early-stage dementia. Instead, it is about developing a procedure that suits the participants in the specific research project. It means more appropriate ways of gaining consent from people with early-stage dementia has to be explored further so future participants are not patronised unnecessarily by well-meaning ethical considerations.

8.2.3 THE PLANNING

The literature review revealed that both formal models of training in research methods and models for participatory research involving people with dementia are lacking (Conder 2011, Yu 2009). Only two participatory models; “*The Partners in projects*” (Parkes, Pyer et al. 2014) and “*Authentic partnership*” (Dupuis, Gillies et al. 2012) were identified in the literature research, which inspired the planning of the project. However, the models were modified to meet the participants’ competences and challenges so the planning was about adjusting to what was possible for them to do, illustrated in the theme “*You may be our conductor*” from the focus groups. Here the participants expressed a need for a conductor who took into consideration their memory and language problems.. Also literature in the field argues that it is important to recognise that dementia influences people differently, meaning those with dementia have different cognitive reserves (Yu 2009), which means it is significant that the researcher has knowledge about the individual participants so relevant participatory research projects can be conducted with this group of participants

The planned research has to be realistic in practice otherwise the use of participatory research models risks being dogmatic and rigid leading to unconstructive collaborations. Having said this, it is of course essential to learn from the existing models as long as they do not stand alone. Every participatory research model has to be adjusted to the involved participants to avoid negative consequences for both the participants and the project. Bergold and Thomas (2012) also argue that participatory

models need to support the participants to articulate their opinions and interests more than following exact pre-formulated steps (Bergold, Thomas 2012).

A finding in the study is that it is necessary to plan a participatory project involving people with early-stage dementia as a process where the researcher uses different data collection methods before the main data collection is conducted because it can be difficult to gain information from people with dementia. For instance, knowledge about the participants can be useful as it makes it easier to understand and support the participants. In the study, information about the participants was gained by using observation and individual interviews before starting the project. These methods are not without challenges as people with dementia do not always possess the discursive capacity to articulate their understanding (Hubbard, Downs et al. 2003). This is also highlighted in Chapter 4. In the study it was also found that the interviews could not stand alone in gaining knowledge about the participants because further background knowledge was needed in the interviews to understand what some participants, especially those with severe language problems, tried to express. Not having any pre-understanding of the participants from the participant observations could have led to the conclusion that they did not express anything relevant in the interviews supporting the negative stereotypical attitude towards people with dementia as having nothing to contribute with as described in Chapter 2. This shows that it can be difficult to use interviews as the only data collection method with people with dementia.

In the study the lifeworld existentials were used as a coding framework for identifying the lifeworld perspectives of the student participants. This can be criticised for imposing pre-defined categories on the interview material and almost contradicting a hermeneutic phenomenological approach. However, Van Manen's work and lifeworld existentials are grounded in a hermeneutic phenomenological approach as described in Chapter 3. Here it is stated that the existentials can guide the reflection in a research process because they are the existential ground in which all human beings experience the world, although not all in the same modality. They are productive categories for the process of phenomenological question, reflection and writing. In the study all four lifeworld existentials: spatiality, corporeality, temporality, and relationality were represented in the participants' interviews but with significant differences. Especially the lived relation (relationality) seemed to be important for them to stay socially engaged and to stay positive to uphold constructive lived relations. To use the lifeworld existentials offered a method to navigate and manage the interview material. It supported and guided the analytical reflection so it extended beyond management of the interview data. Notably, the existentials offered a counterbalance to data immersion and to the researcher's familiarity and closeness with the data. Through the processes of operationalising the lifeworld existentials, I was prompted to explore all aspects of lived experience and not just those that were more prominent or those influenced by own assumptions or presuppositions. This is in correspondence with Rich et al.'s (2013) childlessness study where Van Manen's lifeworld existentials provided a tangible framework that encouraged a truly holistic approach to exploring

lived experience. They found it was a valuable method for reflective analysis to gain an insight into the phenomenon and to uncover the commonalities and shared structures in the experience of being a childless woman (Rich et al. 2013). Also Plazas et al. (2016) found that the four existentials helped them to gain deep insights related to the experience of living with chronic illness in the context of contemporary globalisation forces and how these forces affect the body of research participants.

Challenges with the use of focus groups can also occur. To understand what the participants are contributing with it is relevant to gain pre-knowledge about each participant. In the study the participant observations and interviews were used to gain knowledge about the participants and how they learned and remembered before and after they got dementia. The observations also contributed knowledge about how they normally acted in a learning environment. Together, it helped the planning of the training and the research project as it supported the reflections and guidances needed for the focus groups. It also helped to bring the participants' interests into the group setting for further exploration.

This enabled the perspectives to be nuanced or changed as they were identified in two different contexts, both in an individual context and a group context. There was therefore a continuous learning opportunity about dementia for both the participants and me, which also allowed the themes identified to be further developed by gaining more knowledge about them through a group interaction. The focus groups ensured an interactive process where the participants exchanged views, nuanced and discussed the themes through a group perspective. All this demonstrates the importance of identifying suitable data collection methods and using them in an appropriate order so that people with early-stage dementia are supported to contribute to research. If not chosen carefully the data collection method may inadvertently restrict the voice of people with early-stage dementia instead of supporting it as described in Chapter 4. Based upon the results of the study, traditional data collection methods such as participant observation, interviews and focus groups are suitable to use. However, more creative methods can also be relevant to explore in future research. This is accordance with what "*The Scottish Dementia Working Group*", described in Chapter 2, is arguing for when involving people with dementia in research. Another method of gaining knowledge about the participants involved in research can be by collaborating with professionals who know the participants, which was the case in the Monday group. It can however be questioned if this is acceptable for the participants as it is the participants' experiences that are being researched. This can be seen as intimidating the participants' private sphere. In the ethics chapter it was highlighted that it is important to ensure that this does not happen by not involving the professional directly in the project work. On the other hand, it can support the researcher with significant knowledge about each participant in the group which can ensure a successful outcome of the project. If a professional is included the participants need to give their permission to do so. To avoid the teacher's presence in the Monday group

became unethical. Her role was, as described in the ethics chapter, clearly defined so the participants were comfortable about her attendance.

In the study, the size of the project group was something the participants found important and mentioned in the theme *“It is nice that some will collaborate with us”* from the focus groups; they said it was nice to work in small groups with 5-6 members as it enabled all to have a voice. This supports the argument for not planning for big groups when collaborating with people with early-stage dementia as it is central that the researcher can support all group members if necessary. Nevertheless, the study can be criticised for not being established from a representative point of view but rather from an opportunistic one as the groups were planned according to when the participants attended the school VUK, leading to a Monday group and a Tuesday group. This might not be ideal as it did not take into consideration how the project groups could be most constructively and productively established. Instead it was considered that the participants knew each other and felt secure. Furthermore, it was possible for them to participate in the project on the days they already attended the school so that they were not burdened with concerns about how to come to the project sessions. This was a way of protecting them from unnecessary worries as described in the ethics chapter (Bartlett, Martin 2002).

However, it can be criticised for not providing the best representation of people with early-stage dementia, which might have resulted in the exclusion of some knowledge around the topic researched. According to the literature review there is a risk that people with dementia with the lowest competences are excluded because it is those who have most resources that are generally involved in the dementia activism and research. On the other hand, to establish ideal project groups can be unrealistic as it is difficult to foresee how groups of people with early-stage dementia function when given different tasks. The chosen approach turned out to be positive as illustrated by the theme *“It is nice that some will collaborate with us”*, where the participants emphasised it was positive that trust already existed before starting the project. It seems necessary to balance between what is the ideal for research and what is realistic with the participants involved.

Alternative focus groups were used in the study, which included a loose focus group structure with both individual and group activities. This can be criticised for not really being focus groups when compared to traditional structured focus groups as described in the method chapter (Kamberelis, Dimitriadis 2013). However, the project groups were not traditional working groups either as the researcher used principles from focus groups to establish discussions around topics and lead the process, functioning as a moderator. The purpose was, as mentioned in Chapter 4, to establish an authentic partnership. Indeed, more traditional focus groups were used when conducting the evaluations with the participants. In the study, the use of focus groups worked successfully as also mentioned by the participants in the theme *“It is nice that some*

will collaborate with us". Here the participants argued that I could continue working in the same way I had done in the research project.

8.2.4 THE ESTABLISHMENT OF THE PARTICIPATORY RESEARCH PROJECT

One task when establishing a participatory research project is to find a constructive way to collaborate with the participants with early-stage dementia. Parkes et al (2014) argue it is important the participants are able to form and agree on how they want to participate and collaborate in a project. This can however be difficult to predict with a progressive cognitive decline, which can change agreements and roles within the project, including the role of the researcher. In the study, agreements about the collaboration and the role of the researcher were described in the theme "*Others don't have a clue, let's change it*" from the focus groups. This allowed the participants to form the collaboration. However, they were not asked in detail how they wanted the research work to be organised. They were only asked for their wishes on how they wanted to collaborate and how they wanted to be trained. I decided on the organisation based upon knowledge gained about their competences and challenges. In Chapter 2 it was highlighted that it is difficult to define participatory research as it is not shaped by particular theories and methods. It can therefore be asked "*Who controls the knowledge?*" as asked in the literature review with the purpose of opening up for collaboration and co-produced knowledge. According to Milligan (2015) the study is an example of cooperation, where the responsibility for directing the process remains with the researcher. The participatory research process was therefore restricted as I structured the work. However, cooperation is a type of participatory research (Milligan 2015) although Bergold and Thomas (2012) argue it is only participatory when the participants as a minimum have the same rights as the researcher when it comes to decision-making. This illustrates the ongoing discussion around participatory research also mentioned in the literature review. Conversely, the participants were heard about their learning strategies where they expressed difficulties in articulating how they wanted the training and the participatory research project to be organised as illustrated in the theme gained from the interviews, "*We can still learn but it is challenging*". Also the theme, "*You may be our conductor*" from the focus groups, illustrated a wish for me as the researcher to take the lead when establishing the research project. This allowed me to take control of the structure of the project work.

Another finding was that people with early-stage dementia can be very motivated for research participation. In the study, the participants were motivated for informing society about dementia and for helping with the PhD. Furthermore, they wanted to learn during the research project especially about dementia. This shows that multiple motivations can be identified for participating in research amongst people with early-stage dementia. However, it is essential that these expectations are discussed to find out if they are possible to meet. It is vital to have realistic expectations which at times

can be difficult for people with early-stage dementia as they might have problems with judging their own abilities (Eisner 2013). In the study, the participants wanted their results to make a difference both nationally and internationally. It was not enough they were happy about the results as stated in the theme, *“Others don’t have a clue, let’s change it”* from the focus groups.

It would have been constructive if I had discussed this with the participants since they were novices in research in order to explain how difficult it is to get research results recognised both nationally and internationally. This was not done and it is uncertain whether the participants found this expectation was met during the research process as they did not have any direct contacts with international forums. This could have been explored further in the study as Littlechild et al (2015) argue that it is vital at the start of a project to discuss openly and honestly how far a researcher can appraise the possibility of change. However, Barber et al. (2011) conclude that the fact that ideal involvement cannot be delivered should never become an obstacle in the way of working for the best possible outcome (Barber, Beresford et al. 2011). When recruiting, planning and establishing a participatory research project it is therefore important to be properly prepared. Furthermore, it is essential to have enough time for this phase as it can take time to get access, gain consent and plan the project so it suits the participants with early-stage dementia.

8.3. HOW TO TRAIN AND SUPPORT PEOPLE WITH EARLY-STAGE DEMENTIA IN PARTICIPATORY RESEARCH?

When conducting participatory research it is important to be aware of what is required compared with traditional research. It includes knowledge about research but also about teaching as the participants have to be trained in participatory research. Furthermore, the researcher’s attitude towards the participants is significant to ensure a constructive collaboration. This is highlighted in both the *“Partners in projects”* model (Parkes, Pyer et al. 2014) and in the *“Authentic partnership model”* (Dupuis, Gillies et al. 2012). The researcher has to juggle between different roles in participatory research.

8.3.1 THE NEED OF LEADING AND TRAINING

In participatory research, the researcher has to be both a skilled researcher who ensures the quality of the project and a supporter who ensures that the participants’ voices are heard. However, it can be difficult to find out how to fulfil these roles by consulting the literature as different models of participatory research exist as highlighted in Chapter 3 (Arnstein 1969, Cornwall 2008, White 1996). This is also the case with the participants’ involvement. There is a risk in participatory research as described in the literature review that only pseudo collaborations are established, where the participants are only involved as *“consultants”*. This can lead to participant self-exclusion and participation fatigue if the participants experience no real inclusion

(Cornwall 2008). An acknowledgment of power differentials and a willingness to share professional power are fundamental for successful research relationships (Schneider 2010).

In the study, I chose to take the leading role which the participants asked me to do as they needed the researcher to ensure the work progressed and stayed on track. Consequently I created the structure and led the project and the participants were aware of this. My leading role in the study raises the question about how much control a researcher can take while both allowing the participants' voices and creating progression in the research project. It is a balance as results are needed in the project time scale but, on the other hand, the participants can take the research into other areas or ideas than those planned if they are allowed a voice. This is described in the literature review as one of the positive outcomes of participatory research. It can promote more wide-ranging knowledge and practice (Baldwin 2011), creating a new face of dementia and generating a contradictory discourse to the tragedy discourse so often associated with dementia (Dupuis, Gillies 2014).

It can be questioned whether a truly participatory research project was conducted. In the study, I chose to take the lead of the process because it was difficult for the participants to overview and stay focused with their activities, as mentioned in the theme, *"We try to remember but keep forgetting"* from the interviews. These are some of the symptoms of early-stage dementia as argued in Chapter 2. Taking the lead also ensured the research process did not become too demanding or frustrating for the participants, which is also a consideration for the researcher to ensure an ethical research approach as highlighted in Chapter 5 (Bartlett, Martin 2002). To give voice to people with early-stage dementia in a participatory research project and stay in the background as a researcher does not seem suitable based upon the knowledge gained in the study. Instead, the researcher has to balance between giving and taking control when involving people with early-stage dementia, which means the leading role of the researcher has to be flexible to meet the needs of people with early-stage dementia and to ensure their voice is supported. This is in accordance with Littlechild et al. (2015) who argue that participatory research has to be flexible, sensitive and responsive when collaborating with people with early-stage dementia.

In the study the participants were also given control as they had the power of decision-making in the research project e.g. deciding the research question and the data collection method used in the project. However, it was a restricted choice as I wanted to ensure the participants were able to manage the choices. This again raises the question about what a truly participatory research project is. It indicates the study was not a truly participatory research project as I restricted the choices in the research process. Conversely, it can be seen as a simplistic criticism as I balanced between the ethos of participatory research and ethical considerations in terms of what were possible for the participants. If this was not done the project risked being too demanding for the participants. This is supported by Roy (2012) who argues

participatory research does not guarantee better data, improved understanding, democratising processes or power-free relations. However, a critical focus on outcome and the nature of the knowledge is important to keep this type of research honest (McLaughlin 2009) as the mechanisms of involvement can function as technologies of legitimisation for managerial agendas (Harrison, Mort 1998). In the *theme*, “*It is nice that some will collaborate with us*”, it was stated that although the fact that I led the research project, created structure and tailored the tasks, this was evaluated positively. They experienced having influence on the work and the researcher had supported this by leading the process. The point may be to find the balance of when the participants can lead and when the researcher needs to take the lead and make choices so it is possible to succeed with both the collaboration and the research project. This can be seen as a modified balanced participatory research approach.

Conducting participatory research with people with early-stage dementia is a balancing act based upon a continuous dialogue between the participants and the researcher. This is to ensure a participatory perspective as the researcher must have a dynamic role not only of focusing on collecting data but also about giving voice to the participants. In the study it was about balancing between supporting the participants and allowing their authentic voice to be heard. I worked on both the context and the communication to give them a voice regardless of the challenges the dementia caused. A finding in the study is that dialogue is essential. Freire argued that liberation and transformation can only happen when persons who are marginalised come together as equals to critically reflect and dialogue with others, identify new possibilities for being and act on those possibilities (Shor, Freire 1987). Dialogue is central to making lived experiences transparent, transforming teacher-learners relations and relations to knowledge. Dialogue is the process that enables transformation to take place (Freire 1972).

It was also through dialogue I was asked to lead the project which showed participatory principles were prioritised in the project. A key finding is that participatory research can be seen as an ideal the researcher has to adapt, form and adjust in accordance with the involved participants’ competences and challenges. It is necessary to take the principles of participatory research and apply them where these are relevant, realistic and ethical to conduct when involving people with early-stage dementia in research. Participatory research models for involving people with early-stage dementia also have to include dialogue so it is possible to adjust them to the reality of the participants. A constructive dialogue can ensure the participants a voice in participatory research even though the researcher leads it.

As argued for in the literature review it was found necessary that the participants were trained in research skills. Training and coaching in research methods and facilitation of the research process is necessary (Conder 2011), so that the participants can contribute to research because often they are in a poor position to participate as they

do not have sufficient research knowledge and skills to undertake the role (Fudge N., Wolfe et al. 2007). However, this can be criticised as there is a risk that the training tries to “*educate*” the participants to have a research voice which is not in accordance with participatory research. It means training in research skills can be criticised for trying to make the participants pseudo-academic researchers which can undermine the specific and unique perspectives which the participants have been recruited to add to the study (Tanner 2012). It means tensions can appear between expecting co-researchers to employ recognised research skills on the one hand and honouring and facilitating their unique contribution on the other (Reed, Cook et al. 2006) as highlighted in Chapter 2. However, in the study the training was tailored to the participants in accordance with their cognitive reserves and with the purpose of making them feel comfortable about participating and understanding what the research required. I therefore find it possible to train participants without losing the uniqueness of their voices.

However, it is necessary to identify suitable ways to train people with early-stage dementia in research skills as the literature review showed it is unethical to teach the participants research skills in the same way as other research students, something for which existing courses in participatory research are often criticised (Dewar 2005). It is too challenging. Thus, people with dementia have largely been shut out of educational and learning opportunities due to the stigma about dementia. The assumption is still that people with dementia lack the capacity for growth and new learning (Dupuis, Gillies 2014). Dupuis and Gillies (2014) describe how participants with dementia in their study experienced varying degrees of stigmatisation. Stigma was also something the participants in this study experienced and which they talked about in the theme “*Others don’t have a clue, let’s change it*” from the focus groups. As a result, little knowledge exists about how to train people with early-stage dementia in research skills, meaning the researcher faces the challenge of being a researcher, a supporter and a teacher without much support from the existing literature. This is a problem also described in the literature review. In the study, knowledge about dementia and about each participant was helpful to tailor and simplify the training in research skills to the project group’s competences and challenges. However, more knowledge about how to train people with early-stage dementia in research skills is needed to identify some general guidelines for training research skills when having dementia.

In the study, the different roles of the researcher were not experienced as separate as the training was integrated into the project work. I shifted between the roles continually, so the participants were taught one skill immediately before it was used. The experience of the roles would perhaps have been different if the training and the research had been detached. The study does not, for that reason, contribute to knowledge about how to train people with early-stage dementia when separated from the research project, which can be seen as a limitation. However, it was judged unrealistic that learning would be recalled for a long period because of their short-

term memory problems. This makes it more difficult to learn as described in the literature review as their episodic memory sub-system is significantly impaired. This indicates the importance of contextualising the training of the research skills and using the acquired skills immediately to avoid losing knowledge. Interestingly, another role for the researcher appeared during the participatory research project which was the researcher as a learner too. During the process I learned about how to train and conduct research with people with early-stage dementia. It became a joint learning process for both the participants and me, which is important to recognise so that more knowledge about how to train people with early-stage dementia in research skills can be gained. Freire (1976) advocated for an active inquiry approach where all involved are simultaneously teachers and learners, co-investigators and collaborators in a learning process, which signifies an altered power relationship (Freire 1976). This is very much in accordance with the experiences gained in the study.

Normally, people with early-stage dementia are seen as vulnerable and the researcher as being powerful. The power is retained by researchers by virtue of their specialist knowledge and skills but it does not adequately take account of the complexity and fluidity of power relationships and the different ways in which power is manifested (Tanner 2012). A finding in the study was that the participants held power too, having knowledge about dementia I wanted to learn. This gave the participants the power of deciding to share or not to share their knowledge, which they teased me with in the theme, *“Why does it have to be so negative?”* from the focus groups. It illustrates how the participants also have power in research collaborations as they decide what they want to share with the researcher. Participatory research therefore risks not giving a complete picture of what is researched. This is also something participatory research can be criticised for, as described in Chapter 2. Although, participatory research claims to raise the voice of vulnerable groups, it can only do it to the extent the participants wish themselves. The participants in the study were aware of this power which limited my power as I depended on the participants’ contributions. For that reason, it is important the researcher creates an environment where the participants are comfortable about sharing their voice. The researcher has to balance between getting results and acting in a way the participants appreciate, otherwise they might withdraw. This limits the power of the researcher in participatory research.

8.3.2 THE TRAINING AND SUPPORT

Little knowledge exists about what learning strategies can be used in the training of research skills for people with dementia although the literature review highlights that it has been proven that errorless learning can be a useful way to learn for people with dementia (Mimura, Komatsu 2007). In the study, the starting point was to minimise the possibility of mistakes based upon the positive results with errorless learning which meant that I listened carefully to the participants to identify both their contributions but also if it was not directly relevant for the project. Successfully reminding a person of what he or she still can do fosters feelings of wellbeing (Eisner

2013), which is central to ensuring a successful collaboration. Whenever possible the participants' contributions were interpreted to align with the research project's context as described in the theme, *"You may be our conductor"* from the focus groups. This created a positive and constructive learning environment where the participants contributed what they found relevant and where I focused on what it could bring to the research. The focus of the project could have been disturbed but as the participants' contributions were prompted by the project work it was almost always possible to find connections to the project when their telling was analysed and interpreted. This can be criticised for not being their true voice, which is a risk in participatory research as illustrated in the literature review but it made the participants comfortable about sharing their experiences and meanings, which shows how vital it is that participatory research is conducted in a constructive atmosphere. This was something the participants appreciated and talked about in the theme, *"It is nice that some will collaborate with us"* from the focus groups. Interpretations ensured everyone had something to contribute and, as long as it was confirmed, the interpretations were in line with what the participants wanted to express; it was seen as a constructive way for me to support the inclusion of their voice.

Another challenge in participatory research is that nothing can be rushed through when involving people with early-stage dementia as it takes time for them to take in new information and form new memories as described in the literature review (Clare, Woods 2008, Wesnes 2003). The participants had problems with overviewing and holding onto time, as mentioned in the theme from the interviews *"It takes time to adapt, at the same time we are losing time"*. It meant I structured the time in a way that did not stress the participants as it otherwise would have been difficult for them to be involved in the research project. This challenges participatory research involving people with early-stage dementia as research projects are normally restricted in time and resources.

A key finding in the study was the constructiveness in conducting the training in research skills and the participatory research project as one process due to the participants' short-term memory problems. It was judged not optimal to keep the structure in the *"Partners in projects"* model (Parkes, Pyer et al. 2014), where the participants are taught the research skills before they conduct research in practice. Instead, the researcher trained and conducted the project as a continuous process and the training in research skills was simplified so they could conduct the required tasks immediately to make it possible for them to navigate the research process. This was based upon the knowledge gained from the existing literature and the knowledge about each participant's learning possibilities and challenges. This can be criticised for not really focusing on long-term learning. Furthermore, I limited the participants' learning possibilities by only introducing what was judged relevant for the project. It means the training was connected to a local context for which existing training courses in participatory research are often criticised as described in Chapter 2 (Dewar 2005). However, it might be difficult to develop a generic training course in research skills

for people with early-stage dementia as their progressive cognitive impairment challenges the possibility of long-term learning.

The results of this study advocate for an adjusted, contextualised training that is used immediately to avoid losing knowledge. In the study, I also took into account the resources in the group and the form of the day. More research is needed in this area to locate suitable ways to meet this obstacle in training courses around research skills for people with early-stage dementia. Here researchers have to be aware that equality is not achieved by treating needs in the same way but by ensuring the participants are met in the way most appropriate to them. Consistent with more recent person-centred approaches as unfolded in Chapter 2 people with dementia must be involved in determining what their information needs are and how best to meet these needs (Dupuis, Gillies 2014). This was done in the project by asking for the participants' preferred learning strategies.

Key support mechanisms identified in the study were to use a structure throughout the research process and a folder with session papers although problems occurred with organising the papers. It can be questioned if a folder is the best way to organise the research work although the literature review argues it can be beneficial to keep track of the process by having a folder for storage (Mckillop 2004, Wilkinson 2002). Maybe more pictures would have supported the participants better than the small texts because people with dementia can struggle with reading and writing as the illness progresses (Hellström, Nolan et al. 2007). It is therefore important the researcher considers how artefacts support the participants so the best support mechanisms can be used – this has to be included in the reflections and guidances connected to the participatory research model. Regardless of the critique the participants evaluated in the theme, *“It is nice that some will collaborate with us”* from the focus groups, that the folder was useful as it gave structure and it was possible to go back if they could not remember the work they had done. They appreciated the combination of text and pictures and that they did not have to write. This indicates a need for considering how much written text to be included in participatory research with people with early-stage dementia.

Another supportive strategy was repetition which the participants also mentioned in the theme from the conducted interviews, *“We can still learn but it is challenging”*. Learning was about repetition. Long term memory of a task is necessary in recognising that this is a familiar activity and by accumulation of episodes of engaging in an activity it will contribute to skill development and task complexity (Eisner 2013, Lieberoth 2013). It means that with use of repetition there is a chance for activities that are well practiced to be transferred to the long-term memory. Furthermore, neural reorganisation of a function is possible when the teaching is similar to the reality in which the person is going to use the learned skill (Mogensen 2013). It is therefore relevant to improve or maintain cognitive function by people with dementia by repetitive training (Bach-y-Rita 2003, Yu 2009). This is in accordance with *“The*

Reorganization of Elementary Functions” model described in the literature review. It illustrates how a reorganisation of functions can happen with repeated training.

This demonstrates a key finding that it is possible to learn things in early-stage dementia although it is more demanding than before getting dementia. Repetition is needed as a support mechanism throughout the training and the research process as the study showed that it supported the participants’ ability to learn and remember the work they conducted. Summaries and visual clues as pictures and post-its were also useful for repeating the work. It created an overview of the process and kept attention on the project. At the same time it supported the participants to recall what they worked with as mentioned in the theme, *“It is nice that some will collaborate with us”* from the focus groups. It corresponds with the literature review where creative methods have shown to be a way to engage people with dementia in research by improving the communication and memory together with increasing the social interactions with humour and laughter (Gould 2013, Holm, Lepp et al. 2005). To use pictures in research allows the voice of people with dementia to be heard and help them become active members of research projects (Palibroda, Krieg et al. 2009, Savundranayagam, Dilley et al. 2011, Wiersma 2011). It seemed the participants enjoyed the creative inputs in the project and recalled some of the learning when looking at the pictures. However, an always existing problem with dementia is that the learned skills disappear again due to the progression of the illness. It is therefore necessary to choose what is needed to learn and repeat this to support their memory as it in the existing literature is argued that there can be a ceiling effect of training. This was a strategy the participants also used in their daily life as described in the theme from the conducted interviews, *“We can still learn but it is challenging”*. It is therefore positive if the same strategy can be used within research as a constructive support mechanism.

The study showed that the participants learned more about the structure of the research process than the exact content of the project due to the fact that the content was not repeated the same amount of times as the structure. During the process more participants remembered and recognised the structure of the work as described in the theme, *“You may be our conductor”* from the focus groups. Some could even point out when I changed something within a session from the way it was done earlier. It is therefore important that the researcher prioritises the learning needed within a participatory research project and this is repeated continually throughout the research so that the participants’ resources are used constructively without risking exceeding the ceiling effect of training highlighted in the literature review. In the study, it was the structure of the work that was prioritised but in other projects it can be other elements.

A challenge in participatory research involving people with early-stage dementia is how to communicate constructively as they already can have language problems. The earliest symptoms in spoken language are often word-finding problems, which may

lead to having problems generating coherent speech, or understanding the spoken word as highlighted in the literature review (Hellström, Nolan et al. 2007). It is therefore important to be aware that the language used is direct and precise and not forced in order to give them time to both generate and understand the spoken word. In the study, I supported the participants with language problems by suggesting words and giving verbal and visual clues. Here knowledge about each participant was essential in supporting communication. Also the non-verbal language was included as some used non-verbal signals when it became difficult to explain verbally. This is in accordance with Kitwood (1997) who claimed that because of language difficulties, people with dementia rely more on their non-verbal communication skills and use the verbal element of communication to add decoration to their meaning (Kitwood 1997b). They use non-verbal communication skills to remain socially active, especially when their verbal abilities are declining (Hubbard 2002). It is therefore essential both verbal and non-verbal signals are included in communication to ensure a person-centred approach towards the participants in the research project, which is a constructive way to relate to people with dementia according to the existing literature. In the study, it was also observed that foreign words and research terminology was difficult to understand as described in the theme, *"You may be our conductor"* from the focus groups. Hence, I tried to avoid foreign words and changed most research terms to everyday language. It meant the participants were not taught research terms as it is important to prioritise what people with early-stage dementia need to learn in order to be able to contribute to research. In the study, it was judged more relevant that they focused on the content of the research project than the research terms, raising awareness about dementia and the training possibilities when living with dementia. It was about being pragmatic as it was difficult for them to understand unfamiliar research terms, remember them and pronounce them as several of the participants had difficulties with pronouncing foreign words. This can also be difficult for other lay representatives so it is something researchers always have to be aware of in participatory research, otherwise it can create a feeling of not being competent when not understanding the language being used, which can be a risk in participatory research as mentioned in the literature review.

Questions seemed to be a convenient method of supporting the participants' communication in the research project but the nature of the questions was important. Open, analytical and reflective questions were more difficult to answer than closed direct questions. Sometimes questions also had to be repeated or reformulated. The use of questions also directed the work but it was necessary to balance the questions so that they were not too open or too directive. This was a difficult task that did not always succeed as described in the theme, *"You may be our conductor"* in the focus groups. It meant some questions became too difficult to answer or too rhetorical. However, together with suggestions, the questions helped to elicit the participants' opinions and to reach agreement before any decision was made. This guaranteed the participants' voice was heard by ensuring the participants agreed with all decisions

made. This reveals how vital communication skills are when collaborating with people with early-stage dementia.

8.3.3 PREPARATION FOR DATA COLLECTION

It was constructive to simplify and limit the training to what was needed for the project. For instance, the participants discussed the project topics based upon pictures and drawings which made the research real for them. Also when identifying a research idea and a research question I restricted the process to make it possible for the participants to make decisions and formulate a research question. The recruitment of participants was also simplified in order for them to relate it to themselves as informants in the project groups. Furthermore, the research ethics process was reduced by discussing the information leaflet and consent they themselves had commented on and signed before participating in the study. Also there was a limited choice of qualitative research data collection methods. This finding illustrates the need of simplifying the research when including people with early-stage dementia. However, this approach can be criticised for directing and simplifying the complexity of research, not giving the participants a full understanding of research. Nevertheless, this approach was used to make it real and understandable for them. This illustrates how central it is to be clear on what level the participants are taught research and what is needed for them to contribute to it. In the study, the goal was not that the participants afterwards could conduct research on their own as it is in the *“Partners in projects”* model (Parkes, Pyer et al. 2014) described in Chapter 3. If that had been the case the training should have been planned and executed differently.

When deciding on the data collection method the study showed the participants preferred to work with structured methods as they chose to use interviews with question cards. After having practiced the interviews it proved to be a useful method as everyone was able to conduct an interview, although some required support from me. Nevertheless, it was challenging for some and it might even have been harder if they had to interview people with dementia that they did not know. This could have changed the outcome as interviews can be complicated to use with people with early-stage dementia as they can be seen as a test and direct questions can lead to anxiety and increased confusion (Allen 2001). Difficulties identified within the interviews also includes finding the right words and remembering to answer the questions as described in Chapter 4. A limitation in the study is that the participants did not recruit and interview other participants with early-stage dementia and it can be questioned if the participants would have been able to do this. Instead, the study was a peer-research project where the data collection method was tried out in a safe environment. In Tanner’s (2012) study the researcher experienced that the co-researchers with dementia were sensitive to different issues and came to the interviews from a different angle and were more adept at tuning in to the participants’ communications. They brought an informal conversational style to the interviews, having a shared language and experiences. They were able to empathise and understand significant issues of the

other person's perspective. However, tensions also existed as the co-researcher did not always have the skills to pick up on any significant issues and explore them in depth (Tanner 2012). This shows that there are both pros and cons about conducting interviews with people with early-stage dementia as both interviewer and interviewee. Further research into how people with early-stage dementia can take even more research responsibility is necessary in order to find suitable ways to extend their involvement in data collection in participatory research.

8.3.4 PARTICIPATORY DATA ANALYSIS

In the literature the possibilities and challenges about conducting participatory analysis is debated as there may be limits for what is possible in participatory analysis (Nind 2011). Often the analysis stage is the last area to be used in participatory techniques as data analysis is the researcher's key skill that contributes to the researcher's power in the research process (Jackson 2008). A relative neglect of participation in data analysis exists even though it is often argued that the aim of participatory research is to have active participation of all partners throughout all stages of the research process as argued in the literature review (Conder 2011, Nind 2011). Often academics retain some roles in participatory research, but are not explicit about it (Nind 2011). However, participants involved in the data analysis can assist in identifying themes and selecting those most relevant to them, questioning and modifying researchers' interpretations and adapting ways in which findings are reported (Barber, Beresford et al. 2011). Miller et al. (Miller, Cook et al. 2006) note they can enhance researchers' understanding of the data, enabling them to ask more pertinent questions.

The study shows it is possible to conduct a participatory thematically inspired analysis with people with early-stage dementia by supporting them throughout the process. Also in Littlechild et al.'s (2015) project co-researchers received support in identifying key themes and findings at the analysis stage. In the project, the participants were supported by, for example, me transcribing the interviews and condensing the transcript to an anonymous narrative for each group in order for it to be possible for the participants to overview the text without too many confusing words and repetitions. This can be criticised for possibly not being true to the exact thoughts of the participants and not giving them the full experience of how to conduct an analysis. This is a risk to be aware of as described in the existing literature. However, it would have taken too much time and effort for them to have succeeded with transcribing, leaving no time to conduct in-depth analysis as for some people reading and writing can be a challenge in early-stage dementia (Hellström, Nolan et al. 2007). It is essential to be aware of the symptoms of early-stage dementia as illustrated in the literature review and adjust in accordance to this.

To have an anonymised narrative had both positive and negative consequences. Although it supported them to see their contributions as one text, at the same time

some participants were confused when reading something they could not recognise. In general, it was challenging for them to analyse and interpret the transcripts but, with support, the participants succeeded in identifying and interpreting themes. However, it was easier for the Tuesday group than for the Monday group to conduct the analysis. This demonstrates that people with early-stage dementia have different cognitive reserves and how important it is that the researcher adjusts the level of the analysis to the participants' competences. This indicates the importance of recognising the different cognitive reserves people with early-stage dementia can have as highlighted in the literature review. Based upon the knowledge gained through the project's analysis it can be argued it is possible, to a certain degree, to conduct a participatory data analysis using a thematic approach. It is possible for people with early-stage dementia to conduct an analysis as seen from their perspective of living with the illness. Guest et al. (2012) also experienced that a thematic analysis was useful in their study as the purpose of the data was to describe and understand how people felt, thought and behaved within a particular context related to a specific research question (Guest, MacQueen et al. 2012). This was similar to the focus in the research project as it was the participants' perspective that was interesting, a perspective I could not take.

However, it is necessary to consider whether it is always constructive and productive to include people with early-stage dementia in the analysis process as progression of the dementia was observed in many of the participants during the project, which made it difficult for several to contribute to the analysis. It may be assumed that their addition to the analysis may be limited if it is perceived as too challenging for them. This is also something the literature review highlights as participatory research can be conducted on many different levels. Furthermore, the researcher is obliged not to burden the participants unnecessarily and so it is important to consider what is suitable and ethical for the participants to be involved in as described in Chapter 5. If the participants are involved in the analysis process it is vital enough time is given to the process as it can be time consuming because of the support required.

8.3.5 EVALUATION

In the study it was found challenging to evaluate with people with early-stage dementia because of their short-term memory problems even though it is central to include a systematic process of critical reflection and dialogue with partners throughout a project in the "*Authentic Partnership*" model (Dupuis, Gillies et al. 2012). In the study, each session was evaluated with the purpose of changing or modifying the structure and work if necessary and also a final overall evaluation was conducted. Both evaluations were conducted as focus groups. This shows the difficulties in conducting retrospective reviews, which makes it challenging to capture the experience of being involved in research at the time of completion. This problem is always present when involving people with early-stage dementia in research as described in the literature review. In the study, the participants were able to evaluate

the sessions and the process, mostly with positive sporadic overall answers, showing many had difficulties in recalling what they had worked with in the project. This resulted in an overall, sometimes superficial, evaluation. However, it was easier for them to evaluate their feelings towards the research project. This corresponds with Eisner (2013) who argues that although a person with dementia might not recall what he or she did the person seems to retain how he or she felt when engaged in a positive experience. This means that the participatory research project has to be organised in a way that the participants' experience positive. It also calls for developing alternative ways to evaluate with people with early-stage dementia to prompt their memory to get more in-depth answers. Focus groups helped to prompt the participants' memory as they remembered things when listening to others, allowing in-depth answers, demonstrating that focus groups can be a relevant evaluation method.

Surprisingly the video summarising the project work did not prompt the participants' memory. It was anticipated the video would prompt their memory. However, although I provided commentary and had included short text explanations about each session it seemed to be too difficult for many to follow. It might have been because the video had too many stimuli compared with a picture that did prompt memory positively. It can be difficult for some people to follow things happening on television even in early-stage dementia (Eisner 2013). This can be the case as it can be difficult to take in and recognise new information in the early-stages of dementia as argued in Chapter 2. Based upon the study video seemed not to support the participants' ability to evaluate the research project.

8.3.6 DISSEMINATION

The results of a participatory research project often include the participants as presenters, which can be challenging when involving people with early-stage dementia. Their short-term memory and language problems can make it difficult to present results in public as they are more limited in terms of verbal fluency and expressiveness (Littlechild, Tanner et al. 2015). In the study, the participants chose to supplement their written analysis with pictures and hereafter the dissemination was planned in a way so the participants could present the results to their fellow students at VUK and a journalist and photographers. This was done in a more or less structured manner as it was constrained by time because of the agreement with the journalist and photographers. This was not ideal as it can stress people with dementia unnecessary if things are rushed through (Clare, Woods 2008, Wesnes 2003). It takes time for them to take in information and form new memories as highlighted in the literature review. In the dissemination, I had to structure the participants' presentations even by those who beforehand thought it was unnecessary. It is therefore important that the researcher supports the participants in dissemination as it can be difficult for them to stand up and talk about their work. They can experience word-finding problems in generating coherent speech and they can become repetitive in their presentations because of their short-term memory as revealed in the literature review. It has to be

negotiated who wants to present and they should have the opportunity to withdraw. After the presentation a celebration was held. It is important that people with dementia experience that they have made a significant contribution to research and they have accomplished something. So at the end of the process it is needed to acknowledge this in a manner suitable for the people concerned (Mckillop 2004).

The visit of the journalist and photographers fulfilled the participants' ambition to inform society about their experiences with dementia as their interviews with the journalist resulted in two articles and a short TV report. The journalist was prepared, by me, for his meeting with the participants to ensure a constructive communication around the project results. This can be criticised for influencing the journalist beforehand. However, it is required of the researcher to be aware how the results may be perceived by others to try to avoid people with early-stage dementia are met by a negative stereotype attitude as the one the participants also described in the theme, *"Others don't have a clue, let's change it"* from the focus groups. Here the participants experienced they were seen as incapable in contributing anything. This corresponded with the stigmatised attitude towards dementia described in the literature review. If this is the attitude they are met with it becomes difficult to get their voice out in society, which is a serious concern as people with dementia experience difficulties in accessing alternative discourses than the prominent personal tragedy discourse as highlighted in Chapter 2.

Impressively, the motivation and engagement for participating in the project remained throughout the process, focusing on helping others with dementia and me. They wanted to change the attitude towards dementia in society as mentioned in the theme, *"It is nice that some will collaborate with us"*. Critically, it can be asked if the results contributed anything new about dementia. Reissmann (1993) argues that although there is nothing new in the findings this way of presenting results keeps the participants' stories intact and draws out meanings from the particular way in which the participants' stories are told (Reissman 1993). Participatory research can express various truths by supporting participants who have been traditionally ignored and hidden to lead research and knowledge generation about their lives (Fenge 2010).

It is new that people with dementia are involved in participatory research and have described how dementia is experienced from their perspective. This is something that is missing in the dementia research as mentioned in the literature review. Showing how the participants in the study tried to focus on positive sides of life and live an active social life regardless of dementia can influence the picture and truth about dementia. This is also something the sparse literature in the field describes. Furthermore, they tried to accept, cope and fight the illness by using different strategies, showing they still were competent actors. They gave up things to avoid any risk or harm, showing awareness about their loss of competences. Finally, they focused on the fact that they still had a life to live as life did not end because of a diagnosis of dementia. This is in accordance with Dupuis and Gillies (2014) who

found their participants with dementia expressed there still was a life after being diagnosed. However, it took time to come to terms with living with dementia and to accept that help from family, friends and professionals was needed to live well with dementia. An adjusted life had to be expected, which was not easy to accept. Some did not find life with dementia positive and it was stated they were lucky that dementia came late in life. All this was described in the theme, *“We are still the same even though we are not the same”* from the focus groups, which is relevant for society to try to understand how dementia is experienced when living with it. It shows how dementia affects and is experienced differently by people living with dementia (Martin, Augusto et al. 2013). Furthermore, the description around dementia might have been different if they had been diagnosed with young-onset dementia, for example.

Finally, the project results showed how the participants expressed their opinions and wishes for a life with dementia they found meaningful. They were grateful they had the opportunity to articulate these experiences as illustrated in the theme, *“It is nice some will collaborate with us”* from the focus groups. This indicates they were not used to be asked about their experiences with dementia, showing a need for investigating this further in research as the study showed it is possible for people with early-stage dementia to share their experiences of dementia. We can learn from them about life with dementia, which might create a more nuanced picture of how people with early-stage dementia live their lives. This might also support the development of more relevant services such as leisure activities that might serve significant functions in coping with negative life events such as illness or disability. It can generate hope and optimism about the future and a sense of purpose in life, aiding a reconstruction of the life story and as a vehicle of personal transformation (Hutchinson, Loy et al. 2003, Kleiber, Hutchinson et al. 2002). Unfortunately people with dementia have previously been excluded from this as described in the literature review because it has been anticipated that people with dementia did not have the ability to learn. It is positive if dementia could be seen more as a disability, with focus on remaining strengths and abilities as highlighted in Chapter 2 (Clare, Woods 2008, Papon Young 2012). This might change the negative stereotypical picture of dementia, where it is seen as useless to train or intervene.

8.4. “HOW TO INTERACT AND COLLABORATE WITH PEOPLE WITH EARLY-STAGE DEMENTIA IN PARTICIPATORY RESEARCH?”

When conducting participatory research some sort of a relationship between the participants and the researcher will develop due to the long period of collaboration. This means participatory research has to be conducted in a comprehensive way so the participants are not utilised. It is about ensuring their free will to be a part of the process and letting them make decisions within the research project. The researcher has to handle a degree of insecurity both towards the participants and towards the

project as the process cannot be controlled when working in a participatory way. It is neither possible to predict the quality of the results.

8.4.1 THE ESTABLISHMENT OF A TRUSTING RELATIONSHIP

A key finding in the study was the importance of trust as highlighted in the theme, *"It is nice that some will collaborate with us"* from the focus groups. A trusting relationship seemed to be the cornerstone in the collaboration and therefore essential for conducting participatory research with people with early-stage dementia. However, it was still observed that the participants in the beginning of the research project were reserved when talking about their challenges, which highlights the importance of using time for establishing and developing constructive research relations. However, as the literature review revealed it is difficult to locate how to establish constructive research collaboration with people with early-stage dementia as little knowledge exists in the area (Dupuis, Gillies et al. 2012, Staniszevska 2009). In the study it was done by spending time together with the participants prior to the research project. However, the study cannot contribute knowledge about how to establish trust between the research participants as the participants already knew and trusted each other. It is therefore relevant to explore further how to establish trust between research participants with dementia who have no former history together. It can be anticipated that it would prolong the research process if a relationship between the participants first has to be established.

In general, positive relations seemed vital for the participants in the study both amongst themselves but also in relation to families and friends as stated in the theme, *"We live a social and active life regardless of difficulties"* from the interviews and in the theme from the focus groups, *"To be with the likeminded is liberating"*. This is in accordance with the findings of Dupuis and Gillies (2014) in their study as relationships still can be enjoyed when living with dementia. In addition the literature review revealed that participating in research might give people with dementia an opportunity to develop social relationships with peers. When conducting participatory research with people with early-stage dementia it is therefore relevant to support the participants' opportunity to enjoy a positive relaxed relationship with each other as was the case in the study. It also indicates the importance of services providing the opportunity of being together with others with dementia. However, challenges can also exist between people with early-stage dementia as having the same condition does not mean they share the same experiences around dementia or appreciate each other. Positively, the participants in the study discussed and disagreed in a friendly atmosphere. The researcher has to be aware of these possible challenges as it can create tensions in the collaboration, having a negative influence on the research project.

In the study, the positive relationship meant a committed motivation to help for both the participants and me. The participants wanted to help others with dementia and me

and I wanted to help the participants to have a voice in research. However, the research relationship risks becoming too emotional, leading to the research purpose being lost as the researcher becomes too involved (Hammersley, Atkinson 2007). This was not the case in the study and it is important to be aware that this type of research cannot be conducted if the researcher does not invest in the relationship with the participants as they need to be comfortable and trust the researcher to give their voice. Also the literature review argues that participatory research does not focus on achieving objectivity and a restricted separation between the researcher and the subjects. The researcher has to acknowledge the participants' contributions as dementia is a big challenge to the integrity and intellect of a person and very often people with dementia struggle with believing they have something to contribute as they experience loss of competences and qualifications as seen in the theme, *"We are still the same even though we are not the same"* from the focus groups. At the same time they face a negative stereotypical picture of dementia in society as seen in the theme, *"Others don't have a clue, lets change it"* from the focus groups, which means they often do not have access to be involved in research activities as revealed in Chapter 2. The researcher therefore has to create an environment where the participants feel they can contribute.

8.4.2 PEER-LEARNING AND PEER-SUPPORT

The study indicates information about dementia is important for people with early-stage dementia especially for those who are newly diagnosed with dementia. These participants searched for more information about dementia than those who had lived with the illness for a longer period. This was stated in the theme, *"Others don't have a clue, let's change it"* from the focus groups. Society therefore needs to provide information about dementia but also the researcher needs to have knowledge about dementia to provide the information requested as it is relevant when investigating experiences of dementia. Unfortunately, society does not always provide the information needed as a study of Australian GPs found they were less likely to offer a diagnosis if they did not feel it would benefit the patient. Further to this, the GPs thought that a diagnosis may be more damaging for a patient (Hansen, Hughes et al. 2008). I find this unethical and lacking respect for the person's right to learn and know. Not giving the diagnosis is the same as stealing a person's opportunity to act reasonably towards the illness. It becomes more difficult to develop relevant coping strategies, which was something the participants used to live better with dementia as described in the theme, *"We are still the same even though we are not the same"* from the focus groups. Also in the interviews the themes, *"We try to look at the bright side of life with dementia"* and *"It takes time to adapt, at the same time we are losing time"*, described different coping strategies.

Interestingly, peer-learning about dementia also took place in the project as the participants prompted discussions around dementia and its influence on their lives. This led to a feeling of empowerment by the participants as they learned from each

other's experiences. This can seem surprising as dementia is a progressive illness as described in Chapter 2. Nevertheless, the study showed the participants experienced the research project as a learning situation that empowered and rehabilitated them as they found they were better prepared for a life with dementia after the project. The purpose of rehabilitation is to optimise the ability to function and give people the best possibilities for an independent and meaningful life (REHPA, 2017). Rehabilitation is biopsychosocial initiatives organised in the interaction between the person, relatives and professionals (ibid). However, this interaction is challenged by the cognitive impairment in dementia, meaning it can be difficult to identify relevant initiatives. This study shows that the opportunity to meet and collaborate with other people with dementia in meaningful activities can rehabilitate on a psychosocial level. In the study the participants connected and identified with each other by sharing and learning more about dementia. They saw they were not alone with the illness which otherwise was a feeling connected to being diagnosed with dementia as described in the theme, *"It takes time to adapt, at the same time we are losing time"* from the interviews. According to Dupuis and Gillies (2014) persons with dementia are fully capable of growing and learning. To hear the experiences from others living with dementia validates shared lived experiences which are incredibly empowering and inspirational. When individuals feel connected, safe, supported and in control they can grow and develop and experience life enrichment regardless of the dementia (Dupuis, Gillies 2014). The study also indicates that people with early-stage dementia can identify what they find interesting and can stay motivated and concentrated for a longer period of time when given the right support in the activity. One meaningful rehabilitating initiative can be participating in research as this study shows.

Two reviews within rehabilitation research argue that more knowledge is needed in relation to identify relevant ways in involving and evaluating research that engage people with dementia even though benefits from the involvement already has been recognised (Camden et al. 2015, Joss, Oldenburg 2015). Littlechild et al. (2014) argue for the benefit of involving people with dementia in rehabilitation research as they can support the research process, support the transfer and implementation of results in practice, and create empowerment for those who participate. Littlechild et al. conclude:

"... that it can achieve change at individual and social levels through sustaining a sense of self, building confidence and skills, promoting affirmative social relationships and opportunities and challenging negative attitudes" (Littlechild et al., 2014, p.33)

More research is needed to identify relevant ways of involving more people with dementia in research activities including rehabilitation research. Knowledge gained from this study can contribute with both how to involve people with early-stage dementia in research and how to identify relevant rehabilitation initiatives.

However, much involvement activity which claims to empower the participants can also contribute to their oppression (Carey 2010). This was not the case in the study as the participants both experienced a personal, relational and collective empowerment as described in the literature review. A personal empowerment occurred as they developed a feeling of greater confidence and capacity around their own life with dementia. A relational empowerment related to their feeling of being a part of a team based upon a trusting relationship where they made decisions. Finally, a collective empowerment emerged by taking actions, trying to “educate” the society in the project. These benefits are in accordance with Tanner’s (2012) study where co-researchers experienced gaining knowledge, enhancing skills, developing networks and new opportunities for involvement.

These unexpected side effects were experienced as very positive by the participants. This indicates people with early-stage dementia can experience involvement in participatory research as beneficial also for their everyday life. In Dupuis and Gillies’ (2014) study people with dementia experienced that they could learn from each other and it took less effort than learning from others without dementia as the assimilation of the information seemed to be greater. Given the relevance to their own lives many participants with dementia felt they gained practical information and strategies (Dupuis, Gillies 2014). However, I assume the feeling of empowerment and rehabilitation might not last for a long period due to the progression of dementia but it seemed to give the participants a satisfaction in the moment. As the literature review states there can also be a gap between learning new skills and being able to perform these so it will take time to examine whether they feel empowered in their daily life or not. Interestingly, the participatory research project also empowered me as a researcher as I learned during the research process how to collaborate, train and conduct participatory research with people with early-stage dementia. This led to the realisation that participants are knowledgeable and they, together with researchers, can work towards new analyses and solutions (Littlechild, Tanner et al. 2015). This can help break stigma and create a new face of dementia (Dupuis, Gillies 2014).

In the study, the participants also supported and protected each other during the process. This was characterised as a peer-support described in the theme “*To be with the likeminded is liberating*” from the focus groups. They used their pre-understanding constructively when supporting each other, which created a relaxed atmosphere where it was possible to laugh about difficult things. This meant the project work never became too formal or demanding as the participants empathised with each other. The participants also supported the researcher in keeping focus on the research process, meaning there was a true collaboration between the participants and the researcher, which otherwise can be difficult to establish as described in Chapter 2. Peer-learning and -support therefore has to be embraced by the researcher as it supports the participants to engage further in the research process and strengthens the collaboration.

8.4.3 HUMOUR

Humour still plays a significant role for people with early-stage dementia as the theme, *“Why does it have to be so negative?”* from the focus groups, indicates. The participants used different types of humour and it seemed to link them together as a group. This could have looked different if they first had to establish a relation from the project’s start. They used humour for amusement and as a coping mechanism. In Cook’s (2003) research, humour was also used by participants to hide when they did not know the answer in quizzes and less impaired participants added to the humour by colluding with them and telling them the answers (Cook 2003). In the project humour was also used to cope with difficult tasks in the project work. However, there were situations where the humour created tensions, which meant the researcher had to restrict the humour to avoid tensions and to ensure the project progressed. This was described in the theme, *“To be with likeminded is liberating”* from the focus groups. Humour therefore has to be used wisely. In Dupuis and Gilles’ study (2014) the participants also used humour and tried to focus on the positive things instead of dwelling on the negative side. The researcher found it was refreshing to see people with dementia have a sense of humour, talking openly, sharing and laughing as a lot of research focuses on the negative, the ugly, and the deficits (Dupuis, Gillies 2014). This shows the need of generating alternative pictures of people with early-stage dementia as they use humour in different ways. In essence humour can be a product of both the research as well as everyday life.

8.5. CONCLUSION

This chapter discusses how to plan and establish participatory research involving people with early-stage dementia with the challenges that exist. It can be a time consuming process where it is important to adjust to the specific group of participants. Knowledge about each participant and about dementia is needed to plan and establish the training in research skills and the participatory research project in accordance with the participants’ competences and challenges. Furthermore, it is discussed how to train and support people with early-stage dementia in participatory research as this is compromised by the participants’ short-term memory problems, attention and language problems. Again it is crucial to adjust so it is possible for the participants to be involved which can include the researcher leading the research project to succeed with both the collaboration and the project. The ideal of participatory research has to be adjusted to the reality. Finally, the chapter discusses how to interact and collaborate with people with early-stage dementia in participatory research as a constructive trusting relationship is needed to support the participants’ involvement. Furthermore, it is essential to support the peer-learning and peer-support that happens in participatory research as the participants benefit from it both socially and intellectually. To have fun in the research collaboration is also central as it functions both as amusement and a coping mechanism. The knowledge gained from conducting the participatory research project will inform the participatory research model.

The following chapter describes how a participatory research model can ensure the involvement of people with early-stage dementia, building on the discussion. This is the conclusion of the study.

CHAPTER 9. CONCLUSION

9.1. INTRODUCTION

The previous chapter discussed knowledge gained from the analysis of the focus groups supplemented with the analysis of the interviews, the literature review and other relevant literature with the purpose of supporting a conclusion of how a participatory research model can allow the involvement of people with early-stage dementia in research.

In this chapter, the thesis is summarised and it is concluded that participatory research with people with early-stage dementia is a suitable way to conduct research when wanting to explore their perspective as long as it is adjusted to the participants' competences and challenges. In addition the developed "*Balanced Participation*" model is presented in the chapter, illustrating a complete research process. It is based upon published literature within the field with inspiration from especially the "*Partners in projects*" and "*Authentic partnerships*" models and key findings from the training and the participatory research model conducted with people with early-stage dementia. The model is illustrated and the reflections and guidances relevant for the participatory research model are described. The limitations of the study are summarised, identifying recommendations for future research. Finally, policy implications are described.

9.2. SUMMARY OF THE THESIS

In the introduction, the background of the study was described together with a need for developing a participatory research model allowing people with dementia to be involved in research to ensure that their lifeworld perspectives are explored. This led to the aim of the study:

To develop a participatory research model based on qualitative participatory research on the lifeworld perspectives of people with an early-stage dementia.

By extension, the purpose is to capture the reflections and guidances that are essential, when conducting qualitative participatory research with people with early-stage dementia.

The literature review contextualised the study revealing that research is still needed in dementia, as people with dementia are one of the most stigmatised groups in society and in research resulting in a lack of knowledge about dementia in various ways. It is still uncommon to involve people with dementia as active participants in participatory research. Thus, training is needed before involvement, but varying views on the effect

of different training approaches exist together with a lack of training models for people with dementia to prepare them for participatory research.

A participatory methodological framework was used in the study. Different participatory research models exist, indicating the importance of defining how the research project was participatory in nature. The *“Partners in projects”* and the *“Authentic partnerships”* models inspired the participatory research project. The project drew upon human science and a qualitative paradigm. A hermeneutic phenomenological approach inspired from Van Manen illustrated the researcher’s position within the research field. The overall aim of the study was informed by a participatory research project with people with early-stage dementia. Two teacher advocates were recruited to make sure the student participants were not harmed. Also a pilot participant was recruited along with twelve student and two teacher participants. An advisory group was established to guarantee the study was participatory. The data collection methods used were participant observations, interviews and focus groups with the use of video recordings. The methods contributed knowledge about the individual person, memory and learning (participant observations and interviews) and with the interaction and collaboration within a participatory research process (focus groups). The analysis of the interviews was inspired by Van Manen’s hermeneutic phenomenological lifeworld analysis and four life existentials. The analysis of the focus groups was inspired by Braun and Clark’s thematic analysis.

Ethical considerations about how to plan, recruit and gain consent from people with early-stage dementia are necessary. It was argued that gaining consent from the participants instead of using proxy consent is preferable. However, it is relevant to assess the mental capacity of the participants to consent before involving them. This was achieved by both using a cognitive test and a teacher advocates’ feedback to include all competences. An ongoing consent was also used but several of the participants questioned the relevance of it as they remembered that they had given consent earlier. It is important that the researcher acts in a morally sensitive manner, which includes building up trust and putting the relationship higher than the project results and using the power in favour of the participants.

The interviews of the participants revealed five themes, illustrating some of the tensions they experienced in life with dementia. The themes were: *“We live a social and active life regardless of difficulties”*; *“We try to look at the bright side of life with dementia”*; *“It takes time to adapt, at the same time we are losing time”*; *“We can still learn but it is challenging”* and *“We try to remember but keep forgetting”*. The knowledge gained from the analysis was used in the project. The participants wanted an active role and were motivated towards helping others. They wished the collaboration established on trust and humour could be used to create a relaxed atmosphere. The participants were only able to concentrate for a certain amount of time and supportive strategies such as repetition, patience, note taking and using a

folder including pictures and small texts were employed to support the learning. To learn research terminology and use computers and iPads was considered too challenging. Besides having memory problems, the participants also had attention problems, which was addressed by using a certain structure throughout the project. The participants also had difficulties in recalling recent past learning and therefore it was not expected that the participants could remember the training for a longer period.

The analysis of the focus groups revealed six themes. The themes were: *“Others don’t have a clue, let’s change it”*; *“You may be our conductor”*; *“We are still the same even though we are not the same”*; *“To be with the likeminded is liberating”*; *“Why does it have to be so negative?”* and *“It is nice that some will collaborate with us”*. These themes showed the participants’ desire to “educate” society about dementia by using their own experiences. However, dementia challenged their daily life and participation in the project. Therefore different types of support were needed to make sure their voices were heard. In the project they also supported and “protected” each other. Humour was also something they appreciated as it facilitated the socialisation with others and eased difficult situations, but it had to be used carefully not to hurt anyone. Finally, after the participatory project they still found it interesting and relevant. After the project they found themselves empowered and rehabilitated by learning from each other about dementia and found I had led the project constructively.

In the thesis it was discussed how participatory research can be time consuming and that knowledge about each participant and about dementia is needed in the training of research skills in the participatory research project. However, the training is compromised by the participants’ short-term memory problems, loss of attention and language problems, which may require the researcher taking the lead and adjusting the research project to succeed with the collaboration and the project. Finally, it is vital that a constructive and trusting relationship is established to support the participants. Also peer-learning and peer-support in participatory research has to be supported as the participants benefit from it both socially and intellectually. Using humour is also central as it functions as both amusement and a coping mechanism.

9.3. THE “BALANCED PARTICIPATION” MODEL

The developed *“Balanced Participation”* model is an alternative model for participatory research involving people with early-stage dementia. It is a unique model - differentiating from the *“Partners in Projects”* and the *“Authentic partnerships”* models as it both incorporates a participatory research process and partnership aspects illustrated the role of the researcher when involving people with early-stage dementia. The model illustrates a complete research process from recruitment to dissemination, incorporating also an evaluation of the research process. In contrast to the two mentioned models, the developed model describes the full process of recruiting, gaining consent and training people with early-stage dementia.

The “*Authentic partnerships*” model does not incorporate the research process but only focuses on the constructive and conducive partnership with people with dementia. Furthermore, it does not describe the role of the researcher, incorporating the importance of peer-learning and -support, which is highlighted in the “*Balanced Participation*” model.

Furthermore, the developed model highlights the relevance of conducting the training in research skills and the participatory research project as a continuous process which differs from the “*Partners in projects*” model where the participatory research project is conducted after completion of the training programme. This leads to a more structured and modified participatory research process in the “*Balanced Participation*” model, focusing on specifying the support mechanisms needed. In this model it is not necessary to rely on a long-term learning for the participants to contribute to research, which is vital when involving people with early-stage dementia in participatory research because of their progressive cognitive impairment.

The “*Balanced Participation*” model demonstrates how participatory research with people with early-stage dementia can be conducted, allowing the participants to contribute important knowledge about dementia, which can complement the view of more traditional research knowledge. The model can facilitate constructive and productive research collaboration with people with early-stage dementia based upon a qualitative research process and methods. This is realistic as long as the research is properly prepared and adjusted to the group involved. It can be time-consuming research, as each step in the research process has to be modified to the participants’ competences and challenges, which is a never-ending task because of the progression of dementia. It means guidelines, frameworks, consents, models, methods etc. have to be adapted to the group the researcher collaborates with to create the right conditions for them. It is therefore crucial to make clear what the purpose of the participatory research project and the training in research skills is to ensure a constructive process. It is about prioritising and simplifying the processes so people with early-stage dementia can contribute constructively. It is necessary for people with early-stage dementia to receive training in research skills in participatory research to make sure they can contribute to research but the training has to be altered due to the participants’ resources and the aim of the research. The training and participatory project can successfully be conducted as a continuous process.

Consequently, it can be difficult to give very precise directions or guidelines to how participatory research has to be conducted when involving people with early-stage dementia due to the need of an adaptive approach. However, the study has succeeded in developing a participatory research model with reflections and guidances when involving people with early-stage dementia in participatory research. It is a comprehensive research model, illustrating principles that have to be adjusted to the exact group of people with early-stage dementia the researcher collaborates with. Conversely, it is acknowledged that the understanding of participatory research

depends on the concepts and terminologies used. Unfortunately, no consistency exists in the field but the developed model can be defined as a balanced and structured model as there were constraints to the participants' involvement due to their short-term memory and language problems. For that reason, the study succeeded to a certain degree in conducting a fully participatory research project with people with early-stage dementia and it succeeded in developing a participatory research model based upon this foundation.

In relation to conducting a fully participatory research project with full citizen control with the participants' own agenda, it is concluded that this might not be relevant for people with early-stage dementia as they needed support the whole way through the research process. To insure a constructive and productive process, it is therefore central for the researcher to be aware of the different degrees of participation in participatory research in order to identify the most suitable involvement for people with early-stage dementia. It is also important to acknowledge that involvement in participatory research can be too demanding for some people with early-stage dementia, which was the case for two participants in the study.

The study also displays how significant the role of the researcher is in participatory research when collaborating with people with early-stage dementia. This includes ethical considerations and moral sensitivity about the participants' involvement in the participatory research project focusing on the participants experiencing inclusion. This includes critical considerations of existing guidelines and frameworks to make certain they do not exclude rather than include people with early-stage dementia in participatory research. Also the informed consent has to be conducted in a way that suits but not patronises the participants to guarantee a truly informed consent is gained. The study shows it is possible for people with early-stage dementia to give informed consent when it is adjusted to their cognitive challenges as for instance reading problems and short-term memory problems.

Furthermore, ethical considerations and moral sensitivity during the participatory research project are central to ensuring that participants are not burdened unnecessarily. Here the researcher has to balance between the ethos of participatory research and ethical considerations towards what is possible and ethical for the participants to be involved in. This means balancing between enabling and limiting the participation of the participants to guarantee their continued involvement. Likewise, in the dissemination of the results it is vital to avoid that the participatory research project displays the group in a way that upholds the existing stigma in society. Participatory research risks disempowering rather than empowering the participants if the researcher does not make sure an ethically constructive involvement of the participants and quality in the research results. This is a responsibility the researcher in participatory research involving people with early-stage dementia has to take to guarantee liable and ethical research is conducted.

In addition to responding to ethical issues, the researcher has to establish a constructive and trusting relationship with the participants to give collaborative research the best chance of success. This means the researcher both has to balance the project work and data collection at the same time so the participants feel safe and confident about raising their voice. To ensure this the researcher has to hold the multiple roles of a researcher, a supporter, a teacher and a learner, ensuring that there is a constructive collaboration where participants are simultaneously taught research and supported to contribute their ideas. It is vital the researcher's power is used to support the participants otherwise withdrawal or participation fatigue is a risk. Furthermore, the researcher ought to take the leading role of the participatory research project when involving people with early-stage dementia to allow them a voice and to create progression in the research project. This leads to a paradox in participatory research when involving people with early-stage dementia as the researcher might have to *take* control in order to *give* control to the participants, enabling them to have a voice. Participatory research involving participants with early-stage dementia can therefore be categorised as a “*seesaw balancing*” act where the researcher tries to enable the participants to participate in research and at the same time structures and limits the possibilities in the research process in order for it to succeed. The researcher balances between enabling and limiting the participation of the participants to make it possible for them to be involved throughout the process. This is an ethical and practical balancing act where the researcher has to consider how to dance the dance.

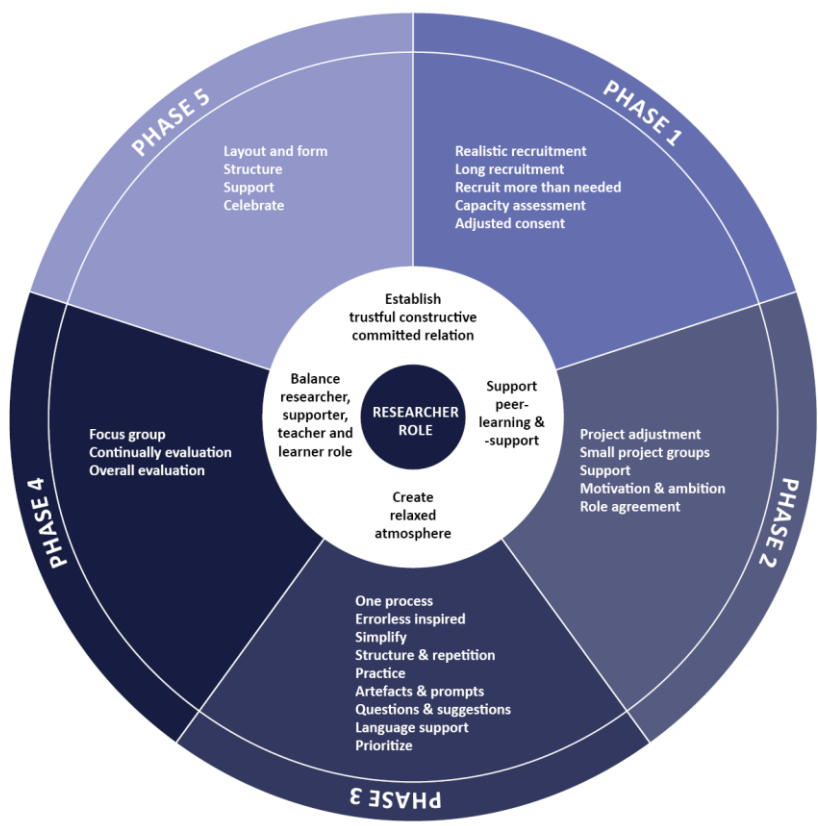
In summary, participatory research involving people with early-stage dementia can be a successful way of conducting research. This study has offered a range of reflections and guidances to underpin research of this kind, culminating in a redesigned participatory research model. This way of conducting research can contribute an important perspective on dementia; it allows those living with the illness to have a voice in research and in society. This is a perspective we still know little about and which is essential to get a more nuanced picture of dementia. Furthermore, it can empower and rehabilitate people with early-stage dementia; participatory research can be a meaningful activity for people with early-stage dementia to be involved in. This is a positive side effect; peer-support and peer-learning are very powerful for participants, although it is not without its challenges, including being time consuming and challenging. The “*Balanced Participation*” model has been designed to allow more people with early-stage dementia to be involved in future successful participatory research.

9.3.1 ILLUSTRATION OF THE “*BALANCED PARTICIPATION*” MODEL

The participatory research model arising from this study builds upon the presented project diagram in fig. 6, page 80, illustrating the phases in a participatory research process. These phases structured the participatory research project with the student participants, taking into consideration the competences and challenges of the participants. The knowledge gained through the research process informed the

participatory research model. See figure 8 for illustration of the developed “*Balanced Participation*” model.

Figure 8: The “*Balanced Participation*” model



The participatory research model includes 5 phases of research, ensuring a constructive research process when collaborating with people with early-stage dementia.

Phase 1 covers a recruitment and consent period where the researcher has to recruit in accordance with guidelines and frameworks from places where it is possible to get access to the participants but without excluding other potential participants. The recruitment period can be long and it can be constructive to recruit more participants than needed because of the progressive nature of dementia. To assess the capacity to consent in more than one way and preferably in collaboration with professionals who

know the participant is constructive. Furthermore, the consent form has to be adjusted to the needs of the people who are recruited.

Phase 2 is the planning and establishing period where the researcher ought to adjust the participatory research project based upon knowledge about existing participatory models and background knowledge about each participant. It is relevant to establish small project groups so the participants are comfortable about raising their voice. If more support is needed than the researcher can provide, a professional who knows the participants can be invited to attend the project group. It is important to identify the motivation, engagement and ambition of the participants so that all are comfortable with the approach taken. Identifying roles between the participants and researcher also support the positive relationships within the group.

In phase 3 the training in research skills and the participatory research project are conducted. Here the researcher needs to offer training in research skills and conduct the participatory research project as one continual process to avoid the learning being lost before newly acquired skills are used. To create a constructive learning environment ensures that participants' contributions are acknowledged and interpreted within the project. It is important to simplify research skills training and the resultant participatory research project so the participants can conduct the tasks as needed. To support the participant's memory it is relevant to use a structure throughout the training and participatory research, using objects or images as prompts, and repetition as needed. Furthermore, simple, concrete and directive questions and suggestions can support the participants' voice. It is also important to use everyday language and support verbal and non-verbal signals to support participants' communication. Finally, it is vital to prioritise what is important to learn as the participants' resources have to be used carefully.

Phase 4 focuses on the evaluation of the research process, where the researcher has to consider the use of focus group evaluation as it can prompt the participant's memory. It is relevant to evaluate each project meeting to be able to adjust the project work continually. Also an overall evaluation is conducted to reveal information about the participants' feelings towards the whole research process can be used but it can be difficult to capture their opinions about the work.

Finally, phase 5 is the dissemination of the results. Here the researcher ought to decide the layout and form of the dissemination together with the participants to allow their voice in the dissemination. The researcher has to structure the planning of dissemination activities and support the participants when they wish to participate in presenting the results. Furthermore, it is important to celebrate the end of the participatory research project to say 'thank you' for their contribution and to bring the project to a close.

The core of the model illustrates the role of the researcher, illustrating the importance of the researcher taking a certain responsibility in the collaboration with people with early-stage dementia.

The researcher needs to establish and develop a trusting committed relationship where the participants can share their experiences and opinions and where both the participants and the researcher commit to the collaboration. Furthermore, the researcher has to support the participants' contribution without becoming too personal or emotional. It is also central that the researcher can juggle between the leading and the supportive role to ensure the participants' participation in the research and a progress in the research process. Furthermore, the researcher has to juggle between the teacher and learner role to train the participants in research skills and to learn from the knowledge the participants pose. The power of the roles have to be balanced to create a constructive collaboration. Also peer-learning has to be supported by the researcher as it can empower and rehabilitate the participants and advocate for the peer-support as it can protect and help the participants during the research work. Peer-support can also include the researcher, showing a true collaboration. Finally, the researcher has to create a relaxed atmosphere, including humour where appropriate and where it does not serve to exclude certain participants.

9.4. LIMITATIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

Different limitations were identified in the study. The study was undertaken in a particular setting (VUK) that I recognise challenge others might have in undertaking research with this group of people where a specialist setting is not available. More investigation into how to recruit people with dementia is therefore needed to find appropriate ways of getting access to different groups of people with dementia. In the study, the participants already knew each other and a trusting relationship between them already existed, which limits the study's possibility to recommend how to establish trustful relations in a project group with unfamiliar participants. Furthermore, the study used an ongoing consent form throughout the process, which was not total successfully accommodated as the participants questioned the need of it. To develop appropriated ways of gaining consent of people with early-stage dementia needs to be further explored as an ongoing consent might not always be appropriated when collaborating with people with early-stage dementia.

In general, the participatory research project can be questioned whether it was characterised as a research project as the student participants conducted a peer-research project where they both acted as researchers and informants. It means the study cannot contribute with knowledge about how people with early-stage dementia can recruit other people to participate in research or how to collect data from unfamiliar participants. The conducted project was therefore not a traditional research project. However, more research-based clarifications are needed in the area of

participatory research because of the variations of concepts and terminologies, which limits the consistency and clarity within the field. Hopefully, the “*Balanced Participation*” model can be a relevant contribution to this research.

Furthermore, the study can be criticised for not allowing a fully participatory research process as the researcher took much control throughout the research process. However, it is important to take into account what people with early-stage dementia can overview and to avoid the process becomes too demanding or frustrating for the participants. More research is needed about how to guarantee the participants most influence in participatory research where the researcher might still needs to take the leading role of the process.

The training of participants in research may also be critiqued for According to the training in research skills it can be critiqued for not focusing on long-term learning. The study is therefore limited regarding how people with early-stage dementia can be taught research skills with focus on long-term memory. Furthermore, the training was modified to the exact type of project conducted and the participants’ capabilities, which meant the training was simplified and contextualised. This limits the possibility to say anything general about how to train people with early-stage dementia in research skills. This area needs further investigation. It might also be relevant to explore how to allow a more detached training from the research process if considered needed.

The study also showed that participating was too challenging for a few participants who withdrew from the participatory research project. It is therefore vital to develop new approaches that can involve people with early-stage dementia who find participatory research, built upon traditional research approaches, too demanding. This has to be further explored in the mind-set of participatory research when collaborating with people with dementia. Hopefully, the participatory research project in this study can inspire others to how a traditional research process can be modified to ensure people with early-stage dementia can be involved in participatory research.

The participatory analysis was much led by me as I prepared the data material for the analysis with the risk the participants lost the context of the data. On the other hand, it can be challenging for people with early-stage dementia to analyse and interpret data and it can be too much to ask them also to prepare data for analysis. Thus, it is important to consider if it can become too demanding for participants with early-stage dementia to participate in analysis because of the progression in dementia. This must be an ongoing reflection, which is situated in the needs of particular participant groups at a particular moment in time.

Finally, a dilemma in the study was identified when conducting participatory research as the study demonstrates it might more give a voice in society than in research. This was apparently not a problem in the study as the participants wanted to “educate” the

society towards getting a more nuanced picture about dementia. It is important to be aware of this potential dilemma, between an academic and a societal voice in participatory research. A limitation in the study was moreover the planning of the dissemination, as it was less structured than the rest of the project work, being forced by time and the agreement with the journalist and photographers. It is important also this part of the project is structured and supported by the researcher.

9.5. POLICY IMPLICATIONS

This thesis and the participatory research model arising from it can be seen in relation to the Danish Government's National Dementia Action plan 2025 (Sundheds og ÆldreMinisteriet 2017). The aim of the Action Plan is to strengthen the area significantly and to help reduce geographical inequalities across municipalities and cities. It is supposed to contribute to making Denmark a dementia friendly country where citizens affected by dementia and their families can live a dignified and secure life based on their current and individual needs - no matter where in the disease progression they are. The preparation of the Action Plan took place in a broad and inclusive process where, for example, people with dementia were included in order to express their priorities in the area (ibid). This is very much in accordance with the aim of participatory research and the "*Balanced Participation*" model. This shows a growing political awareness of the need and benefits in including the voice of the daily experts. As a researcher, I therefore can argue that the model is relevant to implement in practice to make sure more people with dementia have a voice around what they find important in their daily life with dementia.

The values within the Action Plan are similar to the values expressed in the thesis. People with dementia have to be considered as whole people with their own wishes and needs. They should be able to live a dignified and secured life based on their current and individual needs (ibid). Furthermore, they should have influence on own lives, be enabled to participate in meaningful activities and experience positive experiences in daily life. To be able to achieve this it is relevant to include people with dementia, sharing their perspective on what makes a dignified life and what activities they find meaningful. Here participation in research activities can be relevant for some as documented in the thesis. The "*Balanced Participation*" model will allow people to have this opportunity, contributing with knowledge about how they experience a life with dementia and how life quality can be maintained. Political support is needed to enhance the inclusion of people with dementia in knowledge production of how the dementia initiatives should be planned and organised in Denmark.

Compared to the Action Plan the "*Balanced Participation*" model can, in particular, contribute to focus area three around support and counseling to relatives to people with dementia, focus area four about dementia friendly society and residence and focus area five about increased knowledge and level of competence (ibid). In focus area three, the developed model can contribute with knowledge about the content of

the initiatives (courses, daycare services, respite, counseling and activity centers for people with dementia and their relatives) that needs to be promoted and qualified (ibid). In focus area four, it is relevant to include people with dementia around what they think would make a dementia friendly society, municipality and residence. When looking at focus area five, the focus is on gaining more research knowledge, greater knowledge of how dementia is preventable and what best works for people being diagnosed with dementia, but also how the knowledge and skills can be implemented into practice for the benefit of the citizens (ibid). Here the model can contribute with knowledge about how people with dementia themselves believe what works best for them and how research knowledge can be implemented so it benefits them living with the illness.

Unfortunately, when reading through the Action Plan there is no direct reference to how people with dementia can be involved in the various focus areas as participants and producers of knowledge in order to contribute to the development of relevant and useful initiatives. This shows as stated in the literature review that there still is a long way to go before participatory research inclusive PPI is included in the political agenda around the knowledge production about dementia. I therefore argue it is relevant to try to implement the *“Balanced Participation”* model in a Danish context to try to promote more participatory research. Furthermore, it can be relevant to implement the model internationally where there is a political focus on dementia and a responsiveness to involve people with dementia in the development of action plans and initiatives around dementia.

LITERATURE LIST

Agarwal, M., Ferran, J., Ost, K., & Wilkinson, K. (1996). Ethics of "informed consent" in dementia research - the debate continues. *International Journal of Geriatric Psychiatry*, 11, 801-806.

Aggarwal, N., Vass, A. A., & Minardi, H. A. (2003). People with dementia and their relatives: Personal experiences of Alzheimer's and of the provision of care. *Journal Psychiatr Ment Health Nurs*, 10, 187-197.

Aguirre, A., Spector, A., & Orrell, M. (2014). Guidelines for adapting cognitive stimulation therapy to other cultures. *Clinical Interventions in Aging*, 9, 1-5.

Allen, K. (2001). *Communication and consultation. exploring ways for staff to involve people with dementia in developing services*. Bristol: The Policy Press.

Alz.org. (2015a). Dementia – signs, symptoms, causes, tests, treatment, care | alz.org. Retrieved from <http://www.alz.org/what-is-dementia.asp>

Alz.org. (2015b). Dementia – signs, symptoms, causes, tests, treatment, care | alz.org. Retrieved from <http://www.alz.org/what-is-dementia.asp>

Alzheimer Europe. (2012). Annexes - ethics of dementia research - ethical issues in practice - ethics - Alzheimer Europe. Retrieved from <http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/Ethics-of-dementia-research/Annexes#fragment-1>

Alzheimer Europe. (2013). The ethical issues linked to the perceptions and portrayal of dementia and people with dementia - ethical issues in practice - ethics - Alzheimer Europe. Retrieved from <http://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/The-ethical-issues-linked-to-the-perceptions-and-portrayal-of-dementia-and-people-with-dementia>

Alzheimer's Australia. (2016). Dementia language guidelines. Retrieved from <https://fightdementia.org.au/about-dementia/resources/dementia-language-guidelines>

Alzheimer's Disease International. (2015). *World Alzheimer Report 2015. The global impact of dementia. An analysis of prevalence, incidence, cost and trends*. London: Alzheimer's Disease International.

Alzheimer's Society. (2012). The mini mental state examination (MMSE) - Alzheimer's Society. Retrieved from http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=121

Alzheimerforeningen. (2010). Demens koster samfundet milliarder | alzheimerforeningen - livet med demens. Retrieved from <http://www.alzheimer.dk/nyheder/demens-koster-samfundet-milliarder>

Alzheimerforeningen. (2015a). Alzheimerforeningen - livet med demens. Retrieved from <http://www.alzheimer.dk/>

Alzheimerforeningen. (2015b). Forekomst af demens i Danmark - NVD. Retrieved from <http://www.videnscenterfordemens.dk/viden-om-demens/tal-og-statistik-om-demens/forekomst-af-demens-i-danmark/>

Alzheimerforeningen. (2015c). Tænk tank | Alzheimerforeningen - livet med demens. Retrieved from <http://www.alzheimer.dk/raad/tænk-tank>

Alzheimerforeningen. (2016). Giv en håndsækning til mennesker med demens. Retrieved from <http://demensven.dk/>

Alzheimer's Disease International. (2013). World Alzheimer Reports. Retrieved from <http://www.alz.co.uk/research/world-report>

Anstey, K. J., Mack, H. A., & Cherbuin, N. (2009). Alcohol consumption as a risk factor for dementia and cognitive decline: Meta-analysis of prospective studies. *American Journal of Geriatric Psychiatry*, 17, 542-555.

Arnstein, S. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, 35, 216-224.

Ayres, L., Kavanaugh, K., & Knafl, K. A. (2003). Within-case and across-case approaches to qualitative data analysis. *Qualitative Health Research*, 13(6), 871-883.

Bach-y-Rita. (2003). Theoretical basis for brain plasticity after a TBI. *Brain Injury*, 17(8), 643-51.

Bahar-Fuchs, A., Clare, L., & Woods, B. (2013). Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia (review). *The Cochrane Library*, 1-100.

Bahar-Fuchs, A., Hampstead, B. M., & Clare, L. (2014). Cognitive training for older adults with MCI and mild dementia: State of the science, central challenges, and possible solutions. *Alzheimer's & Dementia*, 10(4, Supplement), P157. doi:<http://dx.doi.org.ez-scv.statsbiblioteket.dk/2048/10.1016/j.jalz.2014.04.138>

Baldwin, M. (2011). Resisting the EasyCare model: Building a more radical, communitybased, anti-authoritarian social work for the future. In M. Lavalette (Ed.),

Radical social work today: Social work at the crossroads. (pp. 187-204). Bristol: Lavalette M (ed.).

Barber, R., Beresford, P., Boote, J., Cooper, C., & Faulkner, A. (2011). Evaluating the impact of public involvement on research: A prospective case study. *International Journal of Consumer Studies*, 35, 609-615.

Barnes, D. E., Haight, T. J., Mehta, K. M., Carlson, M. C., Kuller, L. H., & Tager, I. B. (2010). Secondhand smoke, vascular disease, and dementia incidence: Findings from the cardiovascular health cognition study. *American Journal of Epidemiology*, 171, 292-302.

Barnes, D. E., Yaffe, K., Byers, A. L., McCormick, M., Schaefer, C., & Whitmer, R. A. (2012). Midlife vs late-life depressive symptoms and risk of dementia: Differential effects for Alzheimer disease and vascular dementia. *Arch Gen Psychiatry*, 69, 493-498.

Bartlett, H., & Martin, W. (2002). Ethical issues in dementia care research. In H. Wilkinson (Ed.), *The perspectives of people with dementia. Research methods and motivations* (pp. 47-61). London: Jessica Kingsley.

Bartlett, R., & O'Conner, D. (2010). *Broadening the dementia debate: Toward social citizenship*. Bristol: Policy Press.

Bartlett, R. (2012). The emergent modes of dementia activism. *Ageing & Society*, 1-22.

Bartlett, R. (2015). Visualising dementia activism: Using the arts to communicate research findings. *Qualitative Research*, 1-14.

Beauchamp, T., & Childress, J. (2013). *Principles of biomedical ethics* (7th ed.). New York: Oxford University Press.

Behuniak, S. (2011). The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing & Society*, 31, 70-92.

Bengtsson, J. (2006). *Å forske i sykdoms- og pleieerfaringer: Livsverdensfenomenologiske bidrag*. Kristiansand: Høyskoleforlaget AS - Norwegian Academic Press.

Bennett, D. A., Arnold, S. E., Valenzuela, M. J., Brayne, C., & Schneider, J. A. (2014). Cognitive and social lifestyle: Links with neuropathology and cognition in late life. *Acta Neuropathol.*, 127, 137-150.

Bennett, D. A., Schneider, J. A., Tang, Y., Arnold, S. E., & Wilson, R. S. (2006). The effect of social networks on the relation between Alzheimer's disease pathology and level of cognitive function in old people: A longitudinal cohort study. *Lancet Neurol*, 5, 406-412.

Beresford, P. (2005). User involvement, research and health inequalities: Developing new directions. *Health & Social Care in the Community*, 15(4), 306-312.

Beresford, P. (2007). The role of service user research in generating knowledge-based health and social care: From conflict to contribution. *Evidence & Policy*, 3(3), 329-341.

Berghmans, R., & Meulen, T. (1995). Ethical issues in research with dementia patients'. *International Journal of Geriatric Psychiatry*, 10, 647-651.

Bergold, J., & Thomas, S. (2012). Participatory research methods: A methodological approach in motion. *Qualitative Social Research*, 13(1)

Berrios, G. E. (1987). Dementia during the seventeenth and eighteenth centuries: A conceptual history. *Psychological Medicine*, 17(04), 829-837. doi:10.1017/S0033291700000623

Beuscher, L., & Grando, V. T. (2009). Challenges in conducting qualitative research with individuals with dementia. *Res Gerontol Nurs*, 2(1), 6-11.

Bjørner, T. (2015a). Data collection. In T. Bjørner (Ed.), *Qualitative methods for consumer research: The value of the qualitative approach in theory and practice* (1st ed, pp. 57-96). Kbh.: Hans Reitzels Forlag.

Bjørner, T. (2015b). Research design. In T. Bjørner (Ed.), *Qualitative methods for consumer research: The value of the qualitative approach in theory and practice* (1st ed., pp. 17-53). Kbh.: Hans Reitzels Forlag.

Black, B. S., Rabins, P. V., Sugarman, J., & Karlawish, J. H. (2010). Seeking assent and respecting dissent in dementia research. *American Journal of Geriatric Psychiatry*, 18, 77-85.

Blair, T., & Minkler, M. (2009). Participatory action research with older adults: Key principles in practice. *The Gerontologist*, 49(5), 651-662. doi:10.1093/geront/gnp049

Blondell, S. J., Hammersley-Mather, R., & Veerman, J. L. (2014). Does physical activity prevent cognitive decline and dementia?: A systematic review and meta-analysis of longitudinal studies. *BMC Public Health*, 14, 510.

Blumenthal, D. S. (2011). Is community-based participatory research possible? *Am J Prev Med*, 40(3), 386-389.

Boote, J., & Collins, K. (2011). Patient and public involvement in health research. *BASO-ACS Yearbook*, , 61-63.

Boote, J. (2002). Consumer involvement in health research: A review and research agenda. *Health Policy*, 61(2), 213-236. doi:10.1016/S0168-8510(01)00214-7

Borresen, M., Hansen, H. K., & Trangbæk, L. E. (2004). *Socialpædagogik & demens - det vanskelige omsorgsarbejde* (1st ed.). Odense: Styrelsen for Social Service.

Boseley, S. (2012). Dementia research funding to more than double to £66m by 2015 | society | the guardian. Retrieved from <http://www.theguardian.com/society/2012/mar/26/dementia-research-funding-to-double>

Bowling, A. (2013). Research methods in health. Kbh.: Nota. Retrieved from <http://www.e17.dk/bog/622882>

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Brayne, C., Ince, P. G., Keage, H. A., & the EClipSE Collaborative Members. (2010). Education, the brain and dementia: Neuroprotection or compensation? *Brain*, 133, 2210-2216.

Brown, P., & Zavestovski, S. (2004). Social movements in health: An introduction. *Sociology of Health & Illness*, 26(6), 165-181.

Brunnberg, E. (2013). Focus groups with creative elements. In E. Brunnberg, & E. Cedersund (Eds.), *New tools in welfare research* (pp. 113-121). Kbh.: NSU Press; eksp. Århus University Press.

Bull, M. J., Lesley Boaz, R. N., & Sjostedt, J. M. (2014). Public health model identifies recruitment barriers among older adults with delirium and dementia. *Public Health Nursing*, 31(1), 79-87.

Burgener, S. C. (1999). Assessing patients in the early stages of irreversible dementia. the relevance of patient perspectives. *Journal of Gerontological Nursing*, 25(2), 33-41.

Burns, D., Hyde, P., Killett, A., Poland, F., & Gray, R. (2014). Participatory organizational research: Examining voices in the co-production of knowledge. *British Journal of Management*, 25, 133-144.

Byen for livet. (2015). Velkommen til byen for livet, en demensbydel i Odense. Retrieved from <http://byenforlivet.dk/>

Camden C, Shikako-Thomas K, Nguyen T, Graham E, Thomas A, Sprung J, et al. (2015). Engaging stakeholders in rehabilitation research: a scoping review of strategies used in partnerships and evaluation of impacts. *Disabil Rehabil.*, 37(15):1390-400.

Joss N, Cooklin A, Oldenburg B. (2015). A scoping review of end user involvement in disability research. *Disability and health journal*.

Carey, M. (2010). Should I stay or should I go? Practical, ethical and political challenges to "service user" participation within social work research. *Qualitative Social Work*, 10(2), 224-243.

Carmody, J., Traynor, V., & Machetti, E. (2015). Barriers to qualitative dementia research: The elephant in the room. *Qualitative Health Research*, 25(7), 1013-1019.

Chen, R. (2012). Association of environmental tobacco smoke with dementia and Alzheimer's disease among never smokers. *Alzheimer's Dement*, 8, 590-595.

Clare, L., Rowlands, J. M., & Quin, R. (2008). Collective strength. the impact of developing a shared social identity in early stage dementia. *Dementia*, 7, 9-30.

Clare, L., Wilson, B. A., Carter, G., Roth, I., & Hodges, J. R. (2004). Awareness in early-stage dementia: Relationship to outcome of cognitive rehabilitation intervention. *Journal of Clinical and Experimental Neuropsychology*, 26, 215-226.

Clare, L., & Woods, B. (2008). Cognitive rehabilitation and cognitive training for early-stage Alzheimer's disease and vascular dementia (review). *The Cochrane Library*, (4), 1-39.

Clarke, C. L., & Keady, J. (2002). Getting down to brass tasks. A discussion of data collection with people with dementia. In H. Wilkinson (Ed.), *The perspectives of people with dementia - research methods and motivations* (pp. 25-46). London: Jessica Kingsley Publishers.

Clarke, V., & Braun, V. (2013). Teaching thematic analysis. *Methods*, 26(2), 120-123.

Conder, J. (2011). Reflections on a participatory project: The rewards and challenges for the lead researchers. *Journal of Intellectual Developmental Disability*, 36(1), 39-48. doi:10.3109/13668250.2010.548753

Cook, A. (2003). Using video to include the experiences of people with dementia in research. *Research, Planning and Policy*, 21(2), 23-32.

Cornwall, A. (2008). Unpacking participation: Models, meanings and practices. *Community Development Journal*, 43(3), 269-283.

Cornwall, A., & Jewkes, R. (1995). What is participatory research? *Social Science & Medicine*, 41(12), 1667-1676. doi:[http://dx.doi.org.ez-scv.statsbiblioteket.dk/2048/10.1016/0277-9536\(95\)00127-S](http://dx.doi.org.ez-scv.statsbiblioteket.dk/2048/10.1016/0277-9536(95)00127-S)

Cubit, K. (2010). Informed consent for research involving people with dementia: A grey area. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, 34(2), 230-236.

Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research* (2nd ed.). Lund: Studentlitteratur.

Darling, E., & Parra, M. A. (2013). Involving patients and public in research. *Nurse Researcher*, 20(6), 21-25.

DBMAS. (2015). Defining BPSDs | DBMAS | dementia behaviour management advisory service. Retrieved from <http://dbmas.org.au/want-to-know-more/defining-bpsds/>

Demensalliancen. (2016a). Demensvenlige kommuner. Retrieved from <http://demensalliancen.dk/demensrummet/>

Demensalliancen. (2016b). Om demensalliancen. Retrieved from <http://demensalliancen.dk/om-demensalliancen/>

Dementia Alliance International. (2014). - Dementia alliance international. Retrieved from <http://www.dementiaallianceinternational.org/>

Dewar, B. (2005). Beyond tokenistic involvement of older people in research - a framework for future development and understanding. *Journal of Clinical Nursing*, 14(1), 48-53.

Dewing, J. (2007). Participatory research: A method for process consent with persons who have dementia. *Dementia*, 6(1), 11-25. doi:10.1177/1471301207075625

Dilthey, W. (1976). *The development of hermeneutics. Selected writings.* Cambridge: CUP.

Diniz, B. S., Butters, M. A., Albert, S. M., Dew, M. A., & Reynolds, C. F. 3. (2013). Late-life depression and risk of vascular dementia and Alzheimer's disease: Systematic review and meta-analysis of community-based cohort studies. *Br J Psychiatry*, 202, 329-335.

Domecq J.P., Prutsky G., Elraiyah T., Wang Z., Nabhan M., Shippee N. et al. (2014) Patient engagement in research: a systematic review. *BMC Health Serv Res.*;14(1):1-9.

Dougall, N. J., Bruggink, S., & Ebmeier, K. P. (2004). Systematic review of the diagnostic accuracy of 99mTc-HMPAO-SPECT in dementia. *The American Journal of Geriatric Psychiatry*, 12(6), 554-570.

Dowling, M. (2012). Research approaches related to phenomenology: Negotiating a complex landscape. *Nurse Researcher*, 20(2), 21-27.

Dowling, M. (2007). From Husserl to Van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44(1), 131-142. doi:10.1016/j.ijnurstu.2005.11.026

Downs, M. (1997). The emergence of the person in dementia research. *Ageing & Society*, 17, 597-607.

DPI. (2016). Disabled peoples' international. A voice of our own. Retrieved from <http://www.dpi.org/index.html>

Dupuis, S. L., & Gillies, J. (2014). Learning as a vehicle for individual and social transformation. *Therapeutic Recreation Journal*, XLVIII(2), 113-134.

Dupuis, S. L., Gillies, J., & Carson, J. (2012). Moving beyond patient and client approaches: Mobilizing authentic partnerships in dementia care, support and services. *Dementia*, 11(4), 427-452.

Ehde, D. M., Wegener, S. T., Williams, R. M., Ephraim, P. L., Stevenson, J. E., Isenberg, P. J., & MacKenzie, E. J. (2013). Developing, testing, and sustaining rehabilitation interventions via participatory action research. *Archives of Physical Medicine and Rehabilitation*, 94(1), 30-42. doi:<http://dx.doi.org/10.1016/j.apmr.2012.10.025>

Eisner, E. (2013). *Engaging and communicating with people who have dementia. Finding and using their strengths.* Baltimore: Health Professions Press.

Elstad, T. A., & Eide, A. H. (2009). User participation in community mental health services: Exploring the experiences of users and professionals. *Scandinavian Journal of Caring Sciences*, 23, 674-681.

Faulkner, A. (2004). The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors | Joseph Rowntree Foundation. Retrieved from <http://www.jrf.org.uk/publications/ethics-survivor-research-guidelines-ethical-conduct-research-carried-out-mental-health->

Fenge, L. (2010). Striving towards inclusive research: An example of participatory action research with older lesbians and gay men. *British Journal of Social Work*, 40, 878-894.

Fereday, J., Muir-Cochrane, E. (2006). Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. *International Journal of Qualitative Methods*, 5(1), 80-92. Fisk, M., & Wigley, V. (2000). Accessing and interviewing the oldest old in care homes. *Quality in Ageing and Older Adults*, 1(1), 27-33.

Flood, A. (2010). Understanding phenomenology. *Nurse Researcher*, 17(2), 7-15.

Florin, D. (2004). Public involvement in health care. *British Medical Journal*, 328(7432), 159-61.

Forbes, D., Thiessen, E. J., Blake, C. M., Forbes, S. C., & Forbes, S. (2013). Exercise programs for people with dementia. *Cochrane Database of Systematic Reviews*, (12), 1-75.

Freire, P. (1972). *Pedagogy of the oppressed*. Harmondsworth: Penguin.

Freire, P. (1976). *Education, the practice of freedom*. London: Writers and Readers Publishing Cooperative.

Frith, H., & Gleeson, K. (2004). Clothing and embodiment: Men managing body image and appearance. *Psychology of Men & Masculinity*, 5(1), 40-48.

Fudge N., Wolfe, C. D. A., & McKevitt, C. (2007). Involving older people in health research. *Age and Ageing*, 38(5), 492-500.

Gadamer, H. G. (1995). *Gesammelte Werke, Band 10: Hermeneutik im Rückblick*, Tübingen: J.C.B. Mohr

Gadamer, H. G. (1998a). *Praise of theory. Speeches & essays*. New Haven: Yale University Press.

- Gadamer, H. G. (1998b). *Truth and method* (2nd ed.). New York: Continuum.
- Guest, G., MacQueen, K. M., Namey, E. E. (2012). *Applied Thematic Analysis*. United States of America. SAGE Publication, Inc.
- Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach*. Pittsburgh: PA: Duquesne University Press.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity* Prentice-Hall.
- Gould, V. F. (2013). *Reawakening the mind: Evaluation of arts 4 dementia's London arts challenge in 2012: Arts interventions to re-energise and inspire people with the early stages of dementia and their carers*. London: Arts 4 Dementia.
- Graham, N., Lindesay, J., Katona, C., & et al. (2003). Old age psychiatry section, world psychiatric association: World Health Organization. Reducing stigma and discrimination against older people with mental disorders: A technical consensus statement. *International Journal of Geriatric Psychiatry*, 18(8), 670-678.
- Greater Manchester West Mental Health. (2016). *Dementia information*. Retrieved from: <https://www.gmmh.nhs.uk/dementia>.
- Groes, L. (2015). Six specific methods for user insight. In T. Bjørner (Ed.), *Qualitative methods for consumer research: The value of the qualitative approach in theory and practice* (1st ed., pp. 177-187). Kbh.: Hans Reitzels Forlag.
- Groleu, D., Zekowitz, P., & Gabral, I. (2009). Enhancing generalizability: Moving from an intimate to a political voice. *Qualitative Health Research*, 19, 416-426.
- Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Applied thematic analysis*. Thousand Oaks: Ca: Sage.
- Gustavsson, A., Svensson, M., Jacobi, F., & CDBE2010 Study Group. (2011). Cost of disorders of the brain in Europe 2010. *Eur Neuropsychopharmacol*, 21, 718-779.
- Habermas, J. (1984), *The Theory of Communicative Action*, vol. I, trans. McCarthy, T. Boston, MA: Beacon Press.
- Habermas, J. (1987). *The Theory of Communicative Action*, vol. II, trans. McCarthy, T. Boston, MA: Beacon Press.
- Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice* (3rd ed.). London: Routledge.

Hanley, B., Bradburn, J., Barnes, M., & et al. (2003). Involving the public in NHS, public health and social care research: Briefing notes for researchers. (No. 2nd edn.). Eastleigh: INVOLVE.

Hansen, E. C., Hughes, C., Routley, G., & Robinson, A. (2008). General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis. *Social Science & Medicine*, 67(11), 1776-1783.

Hanson, E., Magnusson, L., Arvidsson, H., Claesson, A., Keady, J., & Nolan, M. (2007). Working together with persons with early stage dementia and their family members to design a user-friendly technology-based support service. *Dementia*, 6(3), 411-434.

Hanson, E., Magnusson, L., Nolan, J., & Nolan, M. (2006). Developing a model of participatory research involving researchers, practitioners, older people and their family carers. *Journal of Research in Nursing*, 11(4), 325-342.

Harrison, S., & Mort, M. (1998). Which champions, which people? Public and user involvement in health care as a technology of legitimization. *Social Policy and Administration*, 32(1), 60-70. doi:10.1111/1467-9515.00086
Heggstad, A. K. T., Nortvedt, P., & Slettebø, Å. (2012). The importance of moral sensitivity when including persons with dementia in qualitative research. *Nursing Ethics*, 20(1), 30-40. doi:10.1177/0969733012455564

Heidegger, M. (1962). *Being and Time*. Translated by John Macquarrie & Edward Robinson. London: SCM Press.

Hellström, I., Nolan, M., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5), 608-619. doi:10.1177/0969733007080206

Høiseth, M., Keitsch, M. M., & Holm Hopperstad, M. (2014). Interactions between caregivers and young children. *Qual. Health Res.*, 24(12), 1622-1634.

Holen, M. (2015). Patientinddragelse som politik - hvordan blev det muligt og hvad bliver det til. *Gjallerhorn. Tidsskrift for Professionsuddannelser*, 20, 37-47.

Holloway, I., Todres, L. (2003). The status of method: flexibility, consistency and coherence. *Qualitative Research*, 3(3), 345-357

Holm, A. K., Lepp, M., & Ringsberg, K. C. (2005). Dementia: Involving patients in storytelling - a caring intervention. A pilot study. *Journal of Clinical Nursing*, 14(2), 256-263.

Hørder, M. (2011). Sundhedsforskning - et samarbejde mellem forskere og brugere. (Internet). Det nationale samarbejdsforum for sundhedsforskning.

Howe, E. (2012). Informed consent, participation in research, and the Alzheimer's patient. *Innov Clin Neurosci*, 9(5-6), 47-51.

Hubbard, G., Downs, M., & Tester, S. (2003). Including the perspectives of older people in institutional care during the consent process. In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations* (pp. 63-82). London: Jessica Kingsley Publishers.

Hubbard, G. (2002). Beyond words: Older people with dementia using and interpreting nonverbal behaviour. *Journal of Aging Studies*, 16(2), 155-167. doi:10.1016/S0890-4065(02)00041-5

Hurd, M. D., Martorell, P., Delavande, A., Mullen, K. J., & Langa, K. M. (2013). Monetary costs of dementia in the united states. *N Engl J Med*, 368(14), 1326-1334. doi:10.1056/NEJMsa1204629

Hutchinson, S., Loy, D. P., Kleiber, D. A., & Dattilo, J. (2003). Leisure as a coping resource: Variations in coping with traumatic injury and illness. *Leisure Science*, 25, 143-161.

Ilomaki, J., Jokanovic, N., Tan, E. C., & Lonnroos, E. (2015). Alcohol consumption, dementia and cognitive decline: An overview of systematic reviews. *Curr Clin Pharmacol.*, 10, 204-212.

INVOLVE. (2004). Involving the public in NHS, public health and social care research briefing notes for researchers. Eastleigh. Hampshire: INVOLVE.

Jackson, S. F. (2008). A participatory group process to analyze qualitative data. *Progress in Community Health Partnerships: Research, Education and Action*, 2(2), 161-170.

Kamberelis, G., & Dimitriadis, G. (2013). *Focus groups: From structured interviews to collective conversations*. New York: Routledge.

Karlawish, J., Kim, S. Y., Knopman, D., Van Dyck, C. H., James, B. D., & Marson, D. (2008). The views of Alzheimer disease patients and their study partners on proxy consent for clinical trial enrolment. *American Journal of Geriatric Psychiatry*, 16, 240-247.

Katzman, R. (1976). The prevalence and malignancy of Alzheimer disease: A major killer. *Archives of Neurology*, 33(4), 217-218.

Keady, J., Williams, S., & Hughes-Roberts, J. (2005). Emancipatory practice development through life-story work: Changing care in a memory clinic in North Wales. *Practice Development in Health Care*, 4(4), 203-212.

Kevern, J., & Webb, C. (2001). Focus groups as a tool for critical social research in nurse education. *Nurse Education Today*, 21(4), 323-333. doi:<http://dx.doi.org.ez-scv.statsbiblioteket.dk/2048/10.1054/nedt.2001.0563>

Keyes, S. (2014). Core principles for involving people with dementia in research: Innovative practice. *Dementia*, 13(5), 680-685.

Kitwood, T. (1997a). The experience of dementia. *Aging & Mental Health*, 1(1), 13-22.

Kitwood, T. (1997b). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.

Kleiber, D. A., Hutchinson, S. L., & Williams, R. (2002). Leisure as a resource in transcending negative life events: Self-protection, self-restoration, and personal transformation. *Leisure Sciences*, 24, 219-235.

Knight, B. G., Lutzky, S. M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist*, 33(2), 240-248.

Knight, R. (2005). Interviewing people with dementia using video. *Journal of Dementia Care*, May/June, 31-35.

Knobzi, N., & Flicker, S. (2010). Lessons learned from undertaking community-based participatory research dissertations: The trials and triumphs of two junior health scholars. *Progress in Community Health Partnerships: Research, Education and Action*, 4(4), 347-356.

Koch, T. (2008). Is Tom Shakespeare disabled? *J Med Ethics*, 34, 18-20.

Koltai, D. C., Welsh-Bohmer, K. A., & Smechel, D. E. (2001). Influence of anosognosia on treatment outcome among dementia patients. *Neuropsychological Rehabilitation*, 11(3/4), 455-475.

Krishnaswamy, A. (2004). Participatory research: Strategies and tools. *Practitioner: Newsletter of the National Network of Forest Practitioners*,

Kumar, A. (2012). Using phenomenological research methods in qualitative health research. *International Journal of Human Sciences*, 9(2), 791-804.

Kvale, S., & Brinkmann, S. (2009). Interview: Introduktion til et håndværk (2. udgave ed.). Kbh.: Hans Reitzel.

Kwok, T. C., Chau, W. W., Yuen, K. S., Wong, A. Y., Li, J. C., Shiu, R. Y., & Ho, F. K. (2011). Who would benefit from memory training? A pilot study examining the ceiling effect of concurrent cognitive stimulation. *Clinical Interventions in Aging*, 6, 83-88.

Lacy, M., Kaemmerer, T., & Czipri, S. (2015). Standard mini-mental state examination scores and verbal memory performance at a memory center: Implications for cognitive screening. *American Journal of Alzheimer's Disease and Other Dementias*, 30(2), 145-152.

Laverty, S. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2(3), 21-35.

Law, E. (2013). Dementia research - what do different public groups want? A survey by the Scottish dementia clinical research network. *Dementia*, 12(1), 23-28. doi:10.1177/0142723711420309

Lawn, C. (2006). *Gadamer: A guide for the perplexed*. London: Continuum.

Leamy, M., & Clough, R. (2006). *How older people became researchers*. York: Joseph Rowntree Foundation.

Lewis, J., & Nicholls, C. M. (2014). Design issues. In J. Ritchie, J. Lewis, C. M. Nicholls & R. Ormston (Eds.), *Qualitative research practice. A guide for social science students and researchers* (pp. 47-70). London: Sage Publications.

Lieberoth, A. (2013). Hukommelsessystemer og oplevelseslæring. Hvordan forvandler hjernen episoder til semantisk viden? In T. Schilhab (Ed.), *Pædagogisk neurovidenskab* (pp. 59-82). Aarhus Universitet 2013: Institut for Uddannelse og Pædagogik.

Lleó, A., Greenberg, S. M., & Growdon, J. H. (2006). Current pharmacotherapy for Alzheimer's disease. *Annual Review of Medicine*, 57, 513-533.

Lincoln, Y. (2007). Engaging sympathies: Relationships between action research and social constructivism. In P. Reason, & H. Bradbury (Eds.), *Handbook of action research: The concise paperback edition* (pp. 124-132). London: Sage Publications.

Littlechild, R., Tanner, D., & Hall, K. (2015). Co-research with older people: Perspectives on impact. *Qualitative Social Work*, 14(1), 18-35.

Loewenstein, D. A., Acevedo, A., Czaja, S. J., & Durara, R. (2004). Cognitive rehabilitation of mildly impaired Alzheimer's disease patients on cholinesterase inhibitors. *American Journal of Geriatric Psychiatry*, 12, 395-402.

Løgstrup, K. E., 1905-1981. (1997). *The ethical demand*. Notre Dame, Ind.: University of Notre Dame Press.

Long, R. (2015). *Finding a path for the cure for dementia. an independent report into a integrated approach to dementia research*. London: Information Policy Team. The National Archives.

Lu, F. P., Lin, K. P., & Kuo, H. K. (2009). Diabetes and the risk of multi-system aging phenotypes: A systematic review and meta-analysis. *PLoS ONE*, 4, e4144.

Macnaghten, P., & Myers, G. (2007). Focus groups. In C. Seale (Ed.), *Qualitative research practice* (Paperback ed. ed., pp. 65-79). London: SAGE.

Malterud, K. (2011). *Kvalitative metoder i medisinsk forskning: En innføring* (3rd ed.). Oslo: Universitetsforlaget.

Martin, S., Augusto, J. C., McCullagh, P., Carswell, W., Zheng, H., Wang, H. Mulullvenna, M. (2013). Participatory research to design a novel telehealth system to support the night-time needs of people with dementia: NOCTURNAL - ProQuest. Retrieved from <http://search.proquest.com.ez-scv.statsbiblioteket.dk/2048/docview/1494553085?accountid=35465>

Matthews, F. E., Arthur, A., Barnes, L. E., Bond, J., Jagger, C., Robinson, L., & Brayne, C. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: Results of the cognitive function and ageing study I and II. *Lancet*, 382(9902), 1405-1412.

McKeown, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19(13-14), 1935-43. doi:10.1111/j.1365-2702.2009.03136.x

McKillop, J. (2004). Make it easy on yourself!: Advice to researchers from someone with dementia on being interviewed. *Dementia*, 3(2), 117-125. doi:10.1177/1471301204042332

McLaughlin, H. (2009). What's in a name: 'Client', 'patient', 'customer', 'consumer', 'expert by experience', 'service user'- what's next? *British Journal of Social Work*, 39(6), 1101-1117. doi:10.1093/bjsw/bcm155

Meng, X., & D'Arcy, C. (2012). Education and dementia in the context of the cognitive reserve hypothesis: A systematic review with meta-analyses and qualitative analyses. *PLoS ONE*, 7, e38268.

Meulenbroek, O., Vernooij-Dassen, M., Kessels, R. P. C., Graff, M. J. L., Sjögren, M. J. C., Schalk, B. W. M., Olde Rikkert, M. G. M. (2010). Informed consent in dementia research. Legislation, theoretical concepts and how to assess capacity to consent. *European Geriatric Medicine*, 1(1), 58-63. doi:<http://dx.doi.org.ez-scv.statsbiblioteket.dk/2048/10.1016/j.eurger.2010.01.009>

Miller, E., Cook, A., & Alexander, H. (2006). Challenges and strategies in collaborative working with service user researchers: Reflections from the academic researcher. *Research Policy and Planning*, 24(3), 379-387.

Milligan, C. (2015). Participatory research: Background and outlook. Retrieved from <http://www.lancaster.ac.uk/researchethics/5-2-outlook.html>

Mimura, M., & Komatsu, S. (2007). Cognitive rehabilitation and cognitive training for mild dementia. *Psychogeriatrics*, 7(3), 137-143.

Ministeriet for sundhed og forebyggelse. (2013). Mere borger, mindre patient - et stærkt fælles sundhedsvæsen - sum.dk. Retrieved from <http://www.sum.dk/Aktuelt/Publikationer/Mere-borger-mindre-patient-maj-2013.aspx>

Mogensen, J. (2013). Hjernens funktionelle organisation og reorganisering. Implikationer for pædagogikken. In T. Schilhab (Ed.), *Pædagogisk neurovidenskab* (pp. 33-58). Aarhus Universitet: Institut for Uddannelse og Pædagogik.

Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research*, 5, 147-149.

Müller, N. (2009). Discourses of dementia: A call for an ethnographic, action research approach to care in linguistically and culturally diverse environments. *Seminars in Speech and Language*, 30(3), 198-206. doi:10.1055/s-0029-1225956

Murray, A. (2013). The mental capacity act and dementia research. *Nursing Older People*, 25(3), 14-20.

NICE. (2001). Technology guidance appraisal no. 19: Guidance on the use of donepezil, rivastigmine and galantamine for the treatment of Alzheimer's disease. London: National Institute of Clinical Excellence.

- Nind, M. (2011). Participatory data analysis: A step too far? *Qualitative Research*, 11(4), 349-363.
- Nomura, M. (2009). Empowering older people with early dementia and family caregivers: A participatory action research study. *International Journal of Nursing Studies*, 46(4), 431-441. doi:10.1016/j.ijnurstu.2007.09.009
- Orrell, M., Spector, A., Thorgrimsen, L., & Woods, B. (2005). A pilot study examining the effectiveness of maintenance cognitive stimulation therapy (MCST) for people with dementia. *Int J Geriatr Psychiatry*, 20, 446-451.
- Pahuus, M. (1988). Livsverdenens ubestemmelighedskarakter. *Philosophia*, 17(1-2), 13-25.
- Palibroda, B., Krieg, B., Murdock, L., & Havelock, J. (2009). A practical guide to photovoice: Sharing pictures, telling stories and changing communities. Canada: The Prairie Women's Health Centre of Excellence.
- Pant, M. (2006). Participatory research.
- Parahoo, K. (2014). *Nursing research: Principles, process and issues* (3.th ed.). Basingstoke: Palgrave Macmillan.
- Parkes, J. H., Pyer, M., Wray, P., & Taylor, J. (2014). Partners in projects: Preparing for public involvement in health and social care research. *Health Policy*, 117(3), 399-408. doi:http://dx.doi.org.ez-scv.statsbiblioteket.dk:2048/10.1016/j.healthpol.2014.04.014
- Pedersen, L. (2011). Patientinddragelse: Refleksion, læring, innovation og ledelse. Kbh.: Hans Reitzel.
- Pipon Young, F. (2012). I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study. *Dementia*, 11(5), 597-616. doi:10.1177/1471301211421087
- Plazas, M. d. P. C., Cameron, B. L., Salas, A. S. (2016). Being Attentive to the Inquiry: Lifeworld Existentials to Understand Chronic Illness in the Age of Globalization. 1st International Symposium on Qualitative Research, Volume 5, 113-122.
- Polit, D. (2010). Generalization in quantitative and qualitative research: Myths and strategies. *International Journal of Nursing Studies*, 47(11), 1451-1458. doi:10.1016/j.ijnurstu.2010.06.004

Polit, D. F., & Beck, C. T. (2012). *Nursing research: Generating and assessing evidence for nursing practice* (9th ed.). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Pratt, R., & Wilkinson, H. (2003). A psychological model of understanding the experience of receiving a diagnosis of dementia. *Dementia: The International Journal of Social Research and Practice*, 2, 181-199.

Prince, M., Bryce, R., & Ferri, C. (2011). *World Alzheimer Report 2011: The benefits of early diagnosis and intervention*. Alzheimer's Disease International. London:

Profenno, L. A., Porsteinsson, A. P., & Faraone, S. V. (2010). Meta-analysis of Alzheimer's disease risk with obesity, diabetes, and related disorders. *Biol Psychiatry*, 67, 205-512.

Qiu, C., Xu, W., & Fratiglioni, L. (2010). Vascular and psychosocial factors in Alzheimer's disease: Epidemiological evidence toward intervention. *J Alzheimer's Dis.*, 20, 689-697.

QSR International. (2016). What is NVivo? | QSR international. Retrieved from <http://www.qsrinternational.com/what-is-nvivo>

Rafii, M. S., & Aisen, P. S. (2009). Recent developments in Alzheimer's disease therapeutics. *BMC Medicine*, 7(7)

Ramsden, V. R., & Cave, A. J. (2002). Hypothesis: The research page. Participatory methods to facilitate research. *Can Fam Physician*, Mar(48), 548-554.

Rapley, T. (2007). Interviews. In C. Seale (Ed.), *Qualitative research practice* (Paperback ed. ed., pp. 15-33). London: SAGE.

Rasi, M., Künzler-Heule, P., Schmid, P., Semela, D., Bruggmann, P., Fehr, J., Nicca, D. (2014). "Fighting an uphill battle": Experience with HCV triple therapy: A qualitative thematic analysis. *BMC Infectious Diseases*, 14(507), 1-12.

Reed, J., Cook, G., Bolter, V., & et al. (2006). *Older people 'Getting things done' – involvement in policy and planning initiatives*. York: Joseph Rowntree Foundation.

REHPA. Videncenter for Rehabilitering og Palliation. Definitioner og Begreber (2017). Retrieved from http://www.rehpa.dk/Om_rehabilitering/Definition_begreb.aspx

Reid, D. (2001). What does it mean to listen to people with dementia? *Disability Society*, 16(3), 377-392. doi:10.1080/09687590120045941

Reisberg, B. (1984). Alzheimer's disease: Stages of cognitive decline. *American Journal of Nursing*, 84: 225.

Reissman, C. (1993). *Narrative analysis*. London: Sage.

Requena, C., Maestú, F., Campo, P., Fernández, A., & Ortiz, T. (2006). Effects of cholinergic drugs and cognitive training on dementia: 2-year follow-up. *Dement Geriatr Cogn Disord*, 22(4), 339-345.

Rich, S., Graham M., Taket, A., Shelley, J. (2013). Navigating the Terrain of Lived Experience: The Value of Lifeworld Existentials For Reflective Analysis. *International Journal of Qualitative Methods*, 12, 498-510. Richardson, M. (1997). Participatory research methods: People with learning disabilities. *British Journal of Nursing*, 6(19), 1114-1121.

Ridder, H. M. O. (2011). Musikterapi med demensramte: Hukommelse, identitet og musikreminiscens. In K. Stensæth, & L. O. Bonde (Eds.), *Musikk, helse, identitet* (pp. 61-83). Norge: Senter for musikk og helse.

Robinson, E. (2002). Should people with Alzheimer's disease take part in research? In H. Wilkinson (Ed.), *The perspectives of people with dementia* (pp. 101-107). London, Philadelphia: Jessica Kingsley Publishers.

Ross, F., Donovan, S., Brearley, S., & et al. (2005). Involving older people in research: Methodological issues. *Health and Social Care in the Community*, 13(3), 268-275.

Roy, A. (2012). Avoiding the involvement overdose: Drugs, ethnicity and participatory research practice. *Critical Social Policy*, 32(4), 636-654.

Sadock, B. J., & Sadock, V. A. (2008). *Kaplan and Sadock's concise textbook of clinical psychiatry* (3rd ed.). Philadelphia, Pa.: Wolters Kluwer; Lippincott Williams & Wilkins.

Salmon, A. (2007). Walking the talk: How participatory interview methods can democratize research. *Qualitative Health Research*, 17(7), 982-993.

Savundranayagam, M., Dilley, L., & Basting, A. (2011). StoryCorps' memory loss initiative: Enhancing personhood for storytellers with memory loss. *Dementia*, 10(3), 415-433.

Schneider, B. (2010). *Hearing our voices. Participatory research in mental health*. Toronto: University of Toronto Press.

Schütz, A. & Luckmann, T. (1973). *The Structures of the Life-world*, volume 1. Evanston, Illinois: Northwestern University Press.

Shor, I., & Freire, P. (1987). What is the "dialogical method" of teaching? *Journal of Education*, 169(3), 11-31.

Sitzer, D. I., Twamley, E. W., & Jeste, D. V. (2006). Cognitive training in Alzheimer's disease: A meta-analysis of the literature. *Acta Psychiatrica Scandinavica*, 114(2), 75-90. doi:10.1111/j.1600-0447.2006.00789.x

Sivan, A., & Stebbins, R. A. (2014). Leisure education: Definitions, aims, advocacy and practices - are we talking about the same thing(s)?. In A. Sivan, & R. Stebbins (Eds.), *Leisure education: A cross-national view* (pp. 3-17). Oxon: Routledge.

Skovdahl, K., Kihlgren, A. L., & Kihlgren, M. (2003). Dementia and aggressiveness: Video recorded morning care from different care units. *Journal of Clinical Nursing*, 12(6), 888-898.

Spector, A., Orrell, M., & Hall, L. (2012). Systematic review of neuropsychological outcomes in dementia from cognition-based psychological interventions. *Dement Geriatr Cogn Disord.*, 34, 244-255.

Spector, A., Orrell, M., & Woods, B. (2010). Cognitive stimulation therapy (CST): Effects on different areas of cognitive function for people with dementia. *International Journal of Geriatric Psychiatry*, 25, 1253-1258.

Spector, A., Thorgrimsen, L., Woods, B., & Orrell, M. (2006). *Making a difference: An evidence-based group programme to offer cognitive stimulation therapy (CST) to people with dementia*. London: Hawker Publications.

Stacciarini, J., Shattell, M., Coady, M., & Wiens, B. (2011). Review: Community-based participatory research approach to address mental health in minority populations. *Community Mental Health Journal*, 47(5), 489-497. doi:10.1007/s10597-010-9319-z

Staniszewska, S. (2009). Patient and public involvement in health services and health research: A brief overview of evidence, policy and activity. *Journal of Research in Nursing*, 14(4), 295-298. doi:10.1177/1744987109106811

Stewart, J. T. (2006). The frontal/subcortical dementias: Common dementing illnesses associated with prominent and disturbing behavioural changes. *Geriatrics*, 61(8), 23-27.

Sundheds og Ældreministeriet. (2017). Et trygt og værdigt liv med demens. National Demens-handlingsplan 2015. Januar 2017. Retrieved from http://www.sum.dk/Aktuelt/Publikationer/~media/Filer%20-20Publikationer_i_pdf/2017/Demenshandlingsplan-2025-Et-trygt-og-værdigt-liv-med-demens/Demenshandlingsplan-2025-Et-trygt-og-værdigt-liv-med-demens.ashx

Sundheds og Ældreministeriet. (2015). Ny handlingsplan skal give demente og pårørende et bedre liv. Retrieved from <http://www.sum.dk/Aktuelt/Nyheder/Aeldre/2015/September/Ny-handlingsplan-skal-give-demente-og-paarørende-et-bedre-liv.aspx>

Sundhedsstyrelsen. (2013a). "Demens er noget, vi taler om" - kampagne. Retrieved from <http://sundhedsstyrelsen.dk/da/kampagner/demens-er-noget,-vi-taler-om>

Sundhedsstyrelsen. (2013b). National handlingsplan om demens - sum.dk. Retrieved from <http://www.sum.dk/Aktuelt/Nyheder/Sundhedspolitik/2010/December/Demens.aspx>

Sundhedsstyrelsen. (2013c). Udredning og behandling af demens. Retrieved from <http://sundhedsstyrelsen.dk/da/nyheder/2013/udredning-og-behandling-af-demens>

Sundhedsstyrelsen. (2015a). Demensrejsehold skal styrke demensindsats. Retrieved from <https://sundhedsstyrelsen.dk/da/nyheder/2015/demensrejsehold-skal-styrke-demensindsats>

Sundhedsstyrelsen. (2015b). National klinisk retningslinje for udredning og behandling af demens. Sundhedsstyrelsen,

Sundhedsstyrelsen. (2016). Ny model skal styrke plejen af beboere med demens. Retrieved from <https://sundhedsstyrelsen.dk/da/nyheder/2016/ny-model-skal-styrke-plejen-af-beboere-med-demens>

Swaffer, K. (2015). Dementia and prescribed dis-engagement. *Dementia* (London, England), 14(1), 3-6. doi:10.1177/1471301214548136 [doi]

Swane, C. (2014). Stigmatisering and demenssygdom. *Livet Med Demens*, 1, 18-19.

Tandon, R. (2005). Participatory research: Revisiting the roots. New Delhi: Mosaic Books.

Tanner, D. (2012). Co-research with older people with dementia: Experience and reflections. *Journal of Mental Health*, 21(3), 296-306. doi:10.3109/09638237.2011.651658

Taylor, G. W., & Ussher, J. M. (2001). Making sense of S & M: A discourse analytical account. *Sexualities*, 4(3), 293-314.

The Nuremberg Code. (1949). Trials of war criminals before the Nuremberg military tribunals under control council. Washington, D.C: U.S. Government Printing Office, 10(2), 181-182.

Thorne, S., & Darbyshire, P. (2005). Land mines in the field: A modest proposal for improving the craft of qualitative health research. *Qualitative Health Research*, 15(8), 1105-1113.

Thornton, T. (2006). The discursive turn, social constructionism and dementia. In J. C. Hughes, S. R. Louw & S. R. Sabat (Eds.), *Dementia: Mind, meaning and the person*. Oxford: Oxford University Press.

Tritter, J. Q., & McCallum, A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*, 76(2), 156-168. doi:<http://dx.doi.org/10.1016/j.healthpol.2005.05.008>

Tsolaki, M. (2010). Consensus statement on dementia education and training in Europe. *The Journal of Nutrition, Health Aging*, 14(2), 131-135. doi:10.1007/s12603-009-0238-z

Tuckett, A. G. (2005). Applying thematic analysis theory to practice: A researcher's experience. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, 19, 75-87.

UEA. (2016). Professor Tom Shakespeare. Retrieved from <https://www.uea.ac.uk/medicine/people/profile/tom-shakespeare>

UN. (2006). Convention on the rights of people with disabilities. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>

Unger, H. v. (2012). Participatory health research: Who participates in what? *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 13(1), art. 7.

Vallgård, S., & Koch, L. (2011). *Forskningsmetoder i folkesundhedsvidenskab* (4th ed.). Kbh.: Munksgaard Danmark.

Van Manen, M. (2006). Writing qualitatively, or the demands of writing. *Qual. Health Res.*, 16(5), 713-722.

Van Manen, M. (2007). Phenomenology of practice. *Phenomenology & Practice*, 1(1), 11-30.

Van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. Walnut Creek, CA: Left Coast Press.

Van Manen, M. (1984). "Doing" phenomenological research and writing an introduction (7th ed.) The University of Alberta.

Van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy* (2.th ed.). Ontario: The Althouse Press.

ViBIs. (2015). English | vibis.dk - videnscenter for brugerinddragelse. Retrieved from <http://vibis.dk/english>

Videnscenter for demens. (2006). Daisy. Retrieved from <http://www.videnscenterfordemens.dk/forskning/nvds-forskning/behandling-og-intervention/daisy/>

Videnscenter for demens. (2013). Demensgrader - videnscenterfordemens.dk. Retrieved from <http://www.videnscenterfordemens.dk/viden-om-demens/demenssygdomme/hvad-er-demens/sygdomsforloeb/demensgrader>

Videnscenter for demens. (2015). Forskningsprojekt om fysisk træning og Alzheimer. Retrieved from <http://www.videnscenterfordemens.dk/forskning/adex/>

Videnscenter for demens. (2016). Om nationalt videnscenter for demens. Retrieved from <http://www.videnscenterfordemens.dk/om-os/>

VUK. (2013). Specialskolen for voksne. Retrieved from <http://vuk-aalborg.skoleporten.dk/sp>

Walaszek, A. (2011). Ethical issues in the care of individuals with dementia. In P. McNamara (Ed.), *Dementia treatments and developments* (1st ed., pp. 123-150). Santa Barbara, California: PRAEGER.

Ward, P. R. (2009). Critical perspectives on consumer involvement in health research: Epistemological dissonance and the know-do gap. *Journal of Sociology*, 46(1), 63-82.

Warner, J., McCarney, R., Griffin, M., Hill, K., & Fisher, P. (2008). Participation in dementia research: Rates and correlates of capacity to give informed consent. *J Med Ethics*, 34(3), 167-170.

Weeks, D., Wilkinson, H., Houston, A., & Mckillop, J. (2012). *Perspectives on ageing with dementia*. York: Joseph Rowntree Foundation.

Wertz, F. J. (2011). A phenomenological psychological approach to trauma and resilience. In F. J. Wertz, K. Charmaz, L. M. McMullen, R. Josselson, R. Anderson & E. McSpadden (Eds.), *Five ways of doing qualitative analysis. Phenomenological psychology, grounded theory, discourse analysis, narrative research and intuitive inquiry* (pp. 124-164). New York: The Guilford Press.

Wesnes, K. (2003). The evaluation of cognitive function in the dementias: Methodological and regulatory considerations. *Dialogues in Clinical Neuroscience*, 5(1), 77-88.

Wheeler, S., Holloway, I., & Holloway, I. (2010). *Qualitative research in nursing and healthcare* (3rd ed.). Chichester, West Sussex: Wiley-Blackwell.

White, S. (1996). Depoliticising development: The uses and abuses of participation. *Development in Practice*, 6(1), 142-155.

Whitehouse, P. J. (2000). Ethical issues in dementia. *Dialogues in Clinical Neuroscience*, 2(2), 162-167.

WHO. (2012). *Dementia: A public health priority*. World Health Organization, Geneva; 2012.

WHO. (2015). *First WHO ministerial conference on global action against dementia: Meeting report*. World Health Organization. Geneva: WHO.

Wiersma, E. (2011). Using photovoice with people with early-stage Alzheimer's disease: A discussion of methodology. *Dementia*, 10(2), 203-216.

Wilkinson, H. (2002). Including people with dementia in research: Methods and motivation. In H. Wilkinson (Ed.), *The perspectives of people with dementia: Research methods and motivations* (pp. 9-24). London: Jessica Kingsley Publishers.

Wilkinson, H., & Hubbard, G. (2003). Exploring innovative ways of seeking the views of older people in health and social care research. *Research, Planning and Policy*, 21(2), 1-4.

Wimo, A., Jonsson, L., Bond, J., Prince, M., & Winblad, B. (2013). The worldwide economic impact of dementia 2010. *Alzheimer's Dement.*, 9, 1-11.

Winblad, B., Amouyel, P., Andrieu, S., Ballard, C., Brayne, C., Brodaty, H., Wimo, A. (2016). Defeating Alzheimer's disease and other dementias: A priority for European science and society. *The Lancet Neurology*, 15(5), 455-532.

World Medical Association. (2013). WMA declaration of Helsinki - ethical principles for medical research involving human subjects. Retrieved from <http://www.wma.net/en/30publications/10policies/b3/>

Woods, B., Aguirre, E., Spector, A., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews*, (2)

Woods, B., Spector, A. E., Jones, C. A., Orrell, D., & Davis, S. P. (2009). Reminiscence therapy for dementia (review). *The Cochrane Library*, (1), 1-34.


Xie, J., Brayne, C., & Matthews, F. E. (2008). Survival times in people with dementia; analysis from population based cohort study with 14 year follow up. *British Medical Journal*, 336(7638), 258-262.

Yu, F. (2009). Cognitive training for early-stage Alzheimer's disease and dementia. *Journal of Gerontological Nursing*, 35(3), 23-9.

APPENDICES

Appendix A. Permission from VUK (Skolen for Voksenundervisning og Kommunikation) in Denmark to conduct the participatory research project.	255
Appendix B. Approval from The Committee on Health Research Ethics of the Northern Region in Denmark	257
Appendix C. Approval from The Danish Data Protection Agency.....	261
Appendix D. Example of field notes from the participant observations prior to the semi-structured interviews.....	267
Appendix E. The semi-structured interview guide for the individual student participants interviews	287
Appendix F. The semi-structured interview guide for the focus group evaluations	291
Appendix G. The information leaflet to the student participants. The information leaflet to the relatives	295
Appendix H. Example of a transcript of an interview. Coding of the transcript inspired by the four life existentials.....	309
Appendix I. Example of field notes from the Monday group. Notes taken when observing the video tape. Example of transcript. Coding of the transcript inspired by a thematic analysis	397
Appendix J. The MMSE-test.....	427
Appendix K. Initial Consent: Participation. Renewed Consent: Project work. Renewed consent: Dissemination.....	429
Appendix L. Pictures from the process of the training and participatory research project	435
Appendix M. Poem by one student at VUK.....	501

**Appendix A. Permission from VUK
(Skolen for Voksenundervisning og
Kommunikation) in Denmark to
conduct the participatory research
project**

 AALBORG
KOMMUNE


VUK-Aalborg, 16.01.14


Vedr. PhD. "An insight into the lifeworld of people with early dementia –
A qualitative participatory research project" – af Diana Schack Thoft

VUK-Aalborg giver hermed tilladelse til at Diana Schack Thoft må rekruttere og samarbejde
med skolens kursister med tidlig demens i et partipatorisk projekt efter at disse har afgivet
et informeret samtykke.


Denne tilladelse gives under forudsætning af, at undersøgelsen foregår i samarbejde med
skolens lærere, samt at kursisterne ikke lider overlast og til enhver tid kan trække sig fra pro-
jektet, uden at dette får nogen konsekvens.

Jan Arnbjörn (Forstander, VUK-Aalborg) Kim Sørensen (Speciallærer, VUK-Aalborg)

16/1-14 
Voksenskolen for
Undervisning og
Kommunikation
Forstander Jan Arnbjörn
Studievej 5
9400 Nørresundby

16/1-14 

Skole- og Kulturforvaltningen
VOKSENSKOLEN FOR UNDERVISNING OG KOMMUNIKATION Studievej 5 Tlf. 98177677
9400 Nørresundby Fax 98177086 shvaa@aalborg.dk



Regarding PhD "An insight into the lifeworlds of people with early dementia - A
qualitative participatory research project"- by Diana Schack Thoft

VUK-Aalborg hereby grants permission to Diana Schack Thoft to recruit and work
with the school's students with early-stage dementia in a participatory project after
they have given an informed consent.

This permission is granted; provided that the study is carried out in collaboration with
the teachers and that the students will not be harmed and may withdraw from the
project at any time without any repercussions.

(Own translation)

Appendix B. Approval from The Committee on Health Research Ethics of the Northern Region in Denmark

Fra: Videnskabsetisk Komité [mailto:vek@rn.dk]

Sendt: 28. august 2013 15:24

Til: Diana Schack Thoft

Emne: VS: Henvendelse vedr. krav om anmeldelse af ph.d. projekt

Kære Diana Schack Thoft

På baggrund af de fremsendte oplysninger, er det komitéens opfattelse, at projektet *ikke* er omfattet af komitélovens (lov nr. 593 af 14/6/2011) definition på et sundhedsvidenskabeligt forskningsprojekt, idet der udelukkende er tale om observationer og interviews. Projektet skal derfor ikke anmeldes til og godkendes af komitéen, jf. komitélovens § 14, stk. 1, jf. § 2, nr. 1-3 og kan iværksættes uden yderligere tilbagemelding fra Den Videnskabsetiske Komité for Region Nordjylland.

Klagevejledning: afgørelsen kan, jf. komitélovens § 26, stk. 1, indbringes for Den Nationale Videnskabsetiske Komité senest 30 dage efter, afgørelsen er modtaget. Den Nationale Videnskabsetiske Komité kan, af hensyn til sikring af forsøgspersoners rettigheder, behandle elementer af projektet, som ikke er omfattet af selve klagen. Klagen samt alle sagens dokumenter sendes til: Den Nationale Videnskabsetiske Komité – DKetik@DKetik.dk

Med venlig hilsen

**SEKRETARIATET for DEN VIDENSKABSETISKE KOMITÉ for
REGION NORDJYLLAND**

Regionssekretariatet

Niels Bohrs Vej 30

9220 Aalborg Ø

976 48440

vek@rn.dk

www.vek.rn.dk

Dear Diana Schack Thoft

On the basis of the forwarded information, it is the committee's opinion that the project does *not* lie within the definition of a health scientific research project in the committee-law (law nr. 593 of 14/6/2011), as it only involves observation and interviews. The project does therefore not have to be notified to and approved by

the committee, cf. the committee-law §14, part 1, cf. §2, parts 1-3, and can initiated without further notice from The Committee on Health Research Ethics for the Northern Region.

Kind regards,

The Secretary for The Committee on Health Research Ethics for the Northern Region Regionssekretariatet

Niels Bohrs Vej 30

9220 Aalborg Ø

976 48440

vek@rn.dk

www.vek.rn.dk"

(Own translation)

Appendix C. Approval from The Danish Data Protection Agency

Regarding notification of: “Public engagement in Health research”

Datatilsynet
Borgergade 28, 5.
1300 København K

CBR-nr. 11-88-37-29

Tel +45 3319 3200
Fax +45 3319 3218

E-mail dt@datatilsynet.dk
www.datatilsynet.dk

J.nr. 2013-41-2297

Case Officer
Ms Helene Arensbak Mørk
Dir. Tel +45 3319 3247

On August 22, 2013, the above-mentioned project has been registered with the Danish Data Protection Agency (in Danish: Datatilsynet) according to the Danish Data Protection Act⁷ § 48 (1). Application for authorization has been sent to the Danish Data Protection Agency at the same time.

It is specified in the notification that you are the data controller of the information and data given in the project. Processing of data is requested to commence at the earliest possible date and is expected to end on December 31, 2016.

Data collected for the project will be processed on this address:

University College Nordjylland, Selma Lagerloefs Vej 2, 9220 Aalborg Øst.

AUTHORIZATION

The Danish Data Protection Agency hereby gives authorization to the realization of the project according to the Danish Data Protection Act § 50 (1) no. 1. The following terms are determined by the Danish Data Protection Agency:

General conditions

The authorization is valid until: December 31, 2016

⁷ Act no. 429 of May 31, 2000, on processing of personal data with amendments.

At the expiration of the authorization, please observe:

If you have not received an extension of your authorization by the above-mentioned date, the Danish Data Protection Agency will assume that the project has been terminated, and that personal data have been deleted, depersonalised, destroyed or archived in accordance with the below-mentioned conditions of the closing of the project. After this date the notification of your project will be removed from the register of notified projects on the website of the Danish Data Protection Agency.

The Danish Data Protection Agency draws the attention to the fact that the processing (including the storage) of personal data after the expiration of the authorization will be considered an infringement of the Danish Data Protection Act cf §70.

Associate professor and Ph.D. student Mrs Diana Schack Thoft is responsible for compliance of the set terms.

Data must only be employed for the realization of the project.

Processing of personal data must only be carried out by the data controller or on the justification and responsibility of the data controller.

Anyone processing data in relation to the project must be aware of the set terms and conditions.

The set terms must also be observed by the data processing unit when processing data.

Facilities employed for storing and processing of the project's data must be designed to prevent unauthorised access.

Processing of data must be organised in such a way that data is not accidentally or illegally destroyed, forfeited or impaired. Requisite control must be performed to ensure that no false or misleading data is being processed. False or misleading information or data processed in discrepancy with the law or the set terms of this authorization must be settled or deleted.

Data is not to be stored in a way that could allow for the identification of the registered persons beyond the necessary time frame of the project.

Any publication of the results of the project is not to be effectuated in a way that would enable the identification of individuals.

Any terms set by another statutory law are assumed to be obeyed.

Electronic information – data security requirements

Identification data must be encrypted or replaced by a code number or similar. As an alternative, all data could be stored encrypted. The encryption key, the code key etc. must be stored securely and separate from the personal data.

A confidential password must be employed to access the data of the project. The password must be changed at least once a year, and whenever necessary.

When transferring personal identification data via the internet or another external network, all necessary security measures must be upheld to ensure unauthorised access. As a minimum the data must be securely encrypted during the entire transmission. At the employment of internal networks it must be ensured that no unauthorised access is allowed.

Removable storage mediums, safety copies of data etc. must be stored and locked up securely to prevent unauthorised access.

Manual information – data security requirements

Manual project materials, transcripts, error- and control lists etc., that directly or indirectly could trace back to certain persons must be stored and locked in a way that prevents unauthorised access.

Duty of disclosure to the registered party

16. If data is collected from the registered party (by interviews, questionnaire, clinical or para-clinical examination, observation etc.) information about the project must be distributed or submitted. In the information material the registered party must be informed about the name of the data controller, the purpose of the project, that participation is voluntary, and that consent to participate can be withdrawn at any time. If data is to be handed on for employment in another scientific or statistical relation, the registered party must be informed about the objective of the passing of data and the identity of the receiver.

17. In addition the registered party must be informed that the project has been registered with The Danish Data Protection Agency in accordance with the

Danish Data Protection Act and that The Danish Data Protection Agency has stipulated terms and conditions to protect the privacy of the registered party.

Access to data

18. The registered party has no claim on insight into the information being processed about the party concerned.

Disclosure

19. Disclosure of personal data and information to third party is only allowed when data is to be applied in relevant statistics or scientific research.

20. Any disclosure of data must be authorised by The Danish Data Protection Agency. The Data Protection Agency may set further terms and conditions for passing on data and for the receiver's processing of the data received.

Alterations to the project

21. Any significant alterations to the project require a notification to the Data Protection Agency (as an alteration to the existing notice). Minor alterations can be reported directly to the Data Protection Agency.

22. Modification of the termination date of the project must always be reported.

At termination of the project

23. No later than by the termination date of the project must data be deleted, depersonalised or destroyed in such a way that it is no longer possible to identify individual persons who have formed part of the investigation.

24. Alternatively, data can be transferred to the Danish Public Records Office (including the Danish Data Archive) in accordance with the regulations of the public records act.

25. Deletion of data from electronic media must be performed in such a way that data cannot be restored.

The above mentioned terms apply until further notice. The Data Protection Agency reserves the right to revise the terms if necessary.

The Data Protection Agency directs attention to the fact that this authorization solely is an authorization to process personal data in connection with the realization of the project. The authorization does not include an obligation for authorities, companies etc. to hand over any information to you for the use of the project.

Passing on information *from* statistical records, scientific projects etc. does require that the data controller has been granted special authorization from the Data Protection Agency according to the Data Protection Act § 10, (3).

As a matter of form, the Data Protection Agency directs the attention to the fact that according to The Danish Health Act § 46 special terms and conditions apply to the disclosure of data from patient records to scientific purposes, under this special instructions about approval from the Danish National Board of Health.

The notice is published in the records at the website of the Danish Data Protection Agency; www.datatilsynet.dk.

The Danish Data Protection Act can be accessed /downloaded on the website of the Data Protection Agency, under "Legislation".

Warning – utilization of Excel, Power Point

At any given time the data controller must ensure those documents and other presentations that are published or made accessible to others on the internet, on an USB stick or other electronic devices, do not include personal data.

Special attention must be exercised during employment of graphical presentations in Excel and PowerPoint as they may unintentionally contain embedded personal data in the form of spread sheet, tables, etc. Presentations made public on the internet should be converted to Portable Digital Format (PDF) as this process will remove any embedded Excel tables.

Yours sincerely,

Helene Arensbak Mørk

(Own translation)

Appendix D. Example of field notes from the participant observations prior to the semi-structured interviews



Program for dagen:

Personerne: 41 stykker

Alm. tema:

Interaktionerne:

Kommunikationen:

Kompetencerne:

Udfordringerne:

Life in the world:

live i verden
live i livet
live i sine
live i relation
live i sig selv



Program
 = tænke tanker
 Avis læsning ca. 1 time } sidste tirsdag
 10-15 min ops.
 Besøg
 Her spillet held på iPad i tirsdag
 (cykler så sjældt når først kommer i gang)
 Programmet lægger ikke altid fast. Der
 tales meget om hvad der skal laves og
 hvordan ideerne gennemføres

Person

Svært ved at huske ansiger hvis jeg ikke kan
sætte det i et en situation.
kan huske mig i et englandene
Har svært ved at huske ansiger
kan hjælpe nogle andre
kan fortælle at det er fygtøren
kan huske om atskilleberet

Sommetider går det...
kan huske englandene.
Svært at huske det som selv
bor du i århus? (1/2 huske)
Det er ikke det
Det lyder meget højtideligt ...
Så har det hele været
Det ved du godt man ikke må lade her.

Så selv skrive nature
Svært at huske
ikke, derne på udsende
Spørger som undviser
Et styrende + vendt lade

Har net om det.
Det er fygtøren der åbner
Har manglede med
Et billede
Er omgivelser og vende sig rundt

10:30 - kims les
(vil gerne lave det i samme blok)

11:30 - introduction til at lave en
plakat

imens der er kims les arbejdes der
med krydsord, rebus, sudoku

12:00 - eftermiddag
sudoku nr 9.

12:30 - tolv og planlægger noget
under tirsne. Der forekommer færd
en del uro + tale.

kl. 12:00 - Der tages et fælles stilling
toilet i kl. Der smides snarere efter et
skifte tid. Der begynder
og holder om ledelsen.

12:30 spil Banco pladen fuld. Pladen skal laves
op.

13:00 med sin datter. Der kl. fire børn.
begynder fra bide.

13:00 Trivial Pursuit

kompetencer

14:00 - læser relationen
Bemærk at det ikke er givet
Associerer ikke på tid + Greenland

Alle holder af humør. der gøres om bordet
Hvis man mange af spillene spænder
Her ligger billeder til plakaten om Guinness
Her er kompetencer.

14:30 - alle på iPad. Der laves men vandt
Her problemer med det engelske
Tilføjer håndl.

Her mod på at afprøve

Hvad spil

Godt minner

nu kan jeg huske den gamle med i lygten

kl. 14:30 finde på noget godt nu der er meget

ved iPad.

Tænk over at huske formidlet sig fra hør

ne kan ikke kan finde

Hvad kan de unge mennesker i dag

hvis der kan i en sekunde

fortæller at det der ligger er hvad kan man ikke

me. Hånden og at tilbage kan man huske

meningerne ud på syngen og

vaner og ud at være hvad man

svad hør. kan ikke så let følge

En så holder han forening
i lægen ham ned
Der holder jeg det for det
ville der mig... (ville for ved?),

Udledning:

- Er behält den cover für iPad

1832

1450000

lower (richer) - 1% se did
even over Tale

Kaiser (winner)

laser (opneuksem) har mistet
sæberindhold. Blod taget sidste
gang. Har det

var hje ind leverende.
Her skøn salinger af andelsbe-
hold udstille.

Her vanished and noide sym po
tulate. For help of him 41 at 20 pld
5m place. with 5m. 10m. 15m. 20m. 25m. 30m. 35m. 40m. 45m. 50m. 55m. 60m. 65m. 70m. 75m. 80m. 85m. 90m. 95m. 100m. 105m. 110m. 115m. 120m. 125m. 130m. 135m. 140m. 145m. 150m. 155m. 160m. 165m. 170m. 175m. 180m. 185m. 190m. 195m. 200m. 205m. 210m. 215m. 220m. 225m. 230m. 235m. 240m. 245m. 250m. 255m. 260m. 265m. 270m. 275m. 280m. 285m. 290m. 295m. 300m. 305m. 310m. 315m. 320m. 325m. 330m. 335m. 340m. 345m. 350m. 355m. 360m. 365m. 370m. 375m. 380m. 385m. 390m. 395m. 400m. 405m. 410m. 415m. 420m. 425m. 430m. 435m. 440m. 445m. 450m. 455m. 460m. 465m. 470m. 475m. 480m. 485m. 490m. 495m. 500m. 505m. 510m. 515m. 520m. 525m. 530m. 535m. 540m. 545m. 550m. 555m. 560m. 565m. 570m. 575m. 580m. 585m. 590m. 595m. 600m. 605m. 610m. 615m. 620m. 625m. 630m. 635m. 640m. 645m. 650m. 655m. 660m. 665m. 670m. 675m. 680m. 685m. 690m. 695m. 700m. 705m. 710m. 715m. 720m. 725m. 730m. 735m. 740m. 745m. 750m. 755m. 760m. 765m. 770m. 775m. 780m. 785m. 790m. 795m. 800m. 805m. 810m. 815m. 820m. 825m. 830m. 835m. 840m. 845m. 850m. 855m. 860m. 865m. 870m. 875m. 880m. 885m. 890m. 895m. 900m. 905m. 910m. 915m. 920m. 925m. 930m. 935m. 940m. 945m. 950m. 955m. 960m. 965m. 970m. 975m. 980m. 985m. 990m. 995m. 1000m. 1005m. 1010m. 1015m. 1020m. 1025m. 1030m. 1035m. 1040m. 1045m. 1050m. 1055m. 1060m. 1065m. 1070m. 1075m. 1080m. 1085m. 1090m. 1095m. 1100m. 1105m. 1110m. 1115m. 1120m. 1125m. 1130m. 1135m. 1140m. 1145m. 1150m. 1155m. 1160m. 1165m. 1170m. 1175m. 1180m. 1185m. 1190m. 1195m. 1200m. 1205m. 1210m. 1215m. 1220m. 1225m. 1230m. 1235m. 1240m. 1245m. 1250m. 1255m. 1260m. 1265m. 1270m. 1275m. 1280m. 1285m. 1290m. 1295m. 1300m. 1305m. 1310m. 1315m. 1320m. 1325m. 1330m. 1335m. 1340m. 1345m. 1350m. 1355m. 1360m. 1365m. 1370m. 1375m. 1380m. 1385m. 1390m. 1395m. 1400m. 1405m. 1410m. 1415m. 1420m. 1425m. 1430m. 1435m. 1440m. 1445m. 1450m. 1455m. 1460m. 1465m. 1470m. 1475m. 1480m. 1485m. 1490m. 1495m. 1500m. 1505m. 1510m. 1515m. 1520m. 1525m. 1530m. 1535m. 1540m. 1545m. 1550m. 1555m. 1560m. 1565m. 1570m. 1575m. 1580m. 1585m. 1590m. 1595m. 1600m. 1605m. 1610m. 1615m. 1620m. 1625m. 1630m. 1635m. 1640m. 1645m. 1650m. 1655m. 1660m. 1665m. 1670m. 1675m. 1680m. 1685m. 1690m. 1695m. 1700m. 1705m. 1710m. 1715m. 1720m. 1725m. 1730m. 1735m. 1740m. 1745m. 1750m. 1755m. 1760m. 1765m. 1770m. 1775m. 1780m. 1785m. 1790m. 1795m. 1800m. 1805m. 1810m. 1815m. 1820m. 1825m. 1830m. 1835m. 1840m. 1845m. 1850m. 1855m. 1860m. 1865m. 1870m. 1875m. 1880m. 1885m. 1890m. 1895m. 1900m. 1905m. 1910m. 1915m. 1920m. 1925m. 1930m. 1935m. 1940m. 1945m. 1950m. 1955m. 1960m. 1965m. 1970m. 1975m. 1980m. 1985m. 1990m. 1995m. 2000m. 2005m. 2010m. 2015m. 2020m. 2025m. 2030m. 2035m. 2040m. 2045m. 2050m. 2055m. 2060m. 2065m. 2070m. 2075m. 2080m. 2085m. 2090m. 2095m. 2100m. 2105m. 2110m. 2115m. 2120m. 2125m. 2130m. 2135m. 2140m. 2145m. 2150m. 2155m. 2160m. 2165m. 2170m. 2175m. 2180m. 2185m. 2190m. 2195m. 2200m. 2205m. 2210m. 2215m. 2220m. 2225m. 2230m. 2235m. 2240m. 2245m. 2250m. 2255m. 2260m. 2265m. 2270m. 2275m. 2280m. 2285m. 2290m. 2295m. 2300m. 2305m. 2310m. 2315m. 2320m. 2325m. 2330m. 2335m. 2340m. 2345m. 2350m. 2355m. 2360m. 2365m. 2370m. 2375m. 2380m. 2385m. 2390m. 2395m. 2400m. 2405m. 2410m. 2415m. 2420m. 2425m. 2430m. 2435m. 2440m. 2445m. 2450m. 2455m. 2460m. 2465m. 2470m. 2475m. 2480m. 2485m. 2490m. 2495m. 2500m. 2505m. 2510m. 2515m. 2520m. 2525m. 2530m. 2535m. 2540m. 2545m. 2550m. 2555m. 2560m. 2565m. 2570m. 2575m. 2580m. 2585m. 2590m. 2595m. 2600m. 2605m. 2610m. 2615m. 2620m. 2625m. 2630m. 2635m. 2640m. 2645m. 2650m. 2655m. 2660m. 2665m. 2670m. 2675m. 2680m. 2685m. 2690m. 2695m. 2700m. 2705m. 2710m. 2715m. 2720m. 2725m. 2730m. 2735m. 2740m. 2745m. 2750m. 2755m. 2760m. 2765m. 2770m. 2775m. 2780m. 2785m. 2790m. 2795m. 2800m. 2805m. 2810m. 2815m. 2820m. 2825m. 2830m. 2835m. 2840m. 2845m. 2850m. 2855m. 2860m. 2865m. 2870m. 2875m. 2880m. 2885m. 2890m. 2895m. 2900m. 2905m. 2910m. 2915m. 2920m. 2925m. 2930m. 2935m. 2940m. 2945m. 2950m. 2955m. 2960m. 2965m. 2970m. 2975m. 2980m. 2985m. 2990m. 2995m. 3000m. 3005m. 3010m. 3015m. 3020m. 3025m. 3030m. 3035m. 3040m. 3045m. 3050m. 3055m. 30

stemningen

Acetapod

Humer - lever igen

u. søvel

Stille + uhyggelig

Er god til at lytte og vende til deres
liv.

Idén eller søvne har igen og igen

visker engang og tank søvne

Der rødes hender op

Der laves små hjælpere til

I pausen er der stille og iude en masse

smaltale.

Små drillerer i bl. billeder til plukket
om studieret.

koncenerer sig om opførelse og småsnak
rundt om bordet

- giner og ad kan I iude være be-
været, små og gine. Et lille glas på
studen. Hvorfor er det altid mig...

Der driller mens der spørges om Banko
sætter episoder på daskallerne
og viser sin nøgne uben

[redacted] [redacted]
 [redacted] [redacted] 4:1 sig?
 30 siger alle de andre

Regien:
 for vins 10g.
 vins 10g
 kl. 10:00 - 12:00
 10 hverdags vins under håndklude

(30-45 sek.)
 Tilfalds orden
 kon kunne møde sig selv
 fidusen:
 Officiel gå tilbage
 vi har vist man kan gå frem.
 Test en gang om ugen.
 Indtil jul hver tirsdag.
 Bled lagret i langhids lukkelsen.

Indkøb i butikken

lave det til en mere rigtig handling i
butikken som almindeligt

Idéer til hvad der kan bruges

til at sætte vække ure + delte bord

lave en evalueringssamling på dagen?

Program for dagen lavet visuelt for at
sikre struktur?

Idéer:

lave stenciler med logiske oplysninger fra
høje til venstre.

Programme for the day:

The persons present

The activities

The interactions

The communication

The competences

The challenges

Life existentials:

Lived body

Lived time

Lived relation

Lived space

Programme:

X = thinks thoughts

Newspaper reading ca. one hour – 10-15 minutes assignments (last Tuesday)

Visit

Have played a little on iPad: Tuesday

(Thinks it is funny when they first start)

The programme is not always fixed. It is talked much about what to do and when through the lessons

Person:

X:

Difficulties with remembering faces if I cannot put it in relation to a situation

Do remember me in relation to the English persons - does go outside

Have difficulties with remembering faces

Can help others

Can tell that it is the freezer

Do remember the waste sorting

X:

Sometimes it goes...

Do remember the English persons

Do you live in Aarhus? (Do not remember)

It is not you

It sounds very

Need to have everything

You know that you may not buy it here

Sometimes get support for the assignments

You may ask I do not know

Get so angry if they have cheated me

The firm

X:

Have heard about it

It is the freezer that is opened

Have with

Is quieted

Is aware and turns around

Tell that he is not visual and has lost the ability to numbers

X:

Uses Humour

Asks to the garden + late summer

The sweetest but a new tattoo when out traveling

X:

Asks if the

Is quieted

Answers questions when being asked

Takes the word around EU- the Scandinavians

Has a system to remember Sudoku. Goes from one side to the other

Comments and helps X with cross words

X:

Is quieted

Goodness- agh

Tells about his paper

Short sentences

Can correct pictures

Goes for a while

Comes with suggestions

Put the finger up

I go for myself

Difficulties in recalling inGo

Asks about the week and contact X, % planned for Friday – cancel?

Difficulties in understanding what she has to do

Can correct pictures from Carnival Kim's play

Gets nervous and unsecure

Supported to make her cross word

Activities:

X makes the coffee – cannot remember about 7-8 spoon full

Can see the newspapers are picked up

Talks about the persons

X sits down and reads news paper

Teachers will like to start with test and exercises

At 8.45 am everyone sits around the table and begin to read. My husband the 12/8 ...
in operated a pacemaker. Tired and exhausted

Asks to first page and continues with the pages

The teaches are very controlling

X decides the speed

Takes the Break's Quiz

9.25 am Introduces 2 persons + iPad + practice

9.25 am practice questions from The Europe Game. Goes around the table

10.00 am Break

10.20 am

10.20 am X comes and teachers talk together and the students sit quieted and look around

10.30 am Kim's play

(Would like to do it in same block)

11.30 am the introduction to make a poster

While there is Kim's play there is worked with cross words, rebus and Sudoku

X checks X Sudoku number 9

The teachers talk and plan a lot during the lessons. There seems a great deal of disturbance and talking

12.00 am lunch is eaten. Quieted. X speaks in the mobile phone with her daughter. Mother to four children. Small talking after a while. X and X are both schoolteachers and about the manager.

12.30 pm play Bingo card full. The Card is to be read aloud.

X and X both from XXX

13.00 pm Trivial Pursuit

Competences:

X reads the online newspaper

Does not need to look in the newspaper

Associates further on the temperature and Greenland

All are fond of humour. Laughter around the table

Remembers a lot of the questions of the game

Has taken pictures to the poster about the Wood house

Has IT competences

X does not use iPad. Rehearse flags but difficult

Has problems with the English

Pushes hard

Has the courage to try out

Remembers game

Now I can remember the yellow one down in the corner

Has to figure out something funny when there is something with the iPad

Thinks about how to formulate himself because the grandchildren do not understand

What the young people can today

Loses the concentration in one sentence

Tells that what has just happen he cannot remember. Months and years, back he does remember

X loses the orientation in the hallway and difficult to choose what she wants, cannot choose easily

X so he keeps lectures

We put him down X

That I did before you X

Not for me... (Not too easy?)

Challenges:

Has reservations around the iPad

X

X reads

X reads (a bit insecure) % see it

X takes over. Thanks

X reads (humour)

X reads (attention). Has lost reading ability. Was taken last time. Has rehearsed.

X was just a little absent

Has small sentences to make excuses

A bit insecure

Has difficulties in keeping track of the numbers. Gets help of X to get the card full.
Can I not just play myself

X teases with an X

The atmosphere:

Relaxed

Humour – makes fun

Informal

Quieted and cosy

Is good in listening and wait for their turn

Go for the same turn again and again

Is engaged and thoughtful

The hands are put up

There are made small helping things to

In the break, it is quieted and not a lot small talk

Teasing in relation to pictures to the poster around the Wood house

Concentrate around the tasks and small talk around the table

X laughs and you cannot do that. Smile and laugh. A small punch on the shoulder.
Why is it always me...

Teasing while being asked about Bingo

X puts episodes on the years and shows his great knowledge

X

Rakes X it?

Yes all the others says

Rules:

Kim's play

10.00-12.00 am

10 everyday things under a towel

(30-) 45 seconds

Randomly

Compete against oneself

The trick:

Official go back

We have shown that you can go forward

Test once a week

Until Christmas every Tuesday

Has been stored in the long term memory

Shopping in the canteen:

Make it more realistic shopping in the canteen as normal

Ideas to what can be trained

Make the coffee + set the table

Make an evaluation/resume of the day

Programme of the day made visual for creating structure

Ideas:

Make schemes with logical structure from right to left

Appendix E. The semi-structured interview guide for the individual student participants interviews

Interview guide student participants

Presentation of interviewer and project:

- Interviewer
- Project
- Voluntary and ongoing consent

Can you say something about yourself?

- Age?
- Former employment?
- Family?
- Diagnosis and course of illness?
- Use of technology? (pc, mobile phone, iPad)

What is it like to attend the school VUK?

- Why do you attend the school?
- What is it like to attend the school?

What do you do at the school?

- What tasks do you work on? How is it?
- Is there anything that is difficult to work on at the school?
- What helps you when you work on something difficult?
- Do you work with technology at the school? (pc, mobile phone, iPad) what is that like?

How did you learn best before you got dementia?

- How did you learn new things before getting dementia?
- What has always been difficult for you to learn?
- What activities have you always preferred to do?

How do you learn best after you got dementia?

- How do you manage now, after you got dementia?
- How do you best learn something new now?
- What is difficult for you to learn now?
- What activities do you prefer to work on now?

How do you remember best now?

- How do you remember what you learn at the school?
- What strategies do you use to remember?

How do you wish to work with me when we collaborate on the project?

- What is your preference for training?
- How do you want us to collaborate?
- Would it be relevant to use pictures, videos and text?
- Do you think the surroundings will influence the project?
- Will repetition help?
- What do you expect to get out of your participation in the project?

(Own translation)

Appendix F. The semi-structured interview guide for the focus group evaluations

Focus group evaluation

Experience of the project

- How has it been to conduct the project?
- What has meant something to you during the project work?
- What has completing the project meant to you?
- How have you experienced your role in the project?

The meaning of the project

- Do you take something with you after completing this project?
- What has it meant to you to be a part of the project?
- Has the project changed something for you?

Methods in the project

- What do you think about the use of the folder – at home and at VUK?
- What do you think about getting a work plan every time with pictures and text of what we did last time and what we are doing this time?
- What do you think about the fact that I have been the one who has written and clustered your materials on post-its, papers, videos?
- How have you experienced my role in the project?

Important in a project

- What do you think is important to be aware of when collaborating with people with dementia in a project?
- Is there anything you should avoid when collaborating with people with dementia in a project?
- What do you think a model for a project collaboration should contain when collaborating with people with dementia?

Possible changes for future project collaborations

- Is the anything you would have preferred to have been different in the project?
- Is there anything you would have preferred more of in the project?
- Do you have any suggestions for improvements when collaborating with people with dementia in a project?

(Own translation)

**Appendix G. The information leaflet to
the student participants. The
information leaflet to the relatives**

Insight into the life with early-stage dementia

novonordiskfonden



Information to students at VUK



THE UNIVERSITY OF
NORTHAMPTON



Dear.....



My name is Diana Thoft, and I am an educated nurse. Currently, I am collaborating with the school VUK about a PhD project. You are invited to participate in the project.

Before you decide wherever you want to participate, it is important that you understand why the project is conducted, and what your participation in the project implies. If you find the project unclear, after you have read the leaflet, you are welcome to contact me.

The purpose of the project

The purpose of the project is to develop a model for how to collaborate with people with early-stage dementia in projects. The model is developed as 12 students with early-stage dementia and I conduct a shared project about how life with early-stage dementia is experienced. An advisory group with two

teachers and two students is also established to spar with me in the PhD study.

What does my participation imply in the project?

I will interview you about how you learn best and observe your teaching at VUK. At the same time I will train in how to conduct projects. It means some of the teaching at VUK is changed while you participate in the project. Hereafter we conduct a shared project. Two teacher advocates who do not participate in the project will observe that the project is conducted ethical. After the project we evaluate the process and I develop a model for how to conduct projects with people with early-stage dementia. In the project I use video to record the interview, the training and the project.

Anonymity and confidentiality in the project

All you tell is anonymised so nobody can identify you. The video recording is kept safe and protected by a code. It will be the

advisory group with two teachers and to students, my supervisors and I who see the recordings. The project is registered by The Committee on Health Research Ethics of the Northern Region and the Danish Data Agency.

Risks and benefits of participating in the project

There is no risk involved by participating in the project. I cannot promise the project helps you. The knowledge I get in the project will contribute to greater knowledge about how to conduct projects with people with early-stage dementia and how life with early-stage dementia is experienced.

Am I required to participate?

It is voluntary to participate in the project. Do you wish to participate, please sign for your participation. It happens at Vuk. You can get a teacher as assessor, which ensures that your consent is given ethical. Do you regret on the

way, you can withdraw from the project, even if you have given consent. It will not affect your teaching at Vuk. You will every time we work on the project be asked to give consent that you will continue your participation.

What happens with the results?

The results are presented in my PhD thesis and in scientific papers and at conferences. This will not affect your privacy and all information remains anonymous.

Thank you for reading this leaflet. If you have any questions or need further information, you can contact me at tel. 72 69 10 56 or e-mail dst@ucn.dk. If you experience something illegal or unethical in the project, you can also contact me.

Yours sincerely

Diana Thoft

The project is collaboration between:
School Vuk and Nursing, UCN in Northern
Denmark



www.vuk-aalborg.dk

www.ucn.dk

Aalborg University in Northern Denmark and
University of Northampton in United Kingdom



www.aau.dk

www.northampton.ac.uk

(Own translation)

Insight into the life with early-stage dementia

novonordiskfonden



Information to relatives to students at VUK



THE UNIVERSITY OF
NORTHAMPTON



Dear.....



My name is Diana Thoft, and I am an educated nurse. Currently I am collaborating with the school VUK about a PhD project.

This leaflet is information about the project to relatives for participating students in the project. If you find the project unclear, after you have read the leaflet, you are welcome to contact me.

The purpose with the project

The purpose of the project is to develop a model for how to collaborate with people with early-stage dementia in projects. The model is developed as 12 students with early-stage dementia and I conduct a shared project about how life with early-stage dementia is experienced. An advisory group with two teachers and two students is also established to spar with me in the PhD study.

What does the students' participation imply in the project?

I will interview your relative about how he/she learns best and observe the teaching at VUK. At the same time I will train in how to conduct projects. It means some of the teaching at VUK is changed while your relative participates in the project. Hereafter we conduct a shared project. Two teacher advocates who do not participate in the project will observe that the project is conducted ethical. After the project we evaluate the process and I develop a model for how to conduct projects with people with early-stage dementia. In the project I use video to record the interview, the training and the project.

Anonymity and confidentiality in the project

All what your relative tell is anonymised so nobody can identify him/her. The video recording is kept safe and protected by a code. It will be the advisory group with two teachers and to students, my supervisors and I who see the recordings. The project is registered by The Committee on Health

Research Ethics of the Northern Region and the Danish Data Agency.

Risks and benefits of participating in the project

There is no risk involved by participating in the project. I cannot promise the project helps your relative. The knowledge I get in the project will contribute to more knowledge about how to conduct projects with people with early-stage dementia and how life with early-stage dementia is experienced.

Am I required to participate?

It is voluntary to participate in the project. If your relative wishes to participate, please let him/her sign for the participation. It happens at Vuk. Your relative can get a teacher as assessor, which ensures that their consent is given ethical. Does your relative regret on the way, he/she can withdraw from the project, even if he/she has given consent. It will not

affect the teaching at Vuk. Your relative will every time we work on the project be asked to give consent that he/she will continue to participate.

What happens with the results?

The results are presented in my PhD thesis and in scientific papers and at conferences. This will not affect your relative's privacy and all information remains anonymous.

Thank you for reading this leaflet. If you have any questions or need further information, you can contact me at tel. 72 69 10 56 or e-mail dst@ucn.dk. If you experience something illegal or unethical in the project, you can also contact me.

Yours sincerely

Diana Thoft

The project is collaboration between:

School Vuk and Nursing, UCN in Northern Denmark



www.vuk-aalborg.dk

www.ucn.dk

Aalborg University in Northern Denmark and University of Northampton in United Kingdom



www.aau.dk

www.northampton.ac.uk

(Own translation)

Appendix H. Example of a transcript of an interview. Coding of the transcript inspired by the four life existentials

Interview of Bent – DM650024

Interviewer: Well, then this is also ready. This one is going to help us if the camera does not work. Then I have it on sound also.

Bent: OK

Interviewer: Then this is an extra percussion

Bent: You are welcome

Interviewer: Yes (laughs). Well. Then I just have to – before we start talking together

Bent: Yes

Interviewer: Then I have to explain why I do all this

Bent: Yes, Ok

Interviewer: So you are going to hear this

Bent: Yes

Interviewer: why we are sitting here

Bent: Yes. OK

Interviewer: My name is Diana Thoft and I come from the Nursing department

Bent: Yes

Interviewer: and I am doing my PhD-project

Bent: Yes

Interviewer: And you have agreed to this today

Bent: Yes

Interviewer: that you would like to participate in

Bent: I thank – I thank yes

Interviewer: Yes. And what we are going to collaborate about is that we are going to make a project together

Bent: Yes

Interviewer: where you are one out of twelve student from this school

Bent: Yes

Interviewer: that would like to help me making a project

Bent: Definitely

Interviewer: And where you are deciding what the project is about and where I am going to teach you in how to make projects

Bent: Yes. OK

Interviewer: Yes. And eh what I am also going to say is that it is voluntarily

Bent: Yes

Interviewer: to participate so if you want to at a time to withdraw from the project

Bent: Yes. Yes

Interviewer: so then you have the possibility to that

Bent: Yes, I – but that is no fun

Interviewer: No, you won't do that? (smile in the voice)

Bent: No, that is for sure

Interviewer: (laughs). OK. Well. Are you ready then we can begin?

Bent: Definitely

Interviewer: Well. I would like to start with you telling me something about yourself, Bent

Bent: Yes

Interviewer: Yes

Bent: Yes

Interviewer: Could you tell me something about who you are?

Bent: I eh, is derived from an agricultural home

Interviewer: Yes

Bent: My father and mother had agriculture – a small agriculture

Interviewer: Yes

Bent: and then I attended the s- the school, the secondary school in XXX

Interviewer: Yes? Yes

Bent Yes

Interviewer: Yes. And how old are are you now Bent?

Bent: I was born in 35

Interviewer: You were born in 35. Yes

Bent: Yes

Interviewer: Yes. Then... Yes

Bent: Yes

Interviewer: And – what is the name – what have you worked with?

Bent: I worked as an auditor

Interviewer: Yes

Bent: Well... I eh... have been on an audit office

Interviewer: Yes

Bent: Yes

Interviewer: Yes

Bent: Yes

Interviewer: Then you educated

Bent: Yes

Interviewer: In law

Bent: Yes

Interviewer: or what?

Bent: Yes. As an audit

Interviewer: As an audit

Bent: Yes. Yes

Interviewer: Yes. Ok

Bent: I am a registered registered audit i- if you can say so

Interviewer: Yes. Ok. Bent: Yes

Interviewer: And you had a wife and family

Bent: Yes

Interviewer: or do you have a wife now?

Bent: I have a wife and two children

Interviewer: Yes

Bent: Yes

Interviewer: Yes

Bent: One is a pharmacist and the other one is a schoolteacher

Interviewer: Yes. Yes

Bent: And then I also have a wife out there

Interviewer: Yes

Bent: And she is working at home and she is – she looks after – also the job that I am involved in

Interviewer: Yes

Bent: and s- like like an audit right?

Interviewer: Yes. Then she has been in the firm?

Bent: Yes

Interviewer: Yes. Yes. Yes. And then you also have grandchildren?

Bent: Yes I have

Interviewer: Yes

Bent: Yes. Yes I have... the eh the youngest one, she has two

Interviewer: Yes

Bent: Yes

Interviewer: Yes

Bent: Yes

Interviewer: Good.

Bent: Yes

Interviewer: And no great grandchildren yes?

Bent: No. No

Interviewer: No (smile in the voice)

Bent: No. No

Interviewer: (laughs)

Bent: So far we have not come yet (smile in the voice)

Interviewer: No, so far we have not come (smile in the voice). No

Bent: No

Interviewer: OK

Bent: Yes

Interviewer: Yes. What is the name – at one point you are also told that you have – it is dementia you have been told that you have?

Bent: Yes. Yes.

Interviewer: Yes

Bent: Yes

Interviewer: Can you tell a little about about the process?

Bent: But eh well there are somethings that I cannot remember but after a while then eh then it comes up

Interviewer: Yes

Bent: Right? W-well more and more. I can remember more and more and more

Interviewer: Yes

Bent. And I can also if it is like n-that one says something then I can also remember it

Interviewer: Yes

Bent: Yes

Interviewer: Yes

Bent: Yes. But it is also to an l- le- lesser extent right?

Interviewer: Yes

Bent: Yes

Interviewer: So you do remember less and less?

Bent: Yes

Interviewer: Is that what you say?

Bent: Yes. Yes

Interviewer: Yes

Bent: Yes. Yes

Interviewer: Is that something you discovered yourself or is it something your wife discovers?

Bent: But it is also eh something I discover myself once awhile

Interviewer: Yes

Bent: Otherwise I normally do remember all sort of stuff but I cannot like t-that

Interviewer: Yes

Bent: There is... some things fail now

Interviewer: Yes

Bent: Yes

Interviewer: Yes. Ok

Bent: Yes. Yes

Interviewer: Is it long time since you got your diagnosis if you can say so?

Bent: Noo it is a couple of years ago

Interviewer: Yes

Bent: Yes

Interviewer: OK

Bent: Yes

Interviewer: Have you been told what type of dementia?

Bent: No not like that, not like that

Interviewer: No

Bent: No

Interviewer: Some say that that they got Alzheimer's for instance

Bent: Yes. Yes

Interviewer: It is not like that, what you have been told?

Bent: No not not yet. Yes

Interviewer: No. No. So ... so you have been told

Bent: Yes

Interviewer: that you have dementia

Bent: Yes. Yes

Interviewer: Yes

Bent: Yes

Interviewer: Well. What is the name – so then I also have to hear a little about about when you are at home – do you then use some of the new technology like a computer...

Bent: Yes, comp- I have, I have a computer, yes

Interviewer: Yes

Bent: Yes

Interviewer: Do you use it at home also?

Bent: But yes we do so

Interviewer: Yes

Bent: Yes

Interviewer: What do you use it for?

Bent: To do eh re-, re-, report different things

Interviewer: Yes

Bent: Among others, yes

Interviewer: Yes. Mh

Bent: And I have now m- I am by the way educated auditor right?

Interviewer: Yes

Bent: By the way

Interviewer: Yes

Bent: Yes

Interviewer: Yes. And you still use the computer at home to different things?

Bent: Yes we do. I, I also have a wife who also uses it

Interviewer: Yes

Bent: We have two computers

Interviewer: Yes. Yes

Bent: Yes

Interviewer: What about the mobile phone – is it also something that you use?

Bent: We also have that, yes

Interviewer: Yes. And do you also use it?

Bent: We do that, yes

Interviewer: Yes

Bent: Yes

Interviewer: Do you also have one of the smart ones where you tap?

Bent: Yes

Interviewer: Eh, mobile phone where you tap?

Bent: Yes. Yes

Interviewer: Yes. Or such an iPad?

Bent: ... But we also have such one

Interviewer: You also have such one

Bent: Yes

Interviewer: Do you also use such one at home?

Bent: Yes sometimes

Interviewer: Yes

Bent: But it is my wife – she, she is the fastest one. She does it (laughs)

Interviewer: She uses it a lot? (laughs)

Bent: Yes. She does

Interviewer: Yes

Bent: And then we also have some children and such things, who also use it

Interviewer: Yes

Bent: Yes

Interviewer: Do you like to use it then?

Bent: Yes, but I can do it

Interviewer: Yes

Bent: There, there is nothing in the way of.

Interviewer: No

Bent: But eh my wife she is quicker so eh I think she should be allowed to do such things (laughs)

Interviewer: OK (smile in the voice)

Bent: Yes

Interviewer: But it is not as if you have lost interest in it?

Bent: No, no. No, no. Not at all. Not at all. No

Interviewer: No

Bent: No

Interviewer: Ok. Good. Yes

Bent: Yes

Interviewer: Then then I would like to move onto the school here

Bent: Yes

Interviewer: If you are going to tell a little about attending the school. How...

Bent: I think it is ok

Interviewer: Yes

Bent: Yes. And as long as we have such fresh young people who are just together with us

Interviewer: Yes

Bent: So it is also nice yes. Yes

Interviewer: Yes. Yes. Mh

Bent: Yes, Yes. Yes.

Interviewer: What do you like about attending the school?

Bent: But it is that we we come together

Interviewer: Yes. Yes

Bent: Yes. I do so think that it is nice. We can talk with all people like that

Interviewer: Yes

Bent: Yes

Interviewer So, so it is nice?

Bent: Yes I do think so

Interviewer: Yes. Mh. What do you do at the school?

Bent: We make muc- some programme and so on – we look also eh mak- make eh ... what what is it called that something? You, you, you note different things and some things with...

Interviewer: Yes

Bent: Yes

Interviewer: What have you started with today eh, what have you been doing here today?

Bent: But eh I have not quite – yes, there – we have, we have, we have looked at some different things but otherwise then we have not done something (mumbles, difficult to understand)

Interviewer: No. No. No

Bent: No

Interviewer: Ok. Is there some of the tasks you especially appreciate to do here?

Bent: No, it does not matter

Interviewer: Yes

Bent: Yes

Interviewer: Ok

Bent: Yes

Interviewer: Then...

Bent: Well... I am as said before au- been an audit in many years

Interviewer: Yes

Bent: And it it means that eh some things with numbers to do that is basically what it depends on right?

Interviewer: Yes

Bent: Yes

Interviewer: Have you always been fond of working with numbers?

Bent: Yes, I have, I h-...

Interviewer: Yes

Bent: At the audit office as well

Interviewer: Yes

Bent: In the town

Interviewer: Yes

Bent: In with – in III

Interviewer; Yes

Bent: Yes. Yes

Interviewer: So numbers is where you're strong?

Bent: We have to admit that, yes

Interviewer: Ok. Yes

Bent: Yes. Yes

Interviewer: Yes

Bent: Yes

Interviewer: Mh. Yes. So... can you tell a little, what type of tasks, there there are here at the school? Could you say a little more about it?

Bent: Oh bu-, but well we we had made some thing – what is the name? Some thing... some number- tasks with number by the way

Interviewer: Yes

Bent: We have certainly

Interviewer: Yes

Bent: And this is the strong side I have (laughs)

Interviewer: Yes. Yes. Yes (smile in the voice)

Bent: Yes

Interviewer: Yes

Bent: And then you can also if there are some stories and some thing – this we also can...

Interviewer: Yes

Bent: To follow

Interviewer: Yes

Bent: And - yes

Interviewer: Ok

Bent: Yes. Yes

Interviewer: Mh then I would also like to ask if there are something that is difficult to do here at the school?

Bent: No. I don't think so

Interviewer: No

Bent: No not applicable like that

Interviewer: No. No

Bent: No

Interviewer: So there is nothing you know

Bent: (interrupts). I do like, I do like to go here

Interviewer: Yes

Bent: I think it... Yes

Interviewer: Yes

Bent: Yes

Interviewer: So... Ok. If you now experience that something is difficult eh what do you do then to get some help?

Bent: But I have a wife that eh is quite effective at the office (laughs)

Interviewer: Yes

Bent: Yes

Interviewer: Yes

Bent: And then I also have some... some children. I have two two girls. One of them is a schoolteacher, the other one is eh pharmacist yes

Interviewer: Yes. Yes

Bent: Yes

Interviewer: So...

Bent: So so sometimes then... then we talk with them if there is something, there is some problems. But otherwise then my wife she is yes clever certainly (mumbles)

Interviewer: Yes

Bent: She has been in in the audit office by the way

Interviewer: Yes. Yes

Bent. Yes

Interviewer: So you have good help in your wife

Bent: Definitely

Interviewer: Yes

Bent: Yes

Interviewer: Yes. And when you...

Bent: Also...

Interviewer: Yes?

Bent: Also in my children

Interviewer: Yes and also in your children

Bent: Yes

Interviewer: Yes

Bent: One of them as said before a pharmacist and the...

Interviewer: Yes

Bent: The other one is an ordinary schoolteacher

Interviewer: Yes. Yes. What then if you are sitting here in the school

Bent: Yes

Interviewer: and and you need a little help for an assignment? How do you then get help for it?

Bent: But eh... mostly then I t-try to solve it right?

Interviewer: Yes

Bent: And then if it is like that it is something that I cannot figure out t-then I may have help certainly. Yes

Interviewer: Yes

Bent: Yes

Interviewer: Who do you get help from then? Is it the other students or is it the teachers?

Bent: But this is mo- mostly a teacher right and – if she if she sits and watches that I cannot figure it –what it is

Interviewer: Yes

Bent: Then the I call for her; to come if she just can figure of this here, if there like
(speaks very unclearly)

Interviewer: Yes

Bent: But otherwise – it I it I have no problems with it certainly

Interviewer: No

Bent: No

Interviewer. No. So it is not so often you need help?

Bent: It no. No

Interviewer: No. Ok. Eh so I then have to hear if you work with some more technical
things at the school and if you have worked with iPad here at the school

Bent: Yes we have

Interviewer: Yes, Yes

Bent: I also have an iPad at home so... Yes

Interviewer: Yes. Yes. How is it to work with?

Bent: I think. It is ok

Interviewer. Yes

Bent. Definitely

Interviewer. Yes

Bent. Yes

Interviewer: Yes. So you are not discouraged by

Bent: Definitely not

Interviewer: to work with an iPad?

Bent: no-, not-, at all, no

Interviewer: No. No. Have you worked with computer her at the school also?

Bent: Yes we have – we also have one at home yes

Interviewer: Yes

Bent: Yes

Interviewer: Yes

Bent: As – I am an audit, so... we, we use as well computer and those things

Interviewer: Yes

Bent: Yes

Interviewer: Yes. Have you worked a lot with computer as an audit?

Bent: Yes I have. Yes

Interviewer: Yes

Bent: Yes. Yes

Interviewer. So...

Bent: It is easier, when... (laughs) instead of sitting, sitting and do the other there (mumbles)

Interviewer: Yes

Bent: Yes

Interviewer: But that is right.

Bent: Yes, we have s-, we have one – not to be a lie, then we have two. We have one stationary and then one we carried with yes

Interviewer. Yes. Yes. So you have one on the go

Bent. Yes, we have that

Interviewer: Yes

Bent. Yes

Interviewer. Ok. Good.

Bent: Yes.

Interviewer: Yes... Then I also have – we go to the next page now, definitely.

Bent: Ok

Interviewer. Then we are almost finished with all these questions (laughs)

Bent: But it, it does not bother me certainly (smile in the voice)

Interviewer. That was good (laughs). I would like to, that we could talk a little about before you were told that you had dementia

Bent: Yes

Interviewer: So we rewind back long time ago now .

Bent: Yes. Yes

Interviewer. Eh, do you remember when you learned something new?

Bent: But I attended the secondary school

Interviewer: Yes. Yes

Bent: Pan-; I attended XXX eh secondary school

Interviewer: Yes

Bent: Yes

Interviewer: Yes

Bent: First eh... first we started in primary school right?

Interviewer: Yes

Bent. And then, then s-, then I started at secondary school in XXX

Interviewer: Yes

Bent: Yes

Interviewer. Yes. Mh. And when you had to learn something new in the school in XXX

Bent: Yes

Interviewer: How did you learn then something new? Did you have some good tips?

Bent: But we have – just if there was something I cannot, I could not figure out then I could put the finger up,

Interviewer: Yes

Bent: And the one came and then s- - I talked with one of the teachers

Interviewer: Yes

Bent: We have some I impressive teachers definitely- we do have that in XXX

Interviewer: Yes

Bent: Yes. Yes

Interviewer: Yes. So it was...

Bent: It was named – well in OOO there was no but there was a secondary school in XXX

Interviewer: Yes

Bent: XXX and re-, region secondary school

Interviewer: Yes

Bent: It is placed just where you come into town

Interviewer: Yes

Bent: On left, on right hand

Interviewer: Yes

Bent: Yes

Interviewer: Ok. Yes

Bent: And before that, there wa – I came from... e-, it was named... OOO school
(speaks unclearly)

Interviewer: Yes

Bent: It is down in the end... eh, where we also come – so I had to start at secondary school my father and mother said and then...

Interviewer: Yes

Bent. I have tried to attend secondary school

Interviewer: Yes

Bent: Then afterwards to other schools right?

Interviewer: Yes

Bent: Yes

Interviewer. Yes. Mh. And when you studied for an audit

Bent. Yes

Interviewer. How did you then learn what you needed to learn?

Bent. Yes. T-, this, this, this I learned a., at the same time I,I, I s-studied -

Interviewer. Yes

Bent: the different things, right?

Interviewer. Yes. Yes. How could you remember what you learned?

Bent: But I have always been good at that. I do remember the different things

Interviewer. Yes

Bent: Yes

Interviewer. Yes. But how did you do it?

Bent: I, I have, have a piece of paper, then I write up these different things, if it is something that I: "This we definitely need to get hold of" right?

Interviewer. Yes

Bent: Yes. Yes. Yes

Interviewer. So you have written many notes before?

Bent: I have

Interviewer: To remember...

Bent: This, this, this made – you do write notes right, if it is like that there was something that you t-thought – so... you made a note about these things then

Interviewer: Yes

Bent: like y-, you – now when you were asked about them then you could remember this

Interviewer. Yes. Ok

Bent. Yes, I attended m-, at XXX secondary school

Interviewer. Yes

Bent: Eh if you know where it is so is it just where, where there... there were horseracing courses – I do not know if you know that?

Interviewer. No I am not so well informed in those areas. Unfortunately I am not

Bent. No. No

Interviewer. No

Bent: I w-, I came from OOO school and then my father and mother thought I had to attend secondary school.

Interviewer: Yes

Bent: So I attended the XXX and re-, region secondary school

Interviewer. Yes. Yes

Bent. Yes

Interviewer. Ok. Yes. Mh. If I now had to ask again about like old days-

Bent: Yes. Yes

Interviewer: can we say so?

Bent: Yes, ok

Interviewer. Is there something that has always been difficult for you to learn? Is there something where you said: "This I will never learn!"?

Bent: I, I do not think so, no

Interviewer: No?

Bent: No. No. No

Interviewer. No. So there is nothing, where you thought that is was just difficult?

Bent: No, I have always eh... and in the school – well, we have, we have well OOO School but then we also have XXX and region secondary school,

Interviewer: Yes

Bent: and there I was sent, sent to then...

Interviewer: Yes. Yes

Bent: S-, mm... the other school, it became too small m-...

Interviewer: Yes. Have you...

Bent: And then you bi-, biked over there

Interviewer. Yes. Eh is there never anything that has been difficult for you to learn?

Bent: I do think- not, not immediately I think. No

Interviewer. No

Bent: No

Interviewer: That is lovely

Bent. Yes. But it is. Also, m-. and then I have – as an auditor then you have to remember something d-, of of the other things, t-, that maybe is something back there

Interviewer: Yes

Bent: Yes. Yes

Interviewer: Yes. Mh. Yes. Eh, then I have to ask if there are some activities you always have been fond of doing. If you should think back – is there something you always have been happy about doing?

Bent: Accordingly, n-, eh, something like that or football or handball?

Interviewer: Whatever you think

Bent: Ok. Well I have played a lot of football and a lot of badminton

Interviewer: Yes. Yes

Bent: Yes

Interviewer: Yes

Bent: I have done that in many years

Interviewer: Yes

Bent: And I also play football still but eh it is not as fast as it has been (laughs)

Interviewer: No

Bent: ... have been

Interviewer: Yes

Bent: No

Interviewer: So you are still fond of – of sports?

Bent: Definitely

Interviewer. Yes. Yes

Bent: And then also gymnastics but it is not so much – I am not like some beat patched flak and such things. No

Interviewer: No. No. But also a little gymnastic, gymnastic?

Bent: Yes. Yes

Interviewer. Yes

Bent: Yes

Interviewer. Yes. And you have done that in many years?

Bent. I have, yes

Interviewer. Yes

Bent: And I still do yet but I have become a bit stiffer than I use to be (laughs)

Interviewer: You are a bit stiffer? (smile in the voice)

Bent: Yes

Interviewer: Yes. Ok. Yes. Is there other things you always have appreciated to do?

Bent: No not over there like...

Interviewer. No

Bent: Now – I am educated in ... in a cooperative accordingly Cooperative

Interviewer: Yes

Bent: And... there –there was such a thing, what, what, what you learned

Interviewer: Yes

Bent: I s-, came i – that time I was educated or s-, so I came into work in a cooperative and then , then I came to d- to work other other places also right?

Interviewer: Yes. Yes. Yes

Bent: Yes

Interviewer: So you have worked in Brugsen

Bent: Yes

Interviewer: before you became auditor?

Bent: Yes. Yes. Yes

Interviewer: Or – or was it after, you were...

Bent: No it was before, I became auditor

Interviewer: Auditor, yes

Bent: Yes. It was in OOO cooperative

Interviewer: Yes?

Bent: Yes

Interviewer: So there you worked also. Yes

Bent: Yes

Interviewer: Mh. Yes. Then let us turn the clock forward a bit again (laughs)

Bent: That's ok. Ok

Interviewer: Because I would like to hear eh if you now should learn something new here at the school now

Bent: Yes. Yes

Interviewer: have you then found out a good way to learn things?

Bent: But I writ- - if there is something like eh I have to remember, t-then I write it down on a piece of paper

Interviewer: Yes

Bent: Yes

Interviewer: Ok

Bent: Yes

Interviewer: Yes. Do you always have paper with you in the pocket or...?

Bent: Yes, as s as usual, then I have such a piece

Interviewer: Yes

Bent: Yes

Interviewer: Yes. And then you write...

Bent: (interrupts). But, but eh I think definitely – remember I do that – now now you can always remember, there is such one thing (speaks unclearly, incoherent)

Interviewer: Yes. Yes

Bent: Yes

Interviewer: So there is something for you that is easy enough to remember

Bent: Yes

Interviewer: still?

Bent: Definitely. Definitely. Yes

Interviewer: And then there is some other things

Bent: Yes

Interviewer: that are more difficult to remember

Bent: It is more difficult to remember, yes

Interviewer: Yes. Can you say, what is difficult to remember?

Bent: No, no not immediately, but... but eh... accordingly if it is so we have been somewhere or somewhere along,

Interviewer: Yes

Bent: So I do remember where we have been and such things

Interviewer: Yes

Bent: This is not a problem that

Interviewer: Yes. Is it so just more difficult to remember what day it was?

Bent: No, it is not

Interviewer: No. No

Bent: No. No. No

Interviewer: Ok

Bent: No. No. No

Interviewer: No. It can also...

Bent: It is not disappeared all of it yet (smile in the voice)

Interviewer: No. No. No (smile in the voice)

Bent. No

Interviewer: No. However, sometimes it can maybe be a certain thing that is difficult to remember

Bent: Yes, but it is like that. It can be like that

Interviewer: Yes

Bent: And, and it might be one or another that you should, you should remember and then you say: "What the hell was it now the thing there, it was?"

Interviewer: Yes

Bent: And then then it might come further along on. Yes

Interviewer: Yes. So it might go a while before you then can remember...

Bent: Yes, definitely

Interviewer: one thing yes

Bent: Yes

Interviewer: Yes. Yes. Mh. If you then need to learn something new here

Bent: Yes

Interviewer: well eh, then you say that you write down on paper

Bent: Yes

Interviewer: Is there something else, you do to remember it?

Bent: Yes, eh I can also eh repeat different things for for myself right?

Interviewer: Yes

Bent: Yes

Interviewer: Ok. How do you do it?

Bent: Jamen øh, hvis der er et eller andet, jeg skal huske (tryk på ordet skal).

Bent: Well eh, if there is something I need to remember (press on the word need)

Interviewer: Yes

Bent: well, then eh I connect it with the things there, wh- that was in connection with it

Interviewer: Ok

Bent: Yes

Interviewer: Can you say a bit more about it, as it sounds quite interesting

Bent: Well eh if-if it is like that I need to remember t-then I say it to myself: "This I do have to remember" (drums on the table). For instance if it is like eh... like – what shall I... I, - if I for instance need – I was in a Cooperative and then if I had to remember something with – it was some animal feed and like that. Then when I came down, then, then, then I said: "We need to have this animal feed and we need to have those things" (speaks unclearly)

Interviewer: Yes

Bent: It is like... It then runs like up h-here in eh...

Interviewer: Yes

Bent: In in mi- in the mind, if you can say so

Interviewer: Yes

Bent: right?

Interviewer: Yes. Yes

Bent: Yes

Interviewer: Then you try to connect some things together?

Bent: Yes

Interviewer: Yes

Bent: Also – and on the secondary school when you biked on the secondary school – it was XXX Secondary school. I lived in OOO.

Interviewer. Yes

Bent: So when we biked t-, t-... ”Well what is it now, I need to remember?” so so you repeated it, that, when you biked on the cycle there

Interviewer: Yes

Bent: to XXX. And then when you came to the secondary school, then then you like them in the, and some you also had noted on a piece of paper right?

Interviewer: Yes

Bent: Yes

Interviewer: Yes. So you have always used it

Bent: Yes

Interviewer: to say to yourself: ”What is it I need to remember?” and then repeat it

Bent: Yes

Interviewer: For yourself inside the head?

Bent: Yes

Interviewer: Yes. Ok

Bent: It is only way. So when you get ol- begins to grow old then, then, so ... you need to look after

Interviewer. Ok

Bent: For there are something that fails right?

Interviewer. There is something that fails. Ok. Yes. So then you repeat things several times to remember them?

Bent: No. No, no

Interviewer: No

Bent: It is as if eh, I think I s- get the grip and then...

Interviewer. Yes

Bent: I say to myself: "well you just need to remember and then..."

Interviewer: Yes

Bent: you drive a game

Interviewer: Yes

Bent: And then when you come to this place, where you should be, so you need, so you do remember it – these things there

Interviewer. Yes. Ok

Bent: Yes

Interviewer: Is there something that has become difficult for you to learn now? In relation to...

Bent: Nah sometimes there is something – there is something, I-I that fails but is is not very much

Interviewer. No

Bent: No

Interviewer: Ok

Bent: I do remember both children, both children and grandchildren (mumbles)

Interviewer. Yes

Bent: Yes. Yes

Interviewer: So...

Bent: Names on them and such thing

Interviewer: Yes. Mh. Is it important for you also to remember it – remember it?

Bent: But it is it is definitely

Interviewer: Yes

Bent: Now I have two eh two girls. One is schoolteacher and the other is pharmacist so...

Interviewer. Yes. Yes. Yes

Bent: Yes

Interviewer: Mh

Bent: They both live in SSS by ZZZ

Interviewer: Yes. Yes

Bent: Yes

Interviewer: Yes. It is a way down

Bent: Yes it is certainly (mumbles)

Interviewer. Yes. Yes. Ok

Bent: But we go once a week or once a month, then we drive to ZZZ or otherwise they come up to us

Interviewer: Yes

Bent: We have a summer cottage in WWW and then we n-drive down to the ocean there ... and if we do not use the summer cottage, then is, the others who use it

Interviewer: Yes (smile in the voice)

Bent: So it it is great then

Interviewer: Yes, it is definitely...

Bent: And so follow, then the small children also follow, as they have, those, they also follow with (smile in the voice)

Interviewer: Yes. Yes. So so there is life and happiness

Bent: Yes definitely

Interviewer: Yes (laughs)

Bent: Definitely

Interviewer: How many grandchildren do you have?

Bent: I have two, three – three ones yes

Interviewer. Three ones, yes, yes so it can be busy (smile in the voice)

Bent: Yes one boy and so two girls

Interviewer. Yes. Yes

Bent: Yes. Yes

Interviewer: So things are happening

Bent: Yes it does definitely

Interviewer: (laughs) yes

Bent: Yes, we we drive up to WWW – w-when we come up to W- to WWW church, and then we dri- drive down towards the ocean, and then we go to the left, right in f- when, before we reach ... this one, and so we have the summer cottage up behind

Interviewer: Yes. Yes

Bent: Have had it some years

Interviewer Yes. Lovely

Bent: Yes. Yes

Interviewer. Yes. How nice

Bent: Yes

Interviewer: Yes. Eh I also have to here, if there are some new activities, you have learned to appreciate now here eh, some you have started to do. You told me that you appreciated to play football and gymnastic

Bent: But it – I have played, I have played much football and much badminton and such things through the years.

Interviewer: Yes. Yes. Yes. Is there some new things you have started with in recent years?

Bent: Nah. No nothing else than I ... I yes have started to run some times

Interviewer. Yes?

Bent: W-we thought have a nice beach, like we can run along t- with the beach, if it is

Interviewer. Yes

Bent: and t-t-the summer cottage it is placed like that we just need to get over a dune

Interviewer: Yes

Bent: and so so we are down by the ocean yes

Interviewer: Yes. Yes

Bent: Yes

Interviewer. So you have begun to run a bit

Bent: Yes

Interviewer: down at the beach?

Bent: Certainly. Yes

Interviewer. Yes

Bent: Yes

Interviewer: Is it together with your wife that you go running?

Bent: Yes, sometimes. It is also some eh – I have two girls

Interviewer: Yes

Bent: who also run. So they run with me sometimes definitely

Interviewer: Yes, Yes

Bent: W-well you need to look after - you do not sit down and then say to yourself. "Now it is good enough this over there" You need to ... have some running and something like that (mumbles)

Interviewer. Yes

Bent: Yes

Interviewer. Yes

Bent: And I also, I have also done a lot done with weights (uncertain about word 21:25) and something like that

Interviewer: Yes

Bent: Yes

Interviewer. Yes. Yes

Bent: Because you need... you need to keep yourself fit. It is like that. Yes

Interviewer. So it is important for you,

Bent: Definitely!

Interviewer: To keep yourself active?

Bent: Quite definitely

Interviewer. Yes. Yes

Bent: And but s-, you g-g-g-have get grandchildren, so you need to be able to run a little after them yes (smile in voice)

Interviewer: (laughs). Yes, that is correct. You need to

Bent: Yes (laughs)

Interviewer. It is certain. It can go very fast (laughs)

Bent: It can go very fast definitely

Interviewer: Yes

Bent: Yes. Yes we have – we drive down by WWW church and then is it is just down behind

Interviewer. Yes. Yes

Bent: Yes

Interviewer. Is it also important for you – now you say, it is important to keep yourself active?

Bent: Yes

Interviewer: Is it also important also, your

Bent: (interrupts): Well it is

Interviewer: your brain active also? (speaks up)

Bent: Definitely

Interviewer: Yes

Bent: You need to

Interviewer: Yes. What do you do to keep this, this floor active (smile in the voice)

Bent: I, I read a lot a- lot of articles and something like that

Interviewer. Yes. Yes

Bent: and, and so as auditor, so you need to read these new eh things that comes up right?

Interviewer. Yes. Yes. Exactly. Yes

Bent: And it is definitely not, anyway, no harm

Interviewer. No it is not (smile in the voice)

Bent: (laughs)

Interviewer. So you still read a lot.

Bent Yes, I certainly do at least. Yes

Interviewer: Yes. Is it both books and ...

Bent: Yes, books but not so much

Interviewer. No, No

Bent: But it is most eh articles for

Interviewer: Yes

Bent: F-football and something like that

Interviewer: Yes from the newspaper?

Bent: Yes. Yes

Interviewer: Ok. Mh. Yes. Then I just need to hear how... you work with remembering some of what you learn here at the school

Bent: Yes

Interviewer. Is there a certain way, you try to remember it?

Bent: But normally I repeat so f- like for myself

Interviewer: Yes

Bent: At least. Yes

Interviewer. Yes. Yes

Bent: And then if there is something eh, I need need to remember, so so I write it down on a piece of paper. If there is something ab- I absolutely need to remember right?

Interviewer. Yes. Yes. Mh. Yes

Bent: You can as well use a pen, when it is such one (mumbles)

Interviewer: Yes. Yes. You do not use a Calendar – to write things in the Calendar?

Bent: Yes, well if there, if there are some exact dates I—s-so I use to write the date on this one – this I have to remember and on this date there (mumbles)

Interviewer: Yes

Bent: Yes. Yes. Yes

Interviewer. Ok. Yes. So You go through the Calendar at home?

Bent: Yes

Interviewer: you and your wife?

Bent: No this kno, this kno- - yes we do that too but...

Interviewer: Yes

Bent: Yes

Interviewer: But you also do it yourself?

Bent: Yes, we have such a big Calendar

Interviewer. Yes. Yes. Yes

Bent: If there are something we absolutely need to remember, then then we note, if there is that we shall something

Interviewer. Yes

Bent: Somewhere

Interviewer: Yes. Yes

Bent: Yes. Then you do not have to and be reminded about it, because you you have noted it any way (mumbles)

Interviewer. Yes. Exactly

Bent: And I, I also have such a pocket- pocket Calendar

Interviewer. Yes. Yes. Do you always have it with you then

Bent: Yes

Interviewer. Your pocket Calendar?

Bent: Yes

Interviewer. Yes

Bent: Yes

Interviewer. And you use it

Bent: Yes

Interviewer. To write down in?

Bent: Definitely

Interviewer: Yes

Bent: If there is something, I absolutely need need to remember

Interviewer: Yes

Bent: and need to go to, then I note I just d- little down, and then then it stands:
"Ups we just have to remember this" (mumbles)

Interviewer: Yes

Bent: Bu not – you do either need to go and keep in mind everything. You can as
well writhe it down, when you... (laughs)

Interviewer: Exactly. So you do not need to go and remember everything in the head
(smile in the voice)

Bent: De-definitely

Interviewer: Yes. Correctly. Yes. Yes. So – what is the name – so I am almost down
here, where I have to ask some of the last questions

Bent: You are welcome

Interviewer: It sounds nice. I need to hear a little about, do you have some certain
wishes about how we need to collaborate in the project. If there is something you
have considered.

Bent: It is not – no it...

Interviewer: No. No. Eh I need to teach a little in, how you do projects together

Bent: Yes. Yes, ok. Yes

Interviewer: Eh, how do you like to be taught?

Bent: Well it eh is m... mostly with writings and such things. That is just me.

Interviewer: Yes

Bent: Definitely

Interviewer: So you do like, that there is something in writing?

Bent: Yes, I do. Yes

Interviewer: Yes. So...

Bent: Because it is as some times if you get too much stuffed in, then you cannot
remember it all then

Interviewer: No

Bent: No

Interviewer: No. Yes

Bent: But now – I have ... eh as auditor so, so you note wh-when, when there is something, you need absolutely to remember right ? (mumbles)

Interviewer: Yes. Yes. Yes. So it may be some small pieces of text?

Bent: Definitely

Interviewer: That could be ok for you?

Bent: Yes

Interviewer: Yes. Yes

Bent: S-so... when you – if there is something, you need to remember s-so I always write down

Interviewer. Yes

Bent: So eh... so now, now there go more days like, so you take it forward, if there is, there is something, something there has, we need, we need for

Interviewer. Yes

Bent: Yes

Interviewer. Yes. Good

Bent: Yes

Interviewer: Yes. If we now have to work together now here

Bent: Yes

Interviewer: in the project, is there then a certain way, you would like, we collaborate?

Bent: No it – no, no it does not matter. You decide it it

Interviewer: Do I decide? (laughs). Yes. But there is no special wishes from your point of view?

Bent: No. No

Interviewer. No? Ok

Bent: Yes

Interviewer: I just have to behave decent? (smile in the voice)

Bent: But I think, that that that that it is only fair (laughs)

Interviewer: (laughs) No that is correct. That is correct

Bent: No. No

Interviewer. Yes. Well. If I now want to use some pictures,

Bent: Yes

Interviewer. And some video

Bents. Yes

Interviewer: could it also be...?

Bent: Yes, it is not... yes, we can also use it it,

Interviewer. Yes. Do you think, it could help with remembering some things?

Bent: It could probably, if it is as if... you have...

Interviewer. Yes

Bent: you go along with... it also

Interviewer: Yes

Bent: Yes

Interviewer. So it would also be ok for you to use it?

Bent: Yes. Quite definitely

Interviewer. Yes. If now that eh, we have to think about, how it should be where we collaborate?

Bent: Yes

Interviewer: If we now talk about at classroom beside here

Bent: Yes

Interviewer: do you think it would be ok or...

Bent: But it... it is ok for my sake at least

Interviewer. Yes. Yes. Is der something else, you think there has to – well in relation to learning well?

Bent: No. No not such immediately

Interviewer: No. What about noise and something like that? Can that eh... disturb you?

Bent: It does not bother me, no

Interviewer. No. Ok. And either if there is noise from others?

Bent: No

Interviewer: No

Bent: Eh... I can concentrate at least

Interviewer. Yes. Ok. Yes. So... That was good. What about repetitions? Would it be nice to use repetitions?

Bent: Well it, it, it... in the beginning, so it is yes good enough but next so, so it is yes good enough you, you is-, it is repeated, if you can say so

Interviewer. Yes. Yes

Bent: Yes

Interviewer. So it would be ok if I...

Bent: Yes, definitely

Interviewer. if there is something, where I think: "This point, this is very important" that I then repeat it a couple of times?

Bent: Yes. Yes. Yes

Interviewer: Is that ok?

Bent: Yes, I think

Interviewer: It would not bother you?

Bent: not at all

Interviewer. No. Ok. Yes. Eh so I have to hear to finish off. Bent; what do you expect to get out of this project, we will have together? Do you have some, you... some expectations?

Bent: No, I have not thought about it...

Interviewer: No. No

Bent: I follow it s... as well, as I can

Interviewer. Yes. What would you like, we got out of the project?

Bent: Eh me- -well our memory and such things, I think, that is great at least

Interviewer: Yes. Yes

Bent: Yes. But it is not because I, I am not bad remembering – it is not such such thing, but it is great enough to get something repeated, if you could say so

Interviewer: Yes. Yes. So it would be fine with you. Yes

Bent: Yes

Interviewer. Mh. Is there something you would like to say to, to the world through the project?

Bent: No. It is nothing. No

Interviewer. No, there is not. No

Bent: No. No

Interviewer. No. Ok

Bent: It is just to ask me

Interviewer: It is just to ask you

Bent: Yes

Interviewer: and then we find out, what we can get out of the project together (smile in the voice)

Bent: Definitely

Interviewer: Yes. That is good

Bent: Yes

Interviewer. We are about where we soon have to say that our interview is finished

Bent: Yes

Interviewer: Eh, but I would like to ask as one of the last thing that it is: is there some of what we have talked about, where you think that there is something else, you would like to tell me?

Bent: No not i- not immediately. No

Interviewer. No. No. So there is not something, you want to tell?

Bent: No

Interviewer: No. Mh. Ok. And that is quite the last thing I have to ask you

Bent: Yes

Interviewer: this is, is this ok for me to use this interview

Bent: Definitely

Interviewer: in the project?

Bent: Quite-

Interviewer. There is not nothing we have talked about

Bent: Not at all

Interviewer: like you do not want me to use?

Bent: Not at all. No

Interviewer. No. Ok

Bent: No

Interviewer: So I am allowed to do that?

Bent: You certainly may

Interviewer. It sounds good

Bent: Yes

Interviewer: Yes

Bent: And you may also put my name on, if it is like that (smile in the voice)

Interviewer: I do not do that, cause I have promised, I would not do (smile in the voice). So, so I will not do that

Bent: I do not have it like, it is something secret at least (laughs)

Interviewer: No. It is ok. Yes (smile in voice). But eh, I have promised that you are anonymous in the project, so it...

Bent: We are anonymous, ok

Interviewer. So this I have to keep

Bent: So it will say, it is also anonymous, when we walk around and shout, t- they are just anonymous all those, who goes around (smile in the voice)

Interviewer: (laughs) Yes, but of course they cannot be that. I know that. But when I need to write,

Bent: Yes. Yes

Interviewer: then I write that it is students from the school

Bent: Yes. Yes

Interviewer: And then I do not write it is Bent or it is ...

Bent: You may do that. My...

Interviewer: Yes

Bent: Because it is certain – I have not been in jail or something

Interviewer. No. No (smile in the voice)

Bent: (laughs)

Interviewer: But I know that. I know that (smile in the voice). But it is something I have to keep

Bent: But that is for sure. Yes

Interviewer. I do also have some rules, I do have to keep yes

Bent: Well that is for sure

Interviewer: So... Yes

Bent: but eh, otherwise – all what I say is, that you may bring forward. It is for certain

Interviewer: It sounds good

Bent: Yes

Interviewer. Great. Shall we then shut down all this equipment again?

Bent: I think so

Interviewer. Yes. So... This over here we shut down now

Bent: And, and this one is 11.22 this one

Interviewer: Yes. It is does certainly so ... Good. I shut this there. So. So it stops recording. And this one, then I can also shut this off. So then it should also stop. So we stop it.

(Own translation)

Interview af Bert – DM650024

Interviewer: Sådan, så er den også klar. Den her, den skal hjælpe os, hvis nu kameratek ikke dur. Så har jeg det her på som nyt også.

Bert: Okay.

Interviewer: Så det er en ekstra sikring.

Bert: Du er hjertelig velkommen.

Interviewer: Ja (griner). Godt. Så skal jeg lige – inden vi går i gang med at snakke sammen,

Bert: Ja.

Interviewer: så skal jeg forklare, hvorfor jeg gør at det her.

Bert: Ja. Okay.

Interviewer: Så du kommer lige til at høre,

Bert: Ja.

Interviewer: hvorfor det er, vi sidder her.

Bert: Ja. Okay.

Interviewer: Jeg hedder jo Diana Thoft og kommer ude fra sygeplejerskoleuddannelsen,

Bert: Ja.

Interviewer: og jeg er i gang med at lave mit ph.d.-projekt.

Bert: Ja.

Interviewer: Og det har du sagt ja til i dag.

Bert: Ja.

Interviewer: at du gerne vil deltage i.

Bert: Jeg takker – jeg takker ja.

Interviewer: Ja. Og det vi skal til at arbejde sammen om, det er, at vi skal lave et projekt sammen,

Bert: Ja.

Interviewer: hvor du er en ud af ti elever her på skolen,

Bert: Ja.

Coding Density
Lived body
The ability to learn
Memory difficulties
Strategies in life with dementia
Lived relation
Lived time
The role of family
The present past
Awareness of dementia
The positive school input
Humour and laughter
The decreased use of technology
Repetition
Conversation challenges
Social relationships and activities
Lived space

Interviewer: som gerne vil hjælpe mig med at lave et projekt.
Bent: Helt sikkert.
Interviewer: Og hvor i skal bestemme, hvad projektet skal omhandle, og hvor jeg skal undervise per i, hvordan man laver projekter.
Bent: Ja. Okay.
Interviewer: Ja. Og ah, det jeg så skal sige også, det er, at det er frivilligt
Bent: Ja.
Interviewer: at deltag, så hvis du har lyst til på et tidspunkt, at trække dig fra projektet,
Bent: Ja. Ja.
Interviewer: så har du mulighed for det.
Bent: Ja, jeg – men det er ikke noget ved.
Interviewer: Nej, det vil du ikke? (smil i stemmen)
Bent: Nej, det er helt sikkert.
Interviewer: (griner). Okay, godt. Er du klar til at vi går lige så stille i gang så?
Bent: Helt, helt sikkert.
Interviewer: Godt. Jeg kunne godt tænke mig at starte lidt, om du kunne fortælle lidt om dig selv, Bent.
Bent: Ja.
Interviewer: Ja.
Bent: Ja.
Interviewer: kunne du sige lidt om, hvem du er?
Bent: Jeg ah, stammer fra et landbrugshjem.
Interviewer: Ja.
Bent: Min far og mor havde landbrug – et lille landbrug.
Interviewer: Ja.
Bent: og så har jeg allers gået på 5- på skole, på realakadem i XXX.
Interviewer: Ja? Ja.

2 / 42

Bent: Ja

Interviewer: Ja. Og hvor gammel er, er du nu her, Bent?

Bent: Jeg er født i '35.

Interviewer: Du er født i '35, Ja.

Bent: Ja

Interviewer: Ja. Så.. Ja.

Bent: Ja

Interviewer: Og – hvad hedder det – hvad har du arbejdet med?

Bent: Jeg arbejdede som revisor.

Interviewer: Ja.

Bent: Altså.. Jeg altså.. har været på et revisionskontor.

Interviewer: Ja.

Bent: Ja

Interviewer: Ja.

Bent: Ja

Interviewer: Så du tog uddannelse

Bent: Ja

Interviewer: Indenfor jura.

Bent: Ja

Interviewer: eller hvad?

Bent: Ja. Som revisor.

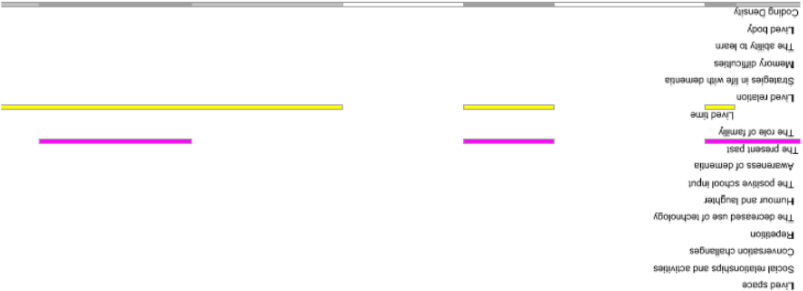
Interviewer: Som revisor.

Bent: Ja Ja

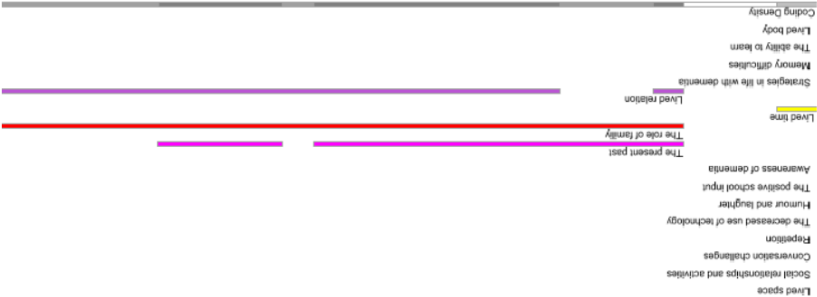
Interviewer: Ja. Okay.

Bent: Jeg er registreret, registreret revisor, hv, hvis man kan sige det sådan.

Interviewer: Ja. Okay.



Bent: Ja.
Interviewer: Og har du haft en kone og familie.
Bent: Ja.
Interviewer: eller har du en kone nu her?
Bent: Jeg har en kone og så to børn.
Interviewer: Ja.
Bent: Ja.
Interviewer: Ja.
Bent: Den ene er farmaceut og den anden er skolelærer.
Interviewer: Ja, Ja.
Bent: Og så har jeg så en kone derude.
Interviewer: Ja.
Bent: Og hun går jo hjemme, og hun har jo – hun passer mit – også det job, som jeg er med i.
Interviewer: Ja.
Bent: Og s-, som, som revisor, ikke også?
Interviewer: Ja. Så hun har været med i firmaet.
Bent: Ja.
Interviewer: Ja, Ja, Ja. Og har du fået børnebørn også?
Bent: Ja, det har jeg.
Interviewer: Ja.
Bent: Ja, Jo, jeg har... den ah, den mindste, hun har to.
Interviewer: Ja.
Bent: Ja.
Interviewer: Ja.
Bent: Ja.
Interviewer: Godt.



Bent: Ja.²

Interviewer: Og der er ingen oldtiden endnu?

Bent: Nej. Nej.

Interviewer: Nej (smil i stemmen).

Bent: Nej. Nej.

Interviewer: (griner).

Bent: Så vidt er vi ikke kommet endnu (smil i stemmen).

Interviewer: Nej, så vidt er vi ikke kommet (smil i stemmen). Nej.

Bent: Nej.

Interviewer: Okay.

Bent: Ja.

Interviewer: Ja. Hvad hedder det – på et tidspunkt, så får du også at vide, at du har – er det demens, du har fået at vide, at du har fået?

Bent: Ja. Ja.

Interviewer: Ja.

Bent: Ja.

Interviewer: Kan du fortælle lidt om, omkring det forløb?

Bent: Jamen ah, altså der er nogle ting, som ikke jeg kan huske, men så efterhånden, så ah, kommer det op.

Interviewer: Ja.

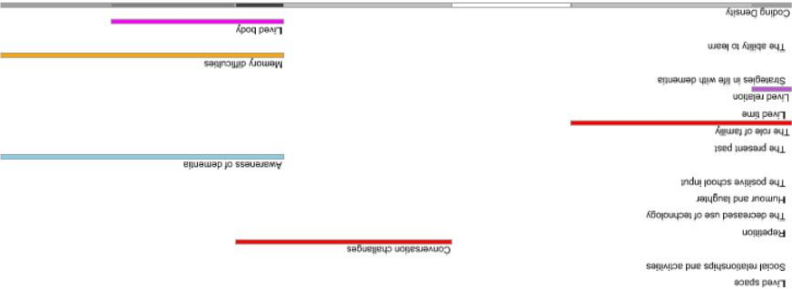
Bent: Ikke også? Altså, mere og mere. Jeg kan huske mere og mere og mere.

Interviewer: Ja.

Bent: Og jeg kan også, hvis det er sådan, næsten siger noget, så kan jeg også huske det jo.³

Interviewer: Ja.

5 / 42



5A

Bent: Ja. Men det er altså m-, m-, mindre grad. Ikke også?

Interviewer: Ja.

Bent: Ja.

Interviewer: Så du kan huske mindre og mindre?

Bent: Ja.

Interviewer: Er det det, du siger?

Bent: Ja. Ja.

Interviewer: Ja.

Bent: Jo, jo.⁴

Interviewer: Er det noget du selv opdager, eller er det noget din kone opdager?

Bent: Jævn det er også eh, noget jeg selv opdager indimellem.

Interviewer: Ja.

Bent: For ellers så plejer jeg at kunne huske alt muligt, men det kan jeg ikke s-, sådan.

Interviewer: Ja.

Bent: Der er... nogle ting, der svigter nu her.

Interviewer: Ja.

Bent: Ja.

Interviewer: Ja. Okay.

Bent: Ja. Ja.

Interviewer: Er det lang tid siden, at du har fået din diagnose, hvis man må sige sådan?

Bent: Nej, det er et par år siden.

Interviewer: Ja.

Bent: Ja.

Interviewer: Okay.

Bent: Ja.

Interviewer: Har du fået at vide, hvad det er for en type af demens?



Bent: Nej, ikke sådan, ikke sådan.

Interviewer: Nej.

Bent: Nej.

Interviewer: Nogen siger, at, at de har fået Alzheimers for eksempel.

Bent: Ja, ja.

Interviewer: Det er ikke sådan, du har fået at vide?

Bent: Nej, ikke, ikke endnu, Nej.

Interviewer: Nej, Nej, Så... så du har fået at vide.

Bent: Ja.

Interviewer: at du har demens.

Bent: Ja, ja.²

Interviewer: Ja.

Bent: Ja.

Interviewer: Godt. Hvad hedder det – så skal jeg også høre lidt om, omkring det her når man er dement – bruger du så sådan nogen nye tekniske ting som computer...

Bent: Ja, comp-, jeg har, jeg har en computer, ja.

Interviewer: Ja.

Bent: Ja.

Interviewer: Bruger du den derhjemme også?

Bent: Jamen det gør vi da.

Interviewer: Ja.

Bent: Ja.

Interviewer: Hvad bruger du den til?

Bent: Til at gå, ind-, ind-, indover de forskellige ting.

Interviewer: Ja.

Bent: Blandt andet, ja.



Interviewer: Ja. Mh.

Bert: Og jeg har jo m – jeg er jo uddannet revisor. Ikke også?

Interviewer: Ja.

Bert: Santidg.

Interviewer: Ja.

Bert: Ja.

Interviewer: Ja. Og du bruger stadigvæk computeren derhjemme til forskellige ting?

Bert: Ja, det gør vi. Jeg, jeg har også en kone, som bruger den også.

Interviewer: Ja.

Bert: Vi har to computere.⁶

Interviewer: Ja. Ja.

Bert: Ja.

Interviewer: Hvad med mobiltelefon – er det også noget, du har?

Bert: Den har vi også, ja.

Interviewer: Ja. Og bruger du også den?

Bert: Det gør vi, ja.

Interviewer: Ja.

Bert: Ja.

Interviewer: Har du også fået de der meget smarte nogen, hvor man trykker på skærmen...?

Bert: Ja.

Interviewer: Oh, mobiltelefoner, hvor man trykker på skærmen?

Bert: Ja, ja.

Interviewer: Ja. Eller sådan en iPad?

Bert: ... jamen den har vi også.

Interviewer: Den har I også.

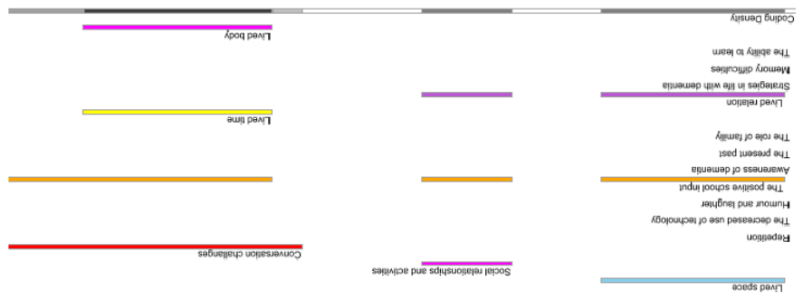
Bert: Ja.⁷



Interviewer: Bringer du sådan en der hjemme også?
Bent: Ja, indeni dem.
Interviewer: Ja.
Bent: Men det er min kone – hun, hun er den hurtigste til det, hun gør det (griner).
Interviewer: Hun bruger den meget? (griner).
Bent: Ja. Det gør hun.
Interviewer: Ja.
Bent: Og så har vi også nogen børn og sådan nogle ting så, som også bruger den.
Interviewer: Ja.
Bent: Ja.
Interviewer: Kan du lide at bruge den også?
Bent: Ja, men det kan jeg godt.
Interviewer: Ja.
Bent: Det, det er der ikke noget i vejen for.
Interviewer: Nej.
Bent: Men øh, min kone hun er hurtigere, så øh, jeg synes, hun skal have lov til sådan noget (griner).
Interviewer: Okay (smil i stemmen).
Bent: Ja.
Interviewer: Men det er ikke sådan, så du har mistet interessen for det?
Bent: Nej, nej, Nej, nej. Slet ikke. Nej.
Interviewer: Nej.
Bent: Nej.
Interviewer: Okay, Godt, Ja.
Bent: Ja.
Interviewer: Så, så vil jeg gerne bevæge os lidt hen til sådan her.
Bent: Ja.



Interviewer: Hvis du vil fortælle lidt omkring det at gå på skolen, hvordan...
Bent: Det synes jeg er godt nok.
Interviewer: Ja?
Bent: Ja. Og så længe vi har sådan nogle friske unge mennesker, som bare er her med os.
Interviewer: Ja.
Bent: Så er det også dejligt jo, ja.⁹
Interviewer: Ja, ja. Mh.
Bent: Ja, ja.
Interviewer: Hvad kan du godt lide ved, ved skolen?
Bent: Jamen det er, at vi, vi kommer tilhønden ved.
Interviewer: Ja, ja.
Bent: Ja. Det synes jeg da hvert fald, at det er dejligt. Vi kan snakke med alle mennesker jo sådan set.
Interviewer: Ja.
Bent: Ja.
Interviewer: Så, så det er rart?
Bent: Ja, det synes jeg i hvert fald.
Interviewer: Ja, Mh. Hvad laver du på skolen?
Bent: Vi laver mgt., sådan programmer og sådan – vi kigger også på, lav, laver mht., hvad hedder det, sådan noget? Mhm, mhm, man noterer forskellige ting og sådan nogle ting med.
Interviewer: Ja.
Bent: Ja.
Interviewer: Hvad har I startet med her i dag?h, hvad har I lavet her i dag?
Bent: Mhm, jeg har ikke sådan lige rettet – jo, der – vi har, vi har, vi har kigget på nogle forskellige ting, men ellers så har vi ikke sådan noget (munter, svarer at først).¹⁰
Interviewer: Nej, Nej, Nej.
Bent: Nej.



Interviewer: Okay. Er der nogen af opgaverne, du sådan særligt godt kan lide at lave her?

Bent: Nej, det er sådan set lige meget.

Interviewer: Ja.

Bent: Ja.

Interviewer: Okay.

Bent: Ja.

Interviewer: Så...

Bent: Altså... Jeg er jo, som sagt, re-, været ret stor i mange år, li

Interviewer: Ja.

Bent: Og det, det gør jo sådan at eh, noget med tal at gøre, de er sådan set det, der kommer an på det, ikke også?

Interviewer: Ja.

Bent: Ja.

Interviewer: Har du altid været glad for at arbejde med tal?

Bent: Ja, det har jeg, jeg s-...

Interviewer: Ja.

Bent: Der på revisionskontoret også.

Interviewer: Ja.

Bent: Inde i byen.

Interviewer: Ja.

Bent: Inde ved - i III.

Interviewer: Ja.

Bent: Ja.

Interviewer: Så tal er din stærke side?

Bent: Det må vi indse, ja.

Interviewer: Okay, ja.

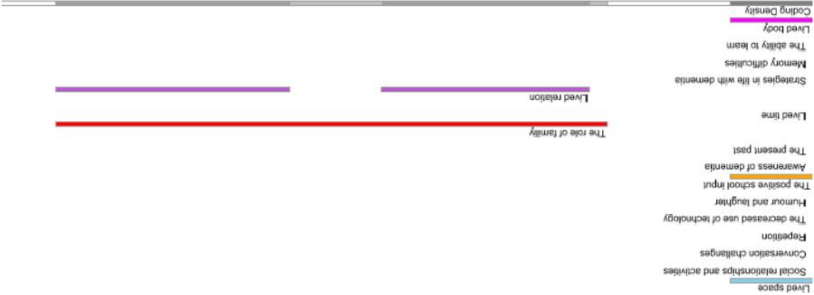


Bent: Ja, ja.
Interviewer: Ja.
Bent: Jo.
Interviewer: Mh, ja, så... kan du fortælle lidt, hvad for nogen opgaver, der, der er her på skolen? Kunne du sige lidt mere om det?
Bent: Ah, jam, jamen, altså, vi, vi havde lavet sådan noget – hvad hedder det? Sådan... nogle val...
ologover blandt andet også.
Interviewer: Ja.
Bent: Det har vi i hvert fald.
Interviewer: Ja.
Bent: Og det er så den stærke side, jeg har (griner).¹²
Interviewer: Ja, ja, ja (smil i stemmen).
Bent: Ja.
Interviewer: Ja.
Bent: Og så kan man jo også, hvis der er sådan nogle historier og sådan nogle ting – det kan vi også godt...
Interviewer: Ja.
Bent: Følg med I.
Interviewer: Ja.
Bent: Og – jo.
Interviewer: Okay.
Bent: Ja, ja.
Interviewer: Mh, så skal jeg også spørge, om der er noget, der er svært at have her på skolen?
Bent: Nej, det synes jeg ikke.
Interviewer: Nej.
Bent: Ikke umiddelbart sådan set.
Interviewer: Nej, Nej.
Bent: Nej.



Interviewer: Så der er ikke noget, du sådan...
Bent: (afbrudt) Jeg kan godt, jeg kan godt lide at gå her.¹³
Interviewer: Ja.
Bent: Jeg synes det... Ja.
Interviewer: Ja.
Bent: Ja.
Interviewer: Så... Okay, hvis du kommer ud for noget, der er svært, ah, hvad gør du så for at få noget hjælp?
Bent: Jamen jeg har en kone, som ah, er ret hurtig på kontoret (griner).
Interviewer: Ja.
Bent: Ja.
Interviewer: Ja.
Bent: Og så har jeg også nogen... nogen børn. Jeg har to, to piger. Den ene er skole lærer, den anden er ah, farmaceut jo.¹⁴
Interviewer: Ja. Ja.
Bent: Ja.
Interviewer: Så...
Bent: Så, så engang imellem så... så snakker vi med dem, hvis det er sådan, der er nogle problemer. Men ellers så min kone, hun er jo dygtig, hvert bild (munker).
Interviewer: Ja.
Bent: Hun har været på, på revidentkontoret også blandt andet.
Interviewer: Ja. Ja.
Bent: Ja.
Interviewer: Så du har god hjælp i din kone.
Bent: Helt sikkert.
Interviewer: Ja.
Bent: Ja.

13 / 42



13A

Interviewer: Ja. Og når du...
Bent: Også...
Interviewer: Ja?
Bent: Også mine børn.
Interviewer: Ja, og 14 år børn også.
Bent: Ja.
Interviewer: Ja.
Bent: Den ene er som sagt farmaceut og så...
Interviewer: Ja.
Bent: Den anden er ganske almindelig skolelærer.
Interviewer: Ja. Ja. Hvad så hvis du sidder her på skolen.
Bent: Ja.
Interviewer: Og, og du har brug for lidt hjælp til en opgave? Hvordan får du så hjælp til det?
Bent: Jamen øh... for det meste så s-forsøger jeg selv at løse den, ikke også?
Interviewer: Ja.
Bent: Og så hvis det er sådan, at der er noget, jeg ikke kan finde ud af, s, så må jeg lige have hjælp i hvert fald. Ja.
Interviewer: Ja.
Bent: Ja.
Interviewer: Hvem får du hjælp af så? Er det de andre elever, eller er det lærerne?
Bent: Jamen det er som rs, som regel en lærer, ikke og – hvis hun, hvis hun sidder og kigger på, at jeg ikke kan, kan finde det – hvad er det for noget.
Interviewer: Ja.
Bent: Så, så kalder jeg lige på hende, at – kom, om hun lige kan finde ud af den der, hvis der sådan (taler meget uvideligt).
Interviewer: Ja.
Bent: Men ellers – det, jeg, det, jeg har ikke problemer med det i hvert fald.



Interviewer: Nej.

Bent: Nej.

Interviewer: Nej, så det er ikke så tit, du har brug for hjælp?

Bent: Det – nej. Nej.

Interviewer: Nej. Okay, så skal jeg også høre, om I arbejder med nogle af de mere tekniske ting her på skolen, og om du har arbejdet med iPad her på skolen.

Bent: Ja, det har vi.

Interviewer: Ja, ja.

Bent: Jeg har også en iPad derhjemme, som... Ja.

Interviewer: Ja, ja. Hvordan er det at arbejde med?

Bent: Det synes jeg, det er godt nok.

Interviewer: Ja.

Bent: Det er helt sikkert.

Interviewer: Ja.

Bent: Ja.

Interviewer: Ja. Så du er ikke afskrækket fra

Bent: Overhovedet ikke.

Interviewer: at skulle arbejde med en iPad?

Bent: Over, overhovedet ikke, nej.

Interviewer: Nej. Nej. Har du arbejdet med computer her på skolen også?

Bent: Ja, det har vi – vi har også den derhjemme jo.

Interviewer: Ja.

Bent: Ja.

Interviewer: Ja.

Bent: Som – jeg er ret sikker, så... Vi bruger jo også computer og sådan nogle ting.

Interviewer: Ja.



Bent: Ja

Interviewer: Ja. Har du arbejdet meget med computer som reviser?

Bent: Ja det har jeg. Ja. **1**

Interviewer: Ja.

Bent: Ja Jo.

Interviewer: Så...

Bent: Det er jo nemmere, når ... (griner) i stedet for at sidde, sidde og gøre det andet der (munker).

Interviewer: Ja.

Bent: Ja.

Interviewer: Jamen det er rigtig.

Bent: Jo, vi har 5, vi har en – for det ikke skal være løgn, så har vi to. Vi har en stationær og så en, vi slæber med jo.

Interviewer: Ja. Ja. Så I har en med på faren.

Bent: Ja, det har vi.

Interviewer: Ja.

Bent: Ja.

Interviewer: Okay. Godt.

Bent: Ja.

Interviewer: Ja... Så skal jeg også – vi går til næste side nu, nemlig.

Bent: Okay.

Interviewer: Så er vi ved at være snart færdige med alle de spørgsmål (griner).

Bent: Jamen det, det generer ikke mig. Hvert fald (smil i stemmen).

Interviewer: Det var godt (griner). Jeg kunne godt tænke mig, at vi kunne snakke lidt om for du fik, at vide, at du havde demens.

Bent: Ja.

Interviewer: Så spoler vi tiden langt tilbage nu.

Bent: Ja. Ja.

Lived space
Social relationships and activities
Conversation challenges and activities
Familiarity
The decreased use of technology
The positive school input
Awareness of dementia
The present past
The role of family
Lived time
Lived relation
Struggles in life with dementia
Memory difficulties
The ability to learn
Lived body
Coding Dementia

Humour and laughter

Interviewer: Øh, kan du huske, hvordan du lærte noget nyt?

Bent: Jamen jeg gik på realskole.

Interviewer: Ja, ja.

Bent: Pn-, jeg gik på XXX øh, Realskole.

Interviewer: Ja.

Bent: Ja.

Interviewer: Ja.

Bent: Først startede vi i grundskolen, ikke også?

Interviewer: Ja.

Bent: Og så, så b-, så blev jeg sat på realskole i XXX.

Interviewer: Ja.

Bent: Ja.

Interviewer: Ja, Mh. Og når du skulle lære noget nyt i skolen i XXX.

Bent: Ja.

Interviewer: Hvordan lærte du dig så selv noget nyt? Havde du nogen gode BF?

Bent: Jamen det har vi – ligesådan, hvis der var noget, jeg ikke, jeg ikke kunne finde ud af, så kunne jeg lige række fingren op.

Interviewer: Ja.

Bent: og så kom der en og så, s – jeg snakkede med en af lærerne.

Interviewer: Ja.

Bent: Vi har nogle dygtige lærere i hvert fald – det har vi i XXX.

Interviewer: Ja.

Bent: Ja, Jo.

Interviewer: Ja, Så det var..

Bent: Det hed – altså, 1000 var der ingen, men der var realskole i XXX.

Interviewer: Ja.

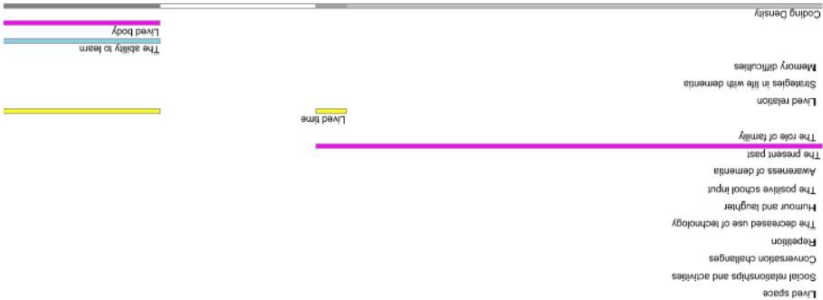
17 / 42



APPENDIX H. EXAMPLE OF A TRANSCRIPT OF AN INTERVIEW. CODING OF THE TRANSCRIPT INSPIRED BY THE
FOUR LIFE EXISTENTIALS

Bent: XXX og om, omegns realskole.
Interviewer: Ja.
Bent: Den ligger lige, hvor man kommer ind i byen.
Interviewer: Ja.
Bent: på vests, på højre hånd.
Interviewer: Ja.
Bent: Ja.
Interviewer: Okay, Ja.
Bent: Og der får, der var – kom jeg fra... å, hed det... OOO Skole (taler utydeligt).
Interviewer: Ja.
Bent: Der nede i bunden derinde... ah, hvor vi kom også – så skulle jeg på realskole, sagde min far og mor, og så...
Interviewer: Ja.
Bent: har jeg prøvet at gå på realskole.
Interviewer: Ja.
Bent: Så bagfter, så på andre skoler, ikke også?
Interviewer: Ja.
Bent: Ja.
Interviewer: Ja. Mh. Og da du lærte til revisor,
Bent: Ja.
Interviewer: hvordan lærte du så det, du skulle lære?
Bent: Ja. O, det, det lærte jeg s, samtidig med jeg, jeg lærte op –
Interviewer: Ja.
Bent: de forskellige ting op, ikke også?
Interviewer: Ja. Ja. Hvordan kunne du huske det, du læste?
Bent: Jamen det har jeg altid været god til, jeg kan godt huske de forskellige ting. I?

18 / 42



18A

Interviewer: Ja.
Bent: Ja.
Interviewer: Ja. Men hvordan gjorde du det?
Bent: Jeg, jeg har, har et stykke papir, så skriver jeg de der forskellige ting op, hvis det er sådan, at der er noget jeg... Det skal vi hvert fald lige have fat i, Åh, også?
Interviewer: Ja.
Bent: Ja, Jo, Ja.
Interviewer: Så du har skrevet mange noter førhen?
Bent: Det har jeg.
Interviewer: For at huske...
Bent: Det, det gjorde – man skrev jo noter, hvis det er sådan, at der var et eller andet, som man s- syntes – åh... lævede man en note til de der ting.¹⁸
Interviewer: Ja.
Bent: som m, man – nu når man blev spurgt om dem, så kunne man huske det der.
Interviewer: Ja. Okay.
Bent: Jo, jeg gik m... på XXX Realskole.
Interviewer: Ja.
Bent: Øh, hvis du ved, hvordan er, så er det lige hvor, hvor der... der var hestevæddeløbsspor – det ved jeg ikke, om du ved?¹⁹
Interviewer: Nej, jeg er ikke så godt orienteret på de der kanter. Det er jeg desværre ikke.
Bent: Nej. Nej.
Interviewer: Nej.
Bent: Jeg v-, jeg kom fra OOO Skole, og så syntes min far og mor, jeg skulle på realskole.
Interviewer: Ja.
Bent: Så gik jeg på XXX og om-, omgæns realskole.
Interviewer: Ja, Ja.
Bent: Ja.



Interviewer: Okay, Ja. Mh. Hvis nu at jeg så skulle spørge igen sådan tilbage gamle dage –
Bent: Ja, Ja.
Interviewer: Kan vi sige det sådan?
Bent: Ja, okay.
Interviewer: Er der noget, der altid har været svært for dig at lære? Er der noget, hvor du sagde: [Det lærer jeg aldrig?]
Bent: Det, det synes jeg ikke, nej.
Interviewer: Nej?
Bent: Nej. Nej. Nej.
Interviewer: Nej, så der er ikke noget, hvor du syntes, at det var bare svært?
Bent: Nej, jeg har altid et... og i skolen – altså, vi har jo OOO Skole, men så har vi så XXX og omgængs realskole.²⁰
Interviewer: Ja.
Bent: Og der blev jeg så sendt, sendt hen dengang...
Interviewer: Ja, Ja.
Bent: S, mm... den anden skole, den var blevet for lille m...
Interviewer: Ja. Har du...
Bent: Og så cy, cyklode man derhen.
Interviewer: Ja, Oh, har der aldrig været noget, der var svært for dig så at lære?
Bent: Det synes jeg – ikke, ikke synes jeg umiddelbart. Nej.
Interviewer: Nej.
Bent: Nej.
Interviewer: Det er jo dejligt.
Bent: Ja, Jamen det er det da, Altså, m-, og så har jeg – som rektor så skal man jo også huske noget d., af, af de andre ting, s-, som måske er noget tilbage der.
Interviewer: Ja.
Bent: Ja, Ja.



Interviewer: Ja. Mh. Ja, oh, så skal jeg spørge, om der er nogen aktiviteter, du altid har holdt af at lave. Hvis du sådan skal tænke tilbage – er der noget, du altid har været glad for at lave?

Bent: Altså, øh, sådan noget som det eller fodbold eller håndbold?

Interviewer: Lige præcis hvad du synes.

Bent: Må. Jamen jeg har spillet meget fodbold og meget badminton.

Interviewer: Ja. Ja.

Bent: Ja.

Interviewer: Ja.

Bent: Det har jeg gået til mange år.

Interviewer: Ja.

Bent: Og jeg spiller også fodbold endnu, men øh, det er ikke så hurtigt, som det har været (griner).

Interviewer: Nej.

Bent: ... har været.

Interviewer: Ja.

Bent: Nej.

Interviewer: Så det er du stadigvæk glad for – at dyrke sport?

Bent: Helt sikkert.

Interviewer: Ja. Ja.

Bent: Og så også redskabsgymnastik, men det er ikke så meget – jeg er ikke sådan noget flittakker og sådan nogle ting. Nej.

Interviewer: Nej. Nej. Men også lidt gymnastik, redskabsgymnastik?

Bent: Ja. Ja.

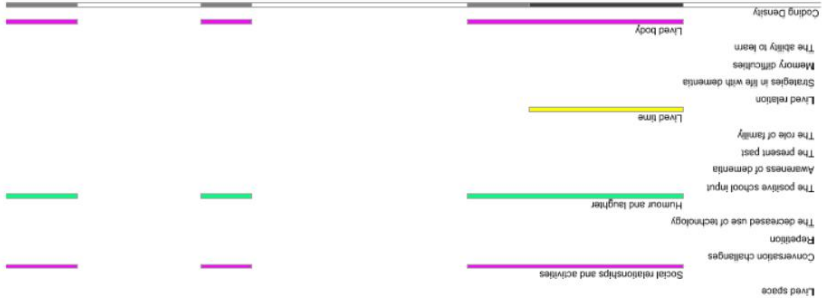
Interviewer: Ja.

Bent: Ja.

Interviewer: Ja. Og det har du gjort i mange år?

Bent: Det har jeg. Ja.

Interviewer: Ja.



Bent: Og jeg gør det også endnu, men jeg er blevet lidt sikker, som jeg plejer at være (griner).

Interviewer: Du er lidt mere aktiv? (smil i stemmen).

Bent: Ja.

Interviewer: Ja. Okay. Ja. Er der andre ting, du altid har holdt af at lave?

Bent: Nej, ikke derhjemme sådan...

Interviewer: Nej.

Bent: Nu – jeg er jo uddannet i... en brugsforsknig, altså... brugsforsknig.

Interviewer: Ja.

Bent: Og... Der – det var sådan en ting, det, det, det har man lært.

Interviewer: Ja.

Bent: Jeg s-, kom i – dengang jeg blev udlært eller s-, så kom jeg ind at arbejde i en brugsforsknig, og så begynder, så kom jeg til d-, at arbejde andre, andre steder også, ikke?

Interviewer: Ja, ja, ja.

Bent: Jo.

Interviewer: Så du har arbejdet i brugsen,

Bent: Ja.

Interviewer: Før du blev revisor?

Bent: Ja, ja.

Interviewer: Eller – eller var det efter, du var...

Bent: Nej, det var før, jeg blev revisor.

Interviewer: Revisor, ja.

Bent: Ja. Det var IODO brugsforsknig.

Interviewer: Ja?

Bent: Ja.

Interviewer: Så der arbejder du også, ja.

Bent: Jo.



Interviewer: Mh. Ja. Så skal vi spole tiden lidt frem igen (griner).

Bent: Det er i orden. Okay.

Interviewer: Fordi jeg kunne godt tænke mig at høre eh, hvis nu du så lare noget nyt herinde på skolen nu.

Bent: Ja. Ja.

Interviewer: Har du så fundet ud af en god måde at lære tingene på?

Bent: Jamen jeg skrive – hvis der er noget, som eh, jeg skal huske, s-så skriver jeg det ned på et stykke papir.

Interviewer: Ja.

Bent: Ja.

Interviewer: Okay.

Bent: Ja.

Interviewer: Ja. Har du altid papir med dig i lommen eller...?

Bent: Ja, som om, som regel, så har jeg sådan et ark.

Interviewer: Ja.

Bent: Ja.

Interviewer: Ja. Og så skriver du...

Bent: (afbrudt) Men, men eh, jeg synes i hvert fald – huske, det gør jeg – nu, nu kan man altid huske, der er sådan en ting (taler utydelig, usammenhængende).

Interviewer: Ja. Ja.

Bent: Ja.

Interviewer: Så der er noget for dig, der er nemt nok at huske.

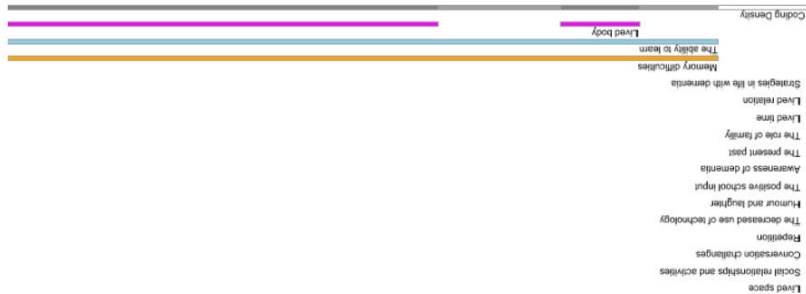
Bent: Ja.

Interviewer: Stådigvæk?

Bent: Helt sikkert. Helt sikkert. Ja.

Interviewer: Og så er der nogle andre ting.

Bent: Ja.



Interviewer: det er sværere at huske.
Bent: Det er sværere at huske, ja.²¹
Interviewer: Ja. Kan du sådan sige, hvad der er svært at huske?
Bent: Nej, sådan ikke umiddelbart, men... altså, hvis det er sådan, vi har været et eller andet sted herne.
Interviewer: Ja.
Bent: Så kan jeg godt huske, hvor vi var herne og sådan nogle ting.
Interviewer: Ja.
Bent: Det er ikke noget problem det der.
Interviewer: Ja. Er det så bare sværere at huske hvad dag, det var?
Bent: Nej, det er ikke det.
Interviewer: Nej, Nej.
Bent: Nej, Nej, Nej.
Interviewer: Okay.
Bent: Nej, Nej, Nej.
Interviewer: Nej, Det kan også...
Bent: Det er ikke forsvundet det hele endnu da (smil, stemmen).
Interviewer: Nej, Nej (smil, stemmen).
Bent: Nej.
Interviewer: Nej. Men nogle gange kan det være måske en bestemt ting, der er svært at huske.
Bent: Ja, men det er jo da det. Det kan godt være.
Interviewer: Ja.
Bent: Og, og der er måske et eller andet, som man skal man skal huske, og så siger man: 'Hvad så kan var det nu det der ligger, det var?'
Interviewer: Ja.
Bent: Og så, så kommer den måske længere herne på, ja.
Interviewer: Ja. Så kan godt gå noget stykke tid, inden du så kan huske...



Bent: Ja, helt sikkert.

Interviewer: en ting, ja.

Bent: Ja.

Interviewer: Ja, ja. Mh, hvis nu du så skal lære nyt nu her,

Bent: Ja.

Interviewer: så eh, så siger du, at du kan skrive ned på papir.

Bent: Ja.

Interviewer: Er der andet, du gør for at kunne huske det?

Bent: Ja, eh, jeg kan også eh, gentage så forskellige ting for, for sig selv, ikke også?

Interviewer: Ja.

Bent: Ja.

Interviewer: Okay, Hvordan gør du det?

Bent: Jamen eh, hvis der er et eller andet, jeg skal huske (tryk på ordet skal).

Interviewer: Ja.

Bent: så, så eh, kryfter jeg sådan de ting der, hv-> som var i forbindelse med det.²²

Interviewer: Okay.

Bent: Ja.

Interviewer: Kan du ikke prøve at sige lidt mere om det, for det lyder ret interessant.

Bent: Jamen eh, hv-hvis det er sådan, at jeg skal huske, s-så siger jeg til mig selv: 'Det skal du lige huske' (formeri på bordet). For eksempel hvis det er sådan eh... som - hvad skal jeg... Jeg, jeg - hvis jeg skal for eksempel - jeg var en brugsforening, og så hvis jeg kunne huske noget med - det var nogle fødestoffer og sådan. Så når jeg kom ned, så, så, så sagde jeg: 'Vi skal lige have de der fødestoffer og vi skal lige have de der ting.' (væder udydeligt).

Interviewer: Ja.

Bent: Det er altså... Det kører jo så d-dropper i eh...

Interviewer: Ja.

Bent: I, i for's, i forstanden, hvis man kan sige det sådan,



Interviewer: Ja.

Bent: Ikke også?

Interviewer: Ja, Ja.

Bent: Jo.

Interviewer: Så du prøver at krytze nogen ting sammen?

Bent: Ja.

Interviewer: Ja.

Bent: Også – og på realkololen, når man cyklede på realkololen – det var XXX realskole. Jeg boede i OOO.

Interviewer: Ja.

Bent: Så når vi cyklede 5-5 – "Jamen hvad er det nu lige, jeg skal huske?" Så, så gentog man det, det der, når man kørte der på cykel der

Interviewer: Ja.

Bent: Til XXX. Og så når man kom hen på realkololen, så, så har man sådan set dem inde i og nogen har man også noteret på et stykke papir, ikke også?

Interviewer: Ja.

Bent: Ja.

Interviewer: Ja. Så du har altid brugt det

Bent: Ja.

Interviewer: at sige til dig selv: 'Hvad er det, jeg skal huske?' og så gentage det

Bent: Ja.

Interviewer: for dig selv inde i hovedet?

Bent: Ja.

Interviewer: Ja, okay.

Bent: Det er den eneste måde. Så når man bliver gammel, begynder at blive gammel, det, det, så.. skal man jo lige passe på.

Interviewer: Okay.

Bent: For der er noget, der svigter, ikke også?



Interviewer: Der er noget, der svigter. Okay. Ja. Skal du så gentage tingene flere gange for at huske dem?

Bent: Nej. Nej, nej.

Interviewer: Nej.

Bent: Det er bare æh, jeg synes jeg s'far fat og så...

Interviewer: Ja.

Bent: Siger jeg til mig selv: 'Nå, det skal du lige huske', og så...

Interviewer: Ja.

Bent: Kører man på en omgang.

Interviewer: Ja.

Bent: Og så når man kommer der frem til det sted, hvor man skal være, så skal man, så kan man godt huske det – de der ting der.

Interviewer: Ja. Okay.

Bent: Ja.

Interviewer: Er der noget, der er blevet vanskeligt for dig at lære nu? I forhold til...

Bent: Nåh, der er sommetider noget – der er noget, jf. der svigter, men det er ikke ret meget. 25

Interviewer: Nej.

Bent: Nej.

Interviewer: Okay.

Bent: Jeg kan huske både børn, både børn og børnebørn (mumler).

Interviewer: Ja.

Bent: Ja. Ja.

Interviewer: Så...

Bent: Navnene på dem og sådan nogen ting.

Interviewer: Ja. Mh. Er det vigtigt for dig også at kunne det – huske det?

Bent: Jamen det er det da i hvert fald.

Interviewer: Ja.



Beit: Nu har jeg to, to piger. Den ene er skolelærer og den anden er farmaceut, så...
Interviewer: Ja, ja, ja.
Beit: Ja.
Interviewer: Mh.
Beit: De bor begge i SS5 ved ZZZ.³⁴
Interviewer: Ja, ja.
Beit: Ja.
Interviewer: Ja. Der er lige et stykke ned.
Beit: Ja, det er der i hvert fald (mumler).
Interviewer: Ja, Ja. Okay.
Beit: Men vi tager sådan en gang om ugen eller en gang hver, om måneden, så kører vi så til ZZZ eller også kommer de op til os.
Interviewer: Ja.
Beit: Vi har sommerhus i WWW, og så n-kører vi ned til vandet der... Og hvis ikke vi bruger sommerhuset, så er, bruger de andre det.
Interviewer: Ja (smil i stemmen).
Beit: Så det, det er allertids jo...
Interviewer: Ja, det er rigtig...
Beit: Og så følger, så følger også der små børn, som de har, dem, de følger jo også med (smil i stemmen).
Interviewer: Ja, Ja. Så så er der liv og glade dage.
Beit: Ja, helt sikkert.
Interviewer: Ja (griner).
Beit: Helt sikkert.
Interviewer: Hvor mange børnebørn har du?
Beit: Jeg har to, to – tre styk, ja.
Interviewer: Tre styk, ja, så kan der være rigtig gang i den (smil i stemmen).



Bent: Ja, en dreng og så to piger.
Interviewer: Ja, ja.
Bent: Jo, jo.
Interviewer: Så sker der noget.
Bent: Ja, det gør der i hvert fald.
Interviewer: (griner) Ja.
Bent: Jo, vi kommer op ved WWW – n-år vi kommer derefter til W, til WWW kille, og så her, her vi ned mod vandet, og så ligger vi så ind til venstre, lige ind for, inden vi når ... den der, og så har vi sommerhuset deroppe bagved.
Interviewer: Ja, ja.
Bent: Har haft det gennem nogen år.
Interviewer: Ja. Deltag.
Bent: Ja, ja.
Interviewer: Ja. Hvor godt.
Bent: Ja.
Interviewer: Ja. Oh, jeg skal også høre, om der er nogen nye aktiviteter, du har haft at holde af nu her øh, som du er begyndt at lave. Du fortalte mig, at du godt kunne lide at spille fodbold og gymnastik.
Bent: Jamen det – jeg har spillet, jeg har spillet fodbold meget og meget badminton og sådan nogen ting igennem årene.
Interviewer: Ja, ja. Er der nogen nye ting, du er begyndt på her indenfor de senere år?
Bent: Næh. Nej, ikke andet end at jeg ... jeg jo begynder at lade sådan engang imellem.
Interviewer: Ja?
Bent: Vi har jo en dejlig strand, så vi kan lade os ned langs s, med stranden, hvis det er.
Interviewer: Ja.
Bent: Og s-sommerhuset det ligger sådan, at vi skal bare lige op over en klit.
Interviewer: Ja.
Bent: Og så, så er vi ned ved vandet jo.



Bent: Helt helt sikkert.

Interviewer: Ja, ja.

Bent: Og men s-, f-4 har man bare børnebørn, så man jo også godt til at skulle løbe lidt efter dem jo (smil i stemmen).

Interviewer: (griner). Ja, det er rigtig. Det er man godt til.

Bent: Ja (griner).

Interviewer: Det er helt sikkert. Det kan godt gå stærkt (griner).

Bent: Det kan gå stærkt i hvert fald.

Interviewer: Ja.

Bent: Jo, vi har – vi kører ned ved WWW kaffe, og så ligger det så derude bagved.

Interviewer: Ja, ja.

Bent: Ja.

Interviewer: Er det også vigtigt for dig – nu siger du, det er vigtigt at holde dig selv aktiv.

Bent: Ja.

Interviewer: Er det også vigtigt, altså, din.

Bent: (afbryder). Jamen det er det.

Interviewer: Sin hjemme aktiv også? (taler højt).

Bent: Helt sikkert.

Interviewer: Ja.

Bent: Det er man godt til.

Interviewer: Ja. Hvad gør du for at holde den, den etage aktiv? (smil i stemmen).

Bent: Jeg læser en masse a-, masse artikler og sådan nogen ting.

Interviewer: Ja, ja.

Bent: og, og så som revision, så er man også godt til at læse de der nye aeh, ting, der kommer frem, kke også?

Interviewer: Ja, ja. Lige præcis, ja.

Bent: Og det er jo heller kke, i hvert fald, ingen skade til.



Interviewer: Nej, det er det ikke (smil i stemmen).

Bent: (griner).

Interviewer: Så du læser stadigvæk rigtig meget?

Bent: Ja, det, det gør jeg i hvert fald. Ja.

Interviewer: Ja. Er det både bøger og...

Bent: Ja, bøger, men ikke så meget.

Interviewer: Nej. Nej.

Bent: Men det er mest øh, artikler for...

Interviewer: Ja.

Bent: F.eks. bøger og sådan nogle ting.

Interviewer: Ja. Fra avisene?

Bent: Ja. Ja. ³⁶

Interviewer: Okay. Mh. Ja. Så skal jeg høre hvordan... du sådan arbejder med at kunne huske noget af det, du lærer her på skolen.

Bent: Ja.

Interviewer: Er der en bestemt område, du prøver på at huske det?

Bent: Jamen jeg plejer at gentage så f., sådan for mig selv.

Interviewer: Ja.

Bent: I hvert fald. Ja.

Interviewer: Ja. Ja.

Bent: Og så hvis der er noget øh, jeg skal huske, så skriver jeg det ned på et stykke papir. Hvis der er noget øh, jeg absolut skal huske, ikke også?

Interviewer: Ja. Ja. Mh. Ja.

Bent: Men han ligner godt bruge en kuglepen, når nu det er sådan (nummer).

Interviewer: Ja. Ja. Du bruger ikke kalender – at skrive ting i kalender?

Bent: Jo, altså, hvis der er nogle bestemte datoer, j – så skriver jeg at skrive datoen på den der – det jeg skal huske, og på den dato der (nummer).



Interviewer: Ja.

Bent: Ja, ja, ja.

Interviewer: Okay, Ja. Går i så ligneren kalenderen derhjemme.

Bent: Ja.

Interviewer: dig og din kone?

Bent: Nej, det ve-, det ve— Ja, det gør vi da også, men...

Interviewer: Ja.

Bent: Ja.

Interviewer: Men du gør det også selv?

Bent: Ja, vi har sådan en stor kalender.

Interviewer: Ja, Ja, Ja.

Bent: Hvis der er nogen ting, vi absolut skal huske, så, så noterer vi, hvis det er, at vi skal se eller andet...

Interviewer: Ja.

Bent: et eller andet sted hen.

Interviewer: Ja, Ja.

Bent: Ja. Så behøver man ikke at gå og blive husket på det, for man, man har noteret det i hvert fald (mumbler).

Interviewer: Ja. Lige præcis.

Bent: Og jeg, jeg har så også en bønne-, jommekalender.

Interviewer: Ja, Ja. Har du altid den med dig så.

Bent: Ja.

Interviewer: din lille kalender?

Bent: Ja.

Interviewer: Ja.

Bent: Ja.

Interviewer: Og den bruger du



Bent: Ja

Interviewer: Til at skrive ned?

Bent: Helt sikkert.

Interviewer: Ja.

Bent: Hvis der er noget, jeg absolut skal, skal huske.

Interviewer: Ja.

Bent: og skal hen til, så noterer jeg lige n, lidt ned, og så, så står det: 'Hov, det skal vi lige huske.' (mumler).

Interviewer: Ja.

Bent: Men ikke – man behøver jo heller ikke s-og og gemme på alt. Man kan jo ligeså godt skrive det ned, når man... (griner).

Interviewer: Lige præcis. Så man ikke skal gå og huske det hele i hovedet (smil i stemmen).

Bent: Hehelt sikkert.

Interviewer: Ja. Rigtigt. Ja. Ja. Så – hvad hedder det – så er jeg faktisk ved at være der nede, hvor jeg skal spørge om nogle af de sidste spørgsmål.

Bent: Du er hjertelig velkommen.

Interviewer: Det lyder dejligt. Jeg skal høre lidt, om du har nogle bestemte ønsker til, hvordan vi skal arbejde sammen i projektet. Om det er noget, du har tænkt over.

Bent: Det er ikke – nej, det...

Interviewer: Nej. Nej. Nej. Jeg skal jo undervise lidt i, hvordan man laver projekter sammen.

Bent: Ja, okay. Ja.

Interviewer: Øh, hvordan kan du godt lide at blive undervist?

Bent: Jamen det øh, er m... helst med skrift og sådan nogen ting. Det er lige mig.

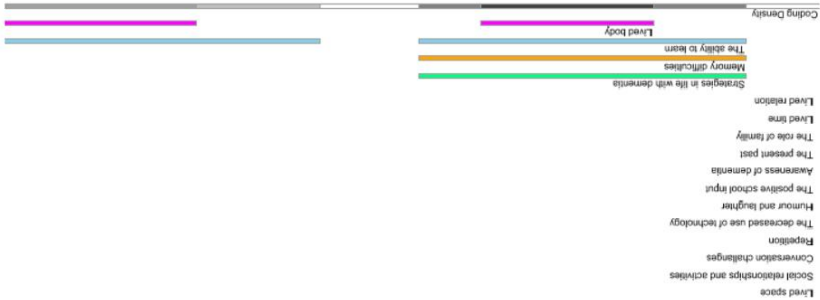
Interviewer: Ja.

Bent: Helt sikkert.

Interviewer: Så du kan godt lide, der er noget på skrift?

Bent: Ja, det kan jeg. Ja.

Interviewer: Ja. Så...



Bent: For det er jo somme tider, hvis man får for meget stoppet i, så kan man ikke huske det hele jo.

Interviewer: Nej.

Bent: Nej.

Interviewer: Nej, Ja.

Bent: Men nu – jeg har... oh, som revisor så, så noterer man nå-neh, når der er noget, man skal absolut huske. Ikke også ikke? (munter).

Interviewer: Ja, Ja. Så det må godt være nogle små tekststøkker?

Bent: Helt sikkert.

Interviewer: Det kunne være okay for dig?

Bent: Ja.

Interviewer: Ja, Ja.

Bent: S-å... når man – hvis der er et eller andet, man skal huske, s-å skriver jeg altid ned.

Interviewer: Ja.

Bent: S-å... så ah... så nu, nu der går flere dage sådan, så tager man så det frem, hvis det er, det er noget, noget der skal vi skal bruge, vi har brug for.

Interviewer: Ja.

Bent: Ja.

Interviewer: Ja, Godt.

Bent: Ja.

Interviewer: Ja. Hvis nu vi skal arbejde sammen nu her

Bent: Ja.

Interviewer: I projektet, er der så en bestemt måde, du gerne vil have, vi arbejder sammen på?

Bent: Nej det – nej, nej, det er lige meget. Det det bestemmer du.

Interviewer: Bestemmer jeg det? (griner). Ja. Men der er ikke nogle særlige ønsker fra din side af?

Bent: Nej, Nej.

Interviewer: Nej? Okay.

Bent: Ja.



Interviewer: Jeg skal bare opføre mig ordentligt? (snål, stemmen)	
Bent: Jamen det synes jeg, det, det, det er ikke mere end rimeligt (griner).	
Interviewer: (griner) Nej, det er rigtigst. Det er rigtigst. ²⁷	
Bent: Nej, Nej.	
Interviewer: Ja, Godt. Hvis nu jeg gerne vil bruge noget billeder.	
Bent: Ja.	
Interviewer: Og noget video.	
Bent: Ja.	
Interviewer: Kunne det også være...?	
Bent: Ja, det er ikke... det, det kan vi også godt bruge, ja.	
Interviewer: Ja, Tænk, du, det vil kunne hjælpe med at kunne huske nogen ting?	
Bent: Det kan det nok, hvis det er sådan... man har...	
Interviewer: Ja.	
Bent: Man kører med... det også.	
Interviewer: Ja.	
Bent: Ja.	
Interviewer: Så det ville også være okay for dig at bruge det?	
Bent: Ja, helt, helt sikkert.	
Interviewer: Ja, Hvis nu at æh, vi skal tænke på, hvordan det skal være, der hvor vi skal arbejde sammen.	
Bent: Ja.	
Interviewer: Hvis nu vi snakker om et klassiske herinde ved siden af.	
Bent: Ja.	
Interviewer: Tænk, du, det vil være okay eller...	
Bent: Jamen det... det er i orden for min skyld hvert fald.	
Interviewer: Ja, Ja. Er der noget andet, du tænker, der skal være – altså, i forhold til at kunne have godt?	
Bent: Nej, Nej, Ikke sådan umiddelbart.	

Coding Density	
Lived body	
Lived space	
Social relationships and activities	
Conversation challenges	
Regretion	
The decreased use of technology	
Humour and laughter	
Awareness of dementia	
The present past	
The role of family	
Lived time	
Lived relation	
Strategies in life with dementia	
Memory difficulties	
The ability to learn	

The possible school input

Interviewer: Nej. Hvad med lyd og sådan noget? Kan det godt eh... forstyrre dig?

Bent: Det generer mig ikke, nej.

Interviewer: Nej. Okay. Og heller ikke hvis der er ure fra andre?

Bent: Nej.

Interviewer: Nej.

Bent: Øh... Jeg kan godt koncentrere mig i hvert fald.

Interviewer: Ja. Okay. Ja. Så... Det var godt. Hvad med gentagelser? Vil det være godt at bruge gentagelser?

Bent: Jamen det, det, det..., i første omgang, så er det jo godt nok, men i næste omgang, så, så er det jo skævt nok men, man bh... det bliver gentaget, hvis man kan sige det sådan.

Interviewer: Ja, ja.

Bent: Ja.

Interviewer: Så ville det være okay, hvis jeg...

Bent: Ja, helt sikkert.

Interviewer: Hvis der er nogle ting, hvor jeg tænker: 'Det her, det er meget vigtigt', at jeg så gentager det et par gange?

Bent: Ja, ja, ja.

Interviewer: Er det i orden?

Bent: Ja, det synes jeg.

Interviewer: Det ville ikke genere dig?

Bent: Overhovedet ikke. ²⁸

Interviewer: Nej. Okay. Ja. Øh, så skal jeg bare her til sidst, Bent, hvad forventer du at få ud af det her projekt, vi skal have sammen? Har du noget, du... sådan forventinger?

Bent: Nej, jeg har sådan set ikke spekuleret på det...

Interviewer: Nej. Nej.

Bent: Jeg følger med i det s... som godt, som jeg kan.

Interviewer: Ja. Hvad kunne du tænke dig, vi skulle få ud af projektet?

Bent: Åh, nu... altså, vores hukommelse og sådan nogle ting, det synes jeg, det er alligevel i hvert fald.



Interviewer: Ja, Ja.

Bent: Ja. Men det er ikke for jeg, jeg er ikke dærlig til at huske – det er ikke noget sådan noget, men det er skævt nok at få noget gentaget, hvis man kan sige det sådan.³⁹

Interviewer: Ja, Ja. Så det ville være fint for dig, Ja.

Bent: Ja.

Interviewer: Mh. Er der noget, du gerne vil have sagt til, til sådan omverdenen gennem projektet?

Bent: Nej, det er ikke noget, Nej.

Interviewer: Nej, det er der ikke, Nej.

Bent: Nej, Nej.

Interviewer: Nej, Okay.

Bent: Det er bare at spørge mig.

Interviewer: Det er bare at spørge dig.

Bent: Ja.

Interviewer: Og så binder vi ud af, hvad vi kan få ud af projektet sammen (smil i stemmen).

Bent: Helt sikkert.

Interviewer: Ja. Det er godt.

Bent: Ja.

Interviewer: Vi er ved at være nået dertil, hvor vi snart skal sige, at vores interview er færdigt.

Bent: Ja.

Interviewer: Oh, men jeg kunne godt tænke mig at spørge som noget af det sidste, det er, er der noget af det, vi har snakket om, hvor du tænker, at der er lige noget andet, du vil fortælle mig?

Bent: Nej, ikke v-, ikke umiddelbart, Nej.

Interviewer: Nej, Nej. Så der er ikke sådan lige noget, du brænder inde med?

Bent: Nej.

Interviewer: Nej, Mh. Okay. Og det helt sidste jeg skal spørge dig om,

Bent: Ja.

Interviewer: det er, er det i orden for mig, at bruge det her interview

Bent: Helt sikkert.

Interviewer: I projektet?

Bent: Helt –

Interviewer: Der er ikke noget vi har snakket om,

Bent: Overhovedet ikke.

Interviewer: som du ikke synes, jeg må bruge?

Bent: Overhovedet ikke. Nej.

Interviewer: Nej. Okay.

Bent: Nej.

Interviewer: Så det må jeg godt gøre?

Bent: Det må du meget gerne.

Interviewer: Det lyder godt.

Bent: Ja.

Interviewer: Ja.

Bent: Og du må også sætte mit navn på, hvis det er sådan (smil i stemmen).

Interviewer: Det gør jeg ikke, for det har jeg lovet, jeg ikke ville gøre (smil i stemmen). Så, så det vil jeg lade være med at gøre.

Bent: Jeg har ikke noget sådan med det er hemmeligt i hvert fald (griner).

Interviewer: Nej. Det er okay. Ja (smil i stemmen). Men øh, jeg har lovet, at I er anonyme i projektet, så det...

Bent: Vi er anonyme, ja vel.

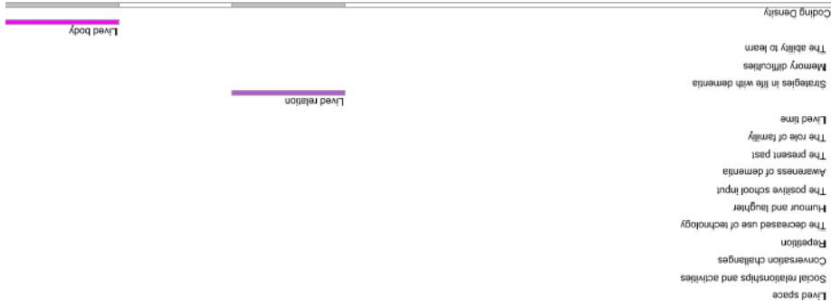
Interviewer: Så det skal jeg nok overholde.

Bent: Så vil det sige, det også er anonymt, når vi går og rører omkring d-, de er bare anonyme alle dem, der går rundt? (smil i stemmen).

Interviewer: (griner) Ja, men det kan de jo ikke være. Det ved jeg godt. Men nå ja, jeg skal skrive.

Bent: Ja. Ja.

Interviewer: Så skriver jeg, at det er elever fra skolen.



Bent: Ja, ja.

Interviewer: Og så skriver jeg ikke at det er Bent eller det er...

Bent: Det må du meget gerne, Mit...

Interviewer: Ja.

Bent: For det er helt sikkert – jeg har ikke været inde at sidde eller nogen ting.

Interviewer: Nej! Nej! (smil i stemmen).

Bent: (griner).

Interviewer: Jamen jeg ved det godt, jeg ved det godt (smil i stemmen). Men det er sådan noget jeg skal overholde.

Bent: Jamen det er helt sikkert, Ja.

Interviewer: Jeg har også nogen regler, jeg skal overholde jo.

Bent: Jamen det er helt sikkert.

Interviewer: Så... Ja.

Bent: men øh, ellers – alt det, som jeg siger, det må du gerne bringe videre. Det er helt afgjort.

Interviewer: Det lyder godt.

Bent: Ja.

Interviewer: Alltidrs. Skal vi så slutte alt det her apparatur igen?

Bent: Det synes jeg.

Interviewer: Ja, Så... Den herovre abkør vi nu her.

Bent: Og, og den hedder 11:22 den der.

Interviewer: Ja, det gør den da godt nok, så... Godt, jeg slukker den her, sådan, Så stopper den med at opføre. Og den her, den skal jeg også slukke, Så skulle den også være færdig. Så stopper vi den.

Annotations

¹ He previously dont answers in the interview. It can also be seen in some of the other interviews e.g. Peter. He is not telling about himself.

- Lived space
- Social relationships and activities
- Conversation challenges
- Reflection
- The decreased use of technology
- Humour and laughter
- The positive school input
- Awareness of dementia
- The present past
- The role of family
- Lived relation
- Strategies in life with dementia
- Memory difficulties
- The ability to learn
- Lived body
- Coding Density

- 2 Again it becomes no more comments from the person even though I try to give him room for answering. Maybe it is so difficult for him to explain everything?
- 3 It is difficult to understand what he means - it almost looks like he has not thought to his illness and situation. But it can also be an example of the differences he experiences. Or he just uses a wrong word - more instead of less.
- 4 Here it seems like he is saying yes to that it is more difficult to remember.
- 5 He does not seem to know what Alzheimer is so the different types of dementia are not something he knows about. He knows it is dementia.
- 6 I am not sure that he still uses the computer but that he has used a computer earlier because of his job.
- 7 I am still not sure that he is understanding what I am asking him about... but he continues with saying yes.
- 8 Here again it is told that the wife has taken over regarding the use of computers and technology and that he is aware of it. And that their children also use it.
- 9 He is very happy to attend the school. It also seems important for him with the relationship to other people.
- 10 It is almost impossible for him to explain what he just has been sitting doing in the class room. He can't explain in detail what he does at the school.
- 11 He goes back to something he is comfortable with when he cannot say more to my question. This seems to be all that he is comfortable with.
- 12 It almost looks like he is repeating what I just have commented about the wrong side. It looks like he is trying to wrap something in the conversation that he cannot answer my question.
- 13 It again surprises me that they are not talking about anything being difficult at the school.
- 14 Again it is the wife/spouse taking over and also the children are mentioned in many interviews after the spouse. If it is too complicated for both him and the wife. It is interesting that no of the interviewpersons are questioning this but instead they seem to very happy and grateful to have a person taking over when it is difficult for them. It seems like they have a good insight to their problems and need of help.
- 15 He is telling the same thing twice about food and computer and it is the same thing he is telling. It seems like he is right about his first comment where I was insecure if he was aware of what he was saying and answering.
- 16 Again he is trying to explain that computer is something he has used as a reviser. This argument he has tried to use another time before.
- 17 Again it seems like it is difficult to explain how you have been before getting dementia. It is again something that just happens when you are studying and working with the things.
- 18 Again when notes are mentioned as a way to try to remember when learning before dementia became a part of life.

Coding Density

Lived body

The ability to learn

Memory difficulties

Struggles in life with dementia

Lived relation

Lived time

The role of family

The present of dementia

Awareness of dementia

The possible school input

Humour and laughter

The decreased use of technology

Repetition

Conversation challenges

Social relationships and activities

Lived space

19 He goes back telling that he went to XXX Beakable and that he is a review several times during the interview. It seems like he is comfortable and proud of talking about that.

20 He tells us some of the other ones that nothing seemed difficult to learn when attending school.

21 It is important to be aware of that it can be different what is possible to remember and what is not. Not everything is impossible to remember.

22 This is a new variant of repeating a thing by putting it together with things who belong to it.

23 I am not sure how much insight he has in his own illness.

24 He has also told about his two daughters before and what they are educated as...

25 It seems like it is important not to give up and just sit. He thinks it is still important to keep being active - to run... it is important to be active.

26 He refers to stay active but it is via newspapers no longer books. Perhaps need to be easy to access?

27 In this interview humour is again used in different answers during the whole interview. It is important to be aware of its function.

28 Many of the informants do not think it will be a problem with repetition when they are being tasked.

29 I am still not sure that he is all aware of his cognitive impairment.

Coding Density
Lived body
The ability to learn
Memory difficulties
Strategies in life with dementia
Lived relation
Lived time
The role of family
The present of past
Awareness of dementia
The positive school input
Humour and laughter
The deceased use of technology
Regression
Conversation challenges
Social relationships and activities
Lived space

Appendix I. Example of field notes from the Monday group. Notes taken when observing the video tape. Example of transcript. Coding of the transcript inspired by a thematic analysis

Udvalgte personer: 1. person
 Jeg oplever at de er ganske over-
 mættede men at de er faktisk under-
 stressede for [redacted] at alle
 og udtrykke sig [redacted] siger
 in det er vanskelig at følge med
 i [redacted] bliver meget klogt
 e. hvedende og siger ikke mere
 under personen faktisk [redacted]
 [redacted] kan formå at sætte
 de ting med sig eller. Kan
 jeg give et godt eksempel.
 [redacted] et en [redacted] vil
 at [redacted] har også problemer
 med at lide blinde men [redacted]
 holder sin veninde og at
 [redacted] fortæller.
 [redacted] bliver til at lave sig
 med de gode ting som in
 drøfter - kan ikke til at

netten passer fram fult. De
opfører sig meget ordentlig og
i overensstemmelse med et
antropologisk system. Endda når
han [redacted] for ham
høder frike sang. De niver id
at gøre det bedste de kan.
De niver id at være tilbage
med deres indtryk. De er dog
meget lidt mere forstående
en at manne gøre /væge i-
der end de var i de enkelte
interviews.

Translated Field notes:

Observations: 1. Session

I experience that they are positive towards me but there are special challenges for XXX + XXX to speak and express themselves. XXX says it is difficult to keep up. Also XXX seems very restrained and does not say very much during the session. Especially XXX+ XXX can formulate answers to the questions that I ask. When I try to check their understanding of a case it seems like XXX every time confirms with a little blink that I interpret as being ok to continue.

XXX seems to make jokes with most things that we discuss – it seems like the role suits him well. They behave very proper and in accordance with a scholastic system. XXX even puts her finger up before she for the first time said something. They try the best they can. They seem to be satisfied with their contribution. However, they maybe are a little cautious about mentioning strong and weak sides than in their individual interviews.

(Own translation)

Man ser 1

[redacted] ansigt vendt mod mig + røker cigaret.
 røm + lyttende

Bliver til gylaget af andet snale (hale om
 Stobenhavn)

Stunner (dramatiske + mandag) + laver jeg
 om dette [redacted] + alle bøger + små børn
 de lige prøver at koncentrere sig om at læse.
 De følger med på paginene når jeg fortæller
 i starten + skifter paginer.

De taler på hvis af gungem når der gives en
 lyd for det. De rører til at høre sig sam
 men.

[redacted] viser at hun har læst nedr. kommentare
 fra 172

[redacted] synes måske det er lidt omvendt
 jeg fanger ikke altid [redacted] stunner
 jeg skal assistere meget aktivt ift at sætte
 bøger hos flere

De har såret ved at udføre pagin + komme og
giver + sætte i magge

jeg bruger gentagelser og fortæller hvor jeg er
på paginene

Snaleten går efter jeg er gået efter magge
 De begynder at høre i magge

jeg rår + (lidt) over ift kommer + magge
 alle begynder at hjælpe med kommer +
 jeg sætter flere magge.

De siger ja til mere arbejde da jeg spørger
om det er ok.
da de får gamle bøgerne de at lægge i dem
og læse
jeg bruger gentagelser
[redacted] rækker hånden og
28.00 X [redacted] måske bruge et blynd hver jeg spørger om hvorfor
de vil deltage
[redacted] bliver begyndt af gennemgå og deltagende og
begynder at tale om U2 + taler om verdens-
mestre (nært v. at holde jalousi)
[redacted] bliver begyndt og inspireret af hinanden
til at komme med forslag
Da [redacted] fortæller han har svært v. følge med
fortæller + støtter [redacted] ham.
jeg spørger dem om hvad jeg må sige
[redacted] er ok i fl. ider til jalousi
jeg bruger min forståelse i fl. [redacted] for at få
en ide frem [redacted]
jeg skriver og de småsnakker og lytter
jeg gentager + grammerer deres arbejde i
gruppen
[redacted] synes at [redacted] har været heldig og har lavet
høje dage
jeg skriver at holder grænser ud af det de
taler om
De holder ikke om grænser Det virker ok
til at være for hårdt for dem

giver [redacted] en slags undersøgelse
De har brug for at jeg giver input til hvad
de er gode til
De har svært ved at sælge at komme med hvad
de er gode til + udfordringer
[redacted] er meget tilbageholden
[redacted] giver udtryk for at hun er ved at være
træt
Jeg rejser for at huske det der har sagt og føle
det videre i gruppen jeg kommer med
forslag og spørger om deres mening
Der kan det også måske gå hen af
gruppen
De følger med på program + i min måde ved
genhængen.
[redacted] skal vi klage?
Der er sporadiske tilbage meldinger fra grup-
pen i evalueringen. Små svar + kommenta-
rer.
De har brug for hjælp til maxymer + væk
ved at forstå de to maxymer.
De virker glade og tilfredse efter sessionen
[redacted] kommer til at rode rundt i maxymer
igen efter hun har glemt om sin maxy-
mer.
12.10.2019

Translated Notes from observing the video tape:

Monday Session 1:

XXX face turned towards me + seems attentive + listening

Becomes easily preoccupied of others talk (speaks about Copenhagen)

Humour (Amanda - Monday) + makes fun about little XXX + all nods + small children

Some try to concentrate about reading

They follow in the papers when I tell in the beginning + turn papers

They speak across the group, when they have the possibility. They seem to have a cosy time together.

XXX shows that she has read according to the comments from UK

XXX thinks maybe that it is a bit intricately

I do not always get the humour of XXX

I have to assist many very active in relation to cross the plan

They have difficulties in putting in the papers + plastic pocket + tasks + put in the folder

I use repetition and tell where I am in the papers

Small talk after I have gone after the folders

They begin to look in the folders

I take (a little) bit over in relation to plastic pockets + folders

Helen begins to help with the plastic pockets

I organise more folders

They say yes to work more when I ask if that is ok

When they get the papers, they begin to look and read in them

I use repetition

XXX puts her finger up

Maybe use a clip, where I ask why they want to participate

XXX becomes preoccupied of the papers and pictures and begins to talk about UK and speaks about world champions (difficult to keep focus)

XXX becomes excited and inspired of each other to come with suggestions

When XXX tells he has difficulties in following. XXX explains and supports him

I ask them about what I may write

Especially XXX is active in relation to ideas to the project

I use my pre-understanding in relation to get an idea from XXX

I write and they small-talk and have a cosy time

I repeat and summarise their work in the group

XXX thinks that XXX have been negative and have sworn the whole day

I try to identify the points from what they are talking about

They do not ask for breaks. It does not seem to be too hard for them.

XXX gives XXX a kind of excuse

They need that I give input to what they are good at

They have difficulties in coming up with what they are good at + challenges

XXX is very restrained

XXX express that she is becoming tired

I make sure to remember what they have said and passing it on in the group. I come with suggestions and ask about their opinion

There can easily arise small talk across the group

They follow in the papers + in my talk in the repetition

XXX should we clap?

There are sporadic feedback from the group in the evaluation. Small answers and comments

They need help for the folders + difficulties in understanding the two folders

They seem happy and satisfied after the session

XXX ends up messing around in the folders again after he has forgotten about his folder at home

(Own translation)

	Timespan	Content
1	27:07,9 - 28:18,1	We talk about having prior experiences with project work but the participants do not have that and we talk about that we then can decide how we want to do it. (I write on a post-it that the participants have not participated in a project before). I then ask why they want to participate in the project work. I: Jeg vil også gerne have lov til at spørge jer for I har været så søde alle sammen og sige at I gerne vil deltage (sætter mig da jeg stiller spørgsmålet)
2	28:18,1 - 28:19,2	Bent: Kan du sige det højt? (smiler)
3	28:19,2 - 28:27,6	I: I har været så søde alle sammen og sige at I gerne vil deltage, så jeg kunne godt tænke mig (smiler). Kunne I sætte ord på hvorfor I gerne vil deltage? (smiler)
4	28:27,6 - 28:34,3	Bent: Vi sy... jeg for mit vedkommende synes jeg at det kun er godt at man finder ud af noget
5	28:34,2 - 28:37,9	I: Ja så det er godt at man finder ud af noget mere (jeg er ved at rejse mig for at gå op og skrive på tavlen) Bent: Ja ja
6	28:37,6 - 28:46,6	Emma: Man vil vel sådan noget fordi man tror man kan bruge det til noget der kan gøre gavn og glæde og selv udvikle en selv noget mere I: (skriver på post-it)
7	28:46,6 - 29:04,6	I: Af noget og gavne ikke også? Emma: Ja I: Og gavne og hjælpe. Ja. Så det er faktisk fordi I rigtig gerne vil have at der kommer noget ud af det. Ja Elsa (har front mod deltagerne. Elsa rækker fingeren op)
8	29:04,5 - 29:20,8	Elsa: Jeg synes jo også når man jo deltager i det her projekt ikke. Så synes jeg også at det er. Så synes jeg også at det er meget vigtigt at vi hele tiden får indblik i det for det er jo en rigtig grim sygdom så... I: Ja ja ja (drejer sig mod tavlen igen for at skrive)
9	29:20,8 - 29:24,5	I: Så jeg må også godt skrive indblik her også? Elsa: Ja
10	29:24,5 - 29:47,8	I: Indblik i sygdommen (skriver). Ja det er nogle rigtige gode bud (front mod deltagerne) Er der noget mere der skal op eller er I enige? (gruppen sidder stille men modsætter sig ikke). I er enige?
11	29:47,8 - 29:55,3	Peter: Ja

		I: Dejligt. Kan I læse det heroppe? Er det ok at sætte det op på denne måde? (jeg peger mod tavlen og alle kigger op på den) Peter: Ja ja Bent: Ja
12	29:55,3 - 30:03,2	Peter: Har du været derovre? (peger på billede af UoN) I: Ja det har jeg Peter: Det har jeg også (lille grin) I: Dejligt sted Peter: Ja det var det I: Det er det
13	30:03,1 - 30:09,1	Ernst: Hvor fanden er det henne du taler om? (pladrer i parpirerne og kigger mod Peter) I: I England Ernst: Nå ja ja
14	30:09,1 - 30:15,7	I: Hvad skal vi have ud af vores projekt? Ernst: Du har da ikke været på det der universitet (læner sig over mod Peter og hans billede af UoN) Peter: Nej det har jeg da heller ikke sagt noget om
15	30:15,7 - 30:24,4	I: Han har været i England Peter: Det har jeg været mange mange gange til dans Ernst: Til dans I: Til dans ja
16	30:24,3 - 30:39,8	Emma: Det må være at få koog ikke føle sig sat til side med en demens men føle at man kan begynde at det kan jeg godt altså og det kan jeg bruge til noget (Peter forsøger fortsat at få min opmærksomhed og formulere noget verbalt. Sidder med parpirerne i hænderne. Har en voldsom grimasering). (Jeg fokuserer min opmærksomhed på Emma men de sidder ved siden af hinanden)
17	30:39,8 - 31:07,3	I: Så det her det... Emma: Man man kommer med på holdet på en måde I: Komme med komme med på holdet. Skal vi skrive det? (begynder at skrive) Emma: Ja selv om man kan føle sig mere og mere udenfor fordi man ikke kunne samles op ellers I: Komme med Emma: Ja det er sådan jeg tro I: Komme med og så ikke og ikke blive (går i stå og bliver hjulpet videre til at skrive) Emma: Ikke blive hængt af I: Og ikke blive
18	31:06,9 - 31:14,9	Elsa: Overset måske?

		<p>Emma: Ja det var..</p> <p>I: Ikke minus overset. Må jeg skrive sådan?</p> <p>Elsa: Ja</p>
19	31:14,9 - 31:29,1	<p>I: Ja det var nogle rigtige gode ting at få ud af det. Ja (pause)</p> <p>I: Er der andet? (jeg sætter mig ned igen)</p>
20	31:29,1 - 31:42,9	<p>Peter: Ja og de blev verdensmestre (har siddet og samlet sin mappe og stadig fokuseret på England)</p> <p>Er: Jamen det er ikke [...] vigtigt. Hvad fanden... (vender sig mod Helen og laver ansigt)</p> <p>I: Det varovre i England da de bleve verdensmeste. Det var rigtig flot. Hvad kunne du Peter tænke dig at få ud af projektet her?</p>
21	31:42,9 - 31:52,4	<p>Peter: Meget meget godt</p> <p>I: Du kunne godt tænke dig...</p> <p>Peter: Og og det er dejligt som du har gjort det</p> <p>I: Ok ja ja</p>
22	31:52,3 - 32:17,1	<p>Peter: Og du gør også noget (peger på Helen)</p> <p>Ernst: Og du vi er ikke ved punkt 9 endnu (Ernst peger på Peters papirer i forhold til evalueringen)</p> <p>I: Nej med det er fint. Det har jeg skrevet mig bag øret. Så vi kan blive enige om her i gruppen at det vi gerne vil have ud af projektet det er at vi får den her følelse af at vi kan komme med og vi kan give noget og vi bliver ikke overset og vi bliver ikke hængt af. Det er det vi faktisk gerne vil have ud af projektet?</p> <p>Emma: (nikker)</p>
23	32:17,1 - 32:26,4	<p>I: Er vi enige i gruppen om det?</p> <p>Gruppen giver samtykker og flere nikker</p> <p>I: Ja det er dejligt at I er så enige</p> <p>Bent: Det er bare lige til at vi kommer udenfor (gruppen griner)</p> <p>I: Nå ok så sker der nogle ting og sager</p>
24	32:26,4 - 32:32,1	<p>Emma: Det er nok nok fordi vi er enige i det fordi det er det vi sidder og og befinder os ligesom person hver især</p> <p>Peter: Det er fordi du ikke kan løbe så meget mere (griner)</p> <p>Bent: Nej (smiler)</p>
25	32:32,0 - 32:36,4	<p>Elsa: Jamen det er jo også vores egen identitet ik? Ja</p> <p>I: Ja</p> <p>Elsa: Ja det må jo os være det der gælder ikke, for vi er alle sammen interesseret i at få det bedre, så godt som vi nu kan ik... det går jeg ud fra</p> <p>Emma: [taler med men kan ikke høre hvad hun siger]</p> <p>I: Ja ja skal vi ikke også skrive det op at få det så godt som vi kan (rejser sig for at gå op og skrive)</p>

26	32:53,4 - 33:05,9	Emma: Fællesskab kan ofte få noget godt op at stå os fordi vi kan beholde lidt forståelsen i hvorfor hvad det er for at vi gør de ting og hvorfor tror vi på det og hvorfor vi vil gerne [...] I: Ja ja Elsa: Ja
27	33:05,8 - 33:17,8	I: Så jeg hører jer tale om fællesskab og få det så godt som muligt Emma: Ja fællesskabet er ihvertald meget værd Bent: Og det at vi tror på vor herre (humor i stemmen) Emma: Hvad for noget? Bent: Og det er fordi vi tror på vore herre er det ikke noget med ham at gøre? Emma: Det må du selv om (griner sammen med Bent)
28	33:17,8 - 33:37,8	I: Godt ja. Vilhelm er du også enig i tingene som står heroppe? (jeg sætter mig) Vilhelm: Jeg tror ikke at jeg kan følge med I: Nej med det er fint nok men vi tager det stille og roligt men der er ikke noget du er uenig i det der er blevet sagt Vilhelm? Vilhelm: Nej I: Nej ok. Godt (jeg rejser mig)
29	33:37,8 - 33:50,1	Elsa: Det kan vi alle sammen få få fællesskabet til at fungere ikke også jo. (klapper Vilhelm på armen) Vilhelm: Jo Emma: Vi hjælper hinanden fortsat. Vi er her alle sammen nu og vi hjælper hianden videre. Vilhelm: Ja Ernst taler med Helen
30	33:50,1 - 34:12,5	I: Skal vi ikke også skrive det op at vi hjælper hinanden. (Har rejst sig og begynder at skrive) Emma: Ja jo det synes jeg er væsentligt. Og så giver vi os til at tid til at høre på dem som er lidt i tvil om hvad det her nu er for noget og så noget og få snakket om det og så noget. Det vil hjælpe meget. Peter: Ja det gør det I: Ja godt. Vi hjælper hinanden. Emma: Ja lige præcis
31	34:12,5 - 34:12,6	I: Ja godt og så sagde I tid (skriver) Emma: Ja I: tusind tak...

1 time span Content

We talk about having prior experience with project work about the participants do not have that and we talk about that we then can decide how we want to do it. (I write on a post-it that the participants have not participated in a project before). I then ask why they want to participate in the project work.

1: I: will also like to ask you cause you have been so kind all of you and say that you will participate (I sit down when I ask the question)

2: Bent: Can you say that aloud? (smiles)

3: I: You have all been so kind and said that you would like to participate so I would like to (smile). Could you put some words on why you want to participate? (smile)

4: Bent: We th... I do for my sake I think it only is good that you find out something

5: I: Yes so it is good that you find out something more (I am about to get up to go to and write on the board)

Bent: Yes. Yes

6: Emma: You probably want something like this because you think you can use it for something that can do good and happiness and self-develop oneself some more

I: (writes on post-it)

7: I: Of something and do good right?

Emma: Yes

I: And do well and help. Yes. So it is actually because you would really like to get something out of it. Yes Elsa (have front to the participants. Elsa puts the finger up)

8: I also think when you participate in this project right. So I think I also that this is. So I also think that this is very important that we all the time get insight into this cause this is a very nasty illness so...

I: Yes yes yes (turns against the board again to write)

9: I: So I may also write insight here also?

Elsa: Yes

10: I; Insight in the illness (writes). Yes this is some really good suggestions (front against the participants). Is there something more which has to get up or do you agree? (the group sits quieted but do not resists) Do you agree?

11: Peter: Yes

I: lovely. Can you read this up here? Is it ok to put it up in this way? (I point towards the board and all look at it)

Peter: Yes

Bent: Yes

12: Peter: Have you been over there? (points towards the picture of UoN)

I: Yes I have

Peter: I have also been there (a small grin)

I: Lovely place

Peter: Yes it was

I: It is

13: Ernst: where the hell is it you are talking about? (looks through the papers and looks at Peter)

I: In England

Ernst: Well yes yes

14: I: what are we going to get out of our project?

Ernst: You have not been on that university (leans towards Peter and his picture of UoN)

Peter: No I have not said anything about that

15: I: He has been in England

Peter: There I have been many many times for dancing

Ernst: For dancing

I: For dancing yes

16: Emma: This may to get koog not feel put aside with a dementia but feel that you can begin that this I can do so and this I can use for something

(Peter continues to get my attention and formulates something verbal. Sits with the papers in the hands. Has a severe grimacing. I focus my attention towards Emma but they sit beside each other).

17: I: So this here this...

Emma: You you get on the team in a way

I: Get on get on the team. Shall I write that? (begins to write)

Emma: Yes even that you can feel more and more outside because you cannot be picked up otherwise

I: Get on

Emma: Yes that is how I believe

I: Get on and so not and not get (stops and gets help to write further)

Emma: Not to be left behind

I: Not to be

18: Elsa: Overlooked perhaps?

Emma: Yes it was...

I: Not minus overlooked. May I write like this?

Elsa. Yes

19: I: Yes that was some really good things to get out of it. Yes (pause)

I: Is there something else? (I sit down again)

20: Peter: Yes and they became world champignons (has been sitting and putting his folder together and still focused on England)

Ernst: Well that is not [...] important. What the hell... (turns around towards Helen and makes facial)

I: It was over in England that they became world champignons. That was impressive. What would you like to get out of the project Peter?

21: Peter: Very very good

I: You would like to...

Peter: And and it is lovely like you have done it

I: Ok yes yes

22: Peter: And you do also something (points towards Helen)

Ernst: And you we are not around point 9 yet (Ernst points on Peter's papers in relation to the evaluation)

I: No with this is fine. I have written it behind the ear. So we can agree about here in the group that this here in the group that this we will like to get out of the project this is that we get this feeling of that we can come with and we can give something and we are not overlooked and we are not left behind. This is what we actually will like to get out of the project?

Emma: (nods)

23: I: do we agree in the group about this?

The group agree and several nods

I: Yes it is nice that you do agree

Bent: It is only until we get outside (the group laughs)

I: Well ok so things happens

24: Emma: It is perhaps perhaps because we agree in it because it is us who sit and find ourselves like each the person Peter: It is because you cannot run so much more (laughs)

Bent: No (smiles)

25: Elsa: Well it is also our own identity right? Yes

I: Yes

Elsa: Yes it may be us it is about right cause we are all interested in getting better as good as we now can right...this I assume

Emma: (speaks but cannot hear what she says)

I: Yes yes shall we not write up to get as well as possible (gets up and walks and writes)

26: Emma: Community can often get some well up and stand because we can keep a little understanding in why what it is cause that we do these things and why we believe in it and why we will like... [...]

I: Yes yes

Elsa: Yes

27: I: So I hear you talk about community and get is as well as possible

Emma: Yes community is definitely very worth full

Bent: And it that we believe in God (humour in the voice)

Emma: What?

Bent: And it is because we believe in our God is it nothing to do with him?

Emma: You can decide (laughs with Bent)

28: I: Good yes. Wilhelm do you agree too in the things up here? (I sit down)

Wilhelm: I do not think I can follow

I: No that is ok but we take it slow but this is not something you disagree with what has been said Wilhelm?

Wilhelm: No

I: No ok. Good (I get up)

29: Elsa: This we can all get get the community to work right? (claps Wilhelm on the arm)

Wilhelm: Yes

Emma: We help each other continually. We are here all together now and we help each other on

Wilhelm: Yes

Ernst speaks with Helen

30: I: should we also write up that we help each other (has got up and begins to write)

Emma: Yes yes I think that is important. And so we give us time to listen to them who are a little in doubt about what this is now is something and so something and get talked about it and so on. It will help a lot.

Peter: Yes it does

I: Yes good. We help each other

Emma: Yes exactly

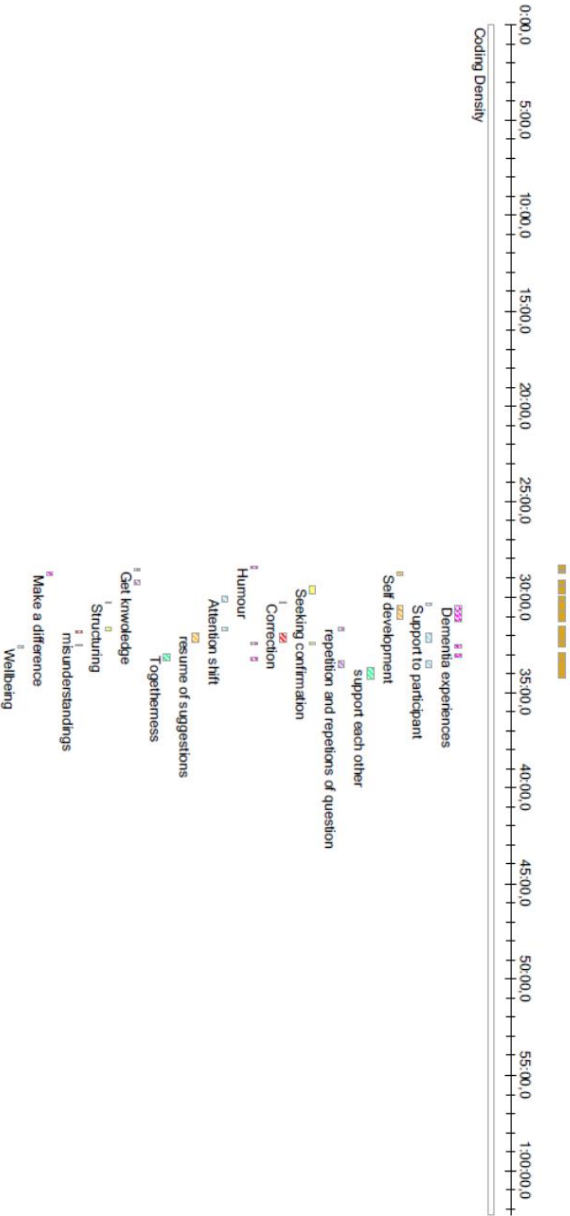
31: I: Yes good and so you said time (writes)

Emma: Yes

I: Thank you a lot...

(Own translation)

APPENDIX I. EXAMPLE OF FIELD NOTES FROM THE MONDAY GROUP. NOTES TAKEN WHEN OBSERVING THE VIDEO TAPE. EXAMPLE OF TRANSCRIPT. CODING OF THE TRANSCRIPT INSPIRED BY A THEMATIC ANALYSIS

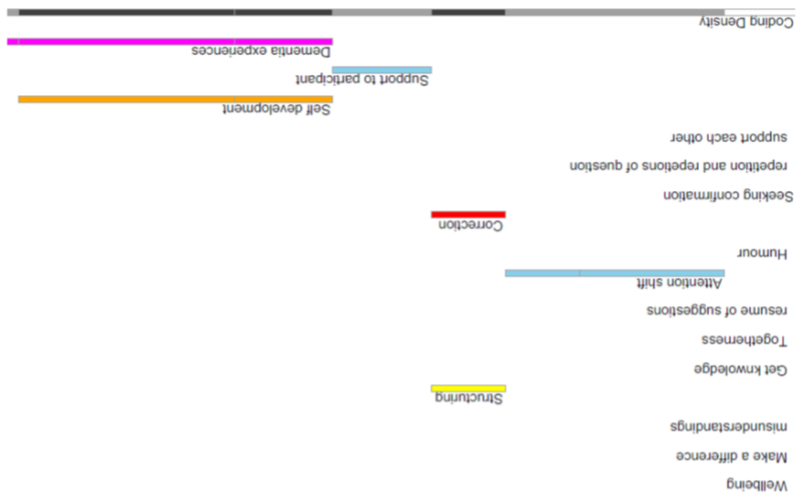


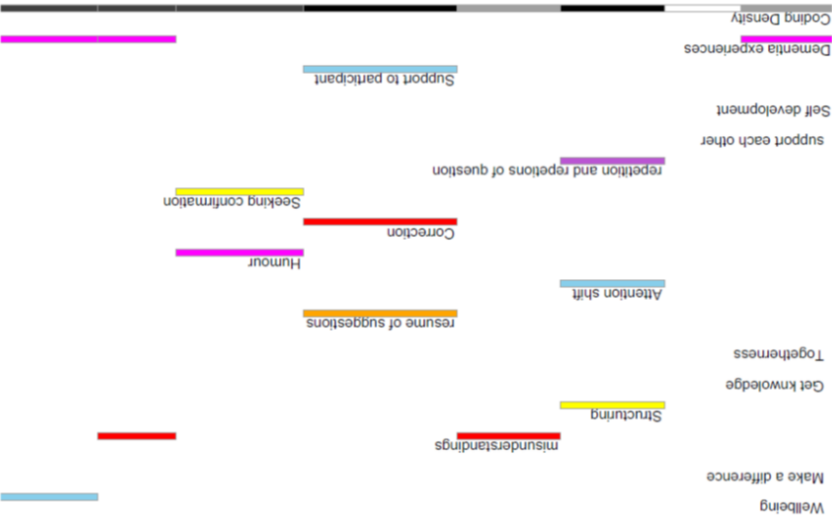
	Timespan	Content
1	27:07,9 - 28:18,1	We talk about having prior experiences with project work but the participants do not have that and we talk about that we then can decide how we want to do it. (I write on a post-it that the participants have not participated in a project before). I then ask why they want to participate in the project work.
		I: Jeg vil også gerne have lov til at spørge jer for I har været så søde alle sammen og sige at I gerne vil deltage (sætter mig da jeg stiller spørgsmålet)
2	28:18,1 - 28:19,2	Bent: Kan du sige det højt? (smiler)
3	28:19,2 - 28:27,6	I: I har været så søde alle sammen og sige at I gerne vil deltage, så jeg kunne godt tænke mig (smiler). ¹ Kunne I sætte ord på hvorfor I gerne vil deltage? (smiler)
4	28:27,6 - 28:34,3	Bent: Vi sy... jeg for mit vedkommende synes jeg at det kun er godt at man finder ud af noget
5	28:34,2 - 28:37,9	I: Ja så det er godt at man finder ud af noget mere (jeg er ved at rejse mig for at gå op og skrive på tavlen)
6	28:37,6 - 28:46,6	Bent: Ja ja Emma: Man vil vel sådan noget fordi man tror man kan bruge det til noget der kan gøre gavn og glæde og selv udvikle en selv noget mere I: (skriver på post-it)
7	28:46,6 - 29:04,6	I: Af noget og gavne ikke også? Emma: Ja I: Og gavne og hjælpe. Ja. Så det er faktisk fordi I rigtig gerne vil have at der kommer noget ud af det. Ja Elisa (har front mod deltagerne. Elisa rækker fingeren op)
8	29:04,5 - 29:20,8	Elisa: Jeg synes jo også når man jo deltager i det her projekt ikke. Så synes jeg også at det er. Så synes jeg også at det er meget vigtigt at vi hele tiden får indblik i det for det er jo en rigtig grim sygdom så...
		I: Ja ja (drejer sig mod tavlen igen for at skrive)
9	29:20,8 - 29:24,5	I: Så jeg må også godt skrive indblik her også? Elisa: Ja
10	29:24,5 - 29:47,8	I: Indblik i sygdommen (skriver). Ja det er nogle rigtig gode bud (front mod deltagerne) Er der noget mere der skal op eller er I enige? (gruppen sidder stille men modsætter sig ikke). I er enige?



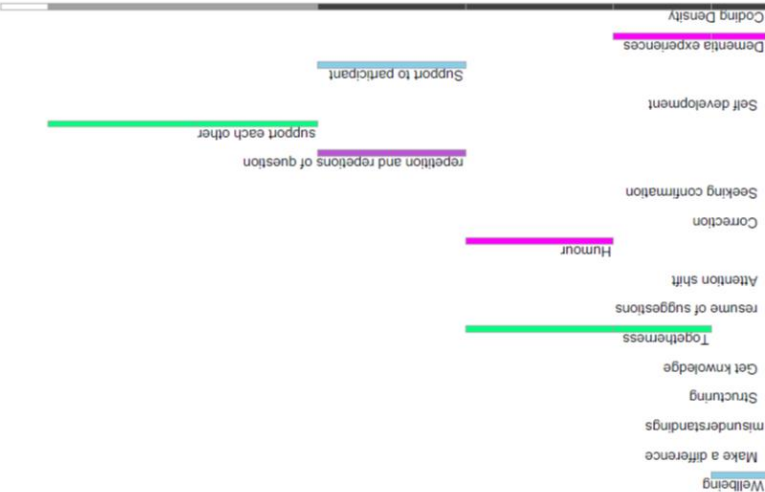
11	29:47,8 - 29:55,3	Peter: Ja I: Dejligt. Kan I læse det heroppe? Er det ok at sætte det op på denne måde? (Jeg peger mod tavlen og alle kigger op på den) Peter: Ja ja Bente: Ja
12	29:55,3 - 30:03,2	Peter: Har du været derovre? (peger på billede af UoN) I: Ja det har jeg Peter: Det har jeg også (lille grin) I: Dejligt sted Peter: Ja det var det I: Det er det
13	30:03,1 - 30:09,1	Ernst: Hvor fanden er det henne du taler om? (pladrer i parpirerne og kigger mod Peter) I: I England Ernst: Nå ja ja
14	30:09,1 - 30:15,7	I: Hvad skal vi have ud af vores projekt? Ernst: Du har da ikke været på det der universitet (læner sig over mod Peter og hans billede af UoN) Peter: Nej det har jeg da heller ikke sagt noget om
15	30:15,7 - 30:24,4	I: Han har været i England Peter: Det har jeg været mange gange til dans Ernst: Til dans I: Til dans ja
16	30:24,3 - 30:39,8	Emma: Det må være at få koog ikke føle sig sat til side med en demens men føle at man kan begynde at det kan jeg godt alltså og det kan jeg bringe til noget (Peter forsøger fortsat at få min opmærksomhed og formulere noget verbalt. Sidder med parpirerne i hænderne. Har en voldsom grimaseret). (Jeg fokuserer min opmærksomhed på Emma men de sidder ved siden af hunden)
17	30:39,8 - 31:07,3	I: Så det her det... Emma: Man man kommer med på holdet på en måde I: Komme med komme med på holdet. Skal vi skrive det? (begynder at skrive) Emma: Ja selv om man kan føle sig mere og mere udenfor fordi man ikke kunne samles op ellers I: Komme med Emma: Ja det er sådan jeg tro

APPENDIX I. EXAMPLE OF FIELD NOTES FROM THE MONDAY GROUP. NOTES TAKEN WHEN OBSERVING THE VIDEO TAPE. EXAMPLE OF TRANSCRIPT. CODING OF THE TRANSCRIPT INSPIRED BY A THEMATIC ANALYSIS





		Bent: Nej (smiler)
25	32:32,0 - 32:36,4	Elsa: Jamen det er jo også vores egen identitet ik? Ja E: Ja Elsa: Ja det må jo os være det der gælder ikke, for vi er alle sammen interesseret i at få det bedre, så godt som vi nu kan ik... det går jeg ud fra Emma: [taler med men kan ikke høre hvad hun siger] E: Ja ja skal vi ikke også skrive det op at få det så godt som vi kan (rejser sig for at gå op og skrive) Emma: Fællesskab kan ofte få noget godt op at stå os fordi vi kan beholde lidt forståelsen i hvorfor hvad det er for at vi gør de ting og hvorfor tror vi på det og hvorfor vi vil gerne [...] E: Ja ja Elsa: Ja
26	32:53,4 - 33:05,9	E: Så jeg hører jer tale om fællesskab og få det så godt som muligt Emma: Ja fællesskabet er iverftald meget værd Bent: Og det at vi tror på vor herre (humor i stemmen) Emma: Hvad for noget? Bent: Og det er fordi vi tror på vore herre er det ikke noget med ham at gøre? Emma: Det må du selv om (griner sammen med Bent)
27	33:05,8 - 33:17,8	E: Godt ja, Vilhelm er du også enig i tingene som står heroppe? (jeg sætter mig) Vilhelm: Jeg tror ikke at jeg kan følge med E: Nej med det er fint nok men vi tager det stille og roligt men der er ikke noget du er uenig i det der er blevet sagt Vilhelm? Vilhelm: Nej E: Nej ok. Godt (jeg rejser mig)
28	33:17,8 - 33:37,8	Elsa: Det kan vi alle sammen få få fællesskabet til at fungere ikke også jo. (klapper Vilhelm på armen) Vilhelm: Jo Emma: Vi hjælper hinanden fortsat. Vi er her alle sammen nu og vi hjælper hinanden videre. Vilhelm: Ja Ernst taler med Hølen
29	33:37,8 - 33:50,1	E: Skal vi ikke også skrive det op at vi hjælper hinanden. (Har rejst sig og begynder at skrive) Emma: Ja jo det synes jeg er væsentligt. Og så giver vi os til at tid til at høre på dem som er lidt i tvil om hvad det her nu er for noget og så noget og få snakket om det og så noget. Det vil hjælpe meget.
30	33:50,1 - 34:12,5	



		Peter: Ja det gør det E: Ja godt. Vi hjælper hinanden. Emma: Ja lige præcis
31	34:12,5 - 34:12,6	E: Ja godt og så sagde I ud (skriver) Emma: Ja E: usind tak...

Annotations		
	Timespan	Content
1		I follow his joke and do what he asks me to do. I talk louder and repeat what I have said.

Wellbeing
Make a difference
misunderstandings
Structuring
Get knowledge
Togetherness
resume of suggestions
Attention shift
Humour
Correction
Seeking confirmation
repetition and repetitions of question
support each other
Self development
Support to participant
Dementia experiences
Coding Density

Appendix J. **The MMSE-test**

MINI MENTAL STATE EXAMINATION (MMSE)

Name:

DOB:

Hospital Number:

One point for each answer

DATE:

ORIENTATION

Year Season Month Date Time

Country Town District Hospital Ward/Floor

...../ 5

...../ 5

...../ 5

...../ 5

...../ 5

...../ 5

REGISTRATION

Examiner names three objects (e.g. apple, table, penny) and asks the patient to repeat (1 point for each correct. THEN the patient learns the 3 names repeating until correct).

...../ 3

...../ 3

...../ 3

ATTENTION AND CALCULATION

Subtract 7 from 100, then repeat from result. Continue five times: 100, 93, 86, 79, 72. (Alternative: spell "WORLD" backwards: DLROW).

...../ 5

...../ 5

...../ 5

RECALL

Ask for the names of the three objects learned earlier.

...../ 3

...../ 3

...../ 3

LANGUAGE

Name two objects (e.g. pen, watch).

...../ 2

...../ 2

...../ 2

Repeat "No ifs, ands, or buts".

...../ 1

...../ 1

...../ 1

Give a three-stage command. Score 1 for each stage. (e.g. "Place index finger of right hand on your nose and then on your left ear").

...../ 3

...../ 3

...../ 3

Ask the patient to read and obey a written command on a piece of paper. The written instruction is: "Close your eyes".

...../ 1

...../ 1

...../ 1

Ask the patient to write a sentence. Score 1 if it is sensible and has a subject and a verb.

...../ 1

...../ 1

...../ 1

COPYING: Ask the patient to copy a pair of intersecting pentagons



...../ 1

...../ 1

...../ 1

TOTAL:

...../ 30

...../ 30

...../ 30

MMSE scoring

24-30: no cognitive impairment

18-23: mild cognitive impairment

0-17: severe cognitive impairment

**Appendix K. Initial Consent:
Participation. Renewed Consent:
Project work. Renewed consent:
Dissemination**

Initial Consent: Participation

	Yes	No
Have you been given the leaflet <i>Insight into life with early-stage dementia</i> ?	<input type="checkbox"/>	<input type="checkbox"/>
Is the project been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had the opportunity to ask questions about the project?	<input type="checkbox"/>	<input type="checkbox"/>
Do you know that it is voluntary to participate in the project?	<input type="checkbox"/>	<input type="checkbox"/>
Do you know it does not influence your attendance at the school if you do not want to participate in the project?	<input type="checkbox"/>	<input type="checkbox"/>
Do you know that your anonymity and confidentiality is protected throughout the project?	<input type="checkbox"/>	<input type="checkbox"/>
Do you know you are going to be video recorded while we collaborate in the project?	<input type="checkbox"/>	<input type="checkbox"/>
Is it acceptable to you that the knowledge gained in the project is written about in professional journals and in the PhD thesis?	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can withdraw from the project at any time without having to explain why?	<input type="checkbox"/>	<input type="checkbox"/>

	Yes	No
May the information collected be used in the project even you cannot or do not wish to participate in the whole project?	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if I during the project discover something unethical, illegal or harmful Diana Thoft is obligated to report it?	<input type="checkbox"/>	<input type="checkbox"/>

Based on my answers to the questions above, I hereby give my informed consent (my yes) to participate in the project

Name.....

Date.....

Signature.....



As the person in charge of the project, I say thank you, because you have gone through the consent with me and any observer. You have the right not to sign the consent if you do not want to participate in the project. The project is voluntary to participate in.

Kind regards

Diana Thoft

Tlf. 72 69 10 56

(Own translation)

Renewed Consent: Project work

	Yes	No
Have you gone through your initial consent?	<input type="checkbox"/>	<input type="checkbox"/>
Do you still wish to participate in the project with your initial consent?	<input type="checkbox"/>	<input type="checkbox"/>
Do you know you will receive training in how to conduct a project?	<input type="checkbox"/>	<input type="checkbox"/>
Do you want to conduct a shared project with selected students and Diana?	<input type="checkbox"/>	<input type="checkbox"/>

Based on my answers to the questions above, I hereby give my informed consent (my yes) to participate in the project

Name.....

Date.....

Signature.....



As the person in charge of the project, I say thank you, because you have gone through the consent with me and any observer. You have the right not to sign the consent, if you do not want to participate in the project. The project is voluntary to participate in.

Kind regards

Diana Thoft

Tlf. 72 69 10 56 (Own translation)

Renewed consent: Dissemination

	Yes	No
Have you gone through your initial informed consent?	<input type="checkbox"/>	<input type="checkbox"/>
Do you still wish to participate in the project with your initial consent?	<input type="checkbox"/>	<input type="checkbox"/>
If possible do you want to disseminate the results of the shared project in a newspaper article with name and eventual picture?	<input type="checkbox"/>	<input type="checkbox"/>
Do you give permission that Diana may show video clips and pictures of the project work at conferences and in articles where your face is blurred so you cannot be recognised?	<input type="checkbox"/>	<input type="checkbox"/>
Do you want to participate in a focus group evaluation, with the group you have been a part of in the project, about your experiences of conducting a shared project with Diana?	<input type="checkbox"/>	<input type="checkbox"/>

Based on my answers to the questions above, I hereby give my informed consent (my yes) to participate in the project

Name.....

Date.....

Signature.....

Appendix L. Pictures from the process of the training and participatory research project

Phase 3: Introduction to project and establishment of the project groups
Monday group



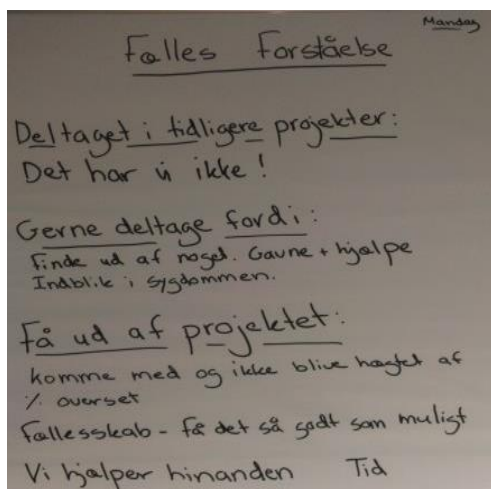
Title of the folder: Insight into the life with an early-stage dementia

Plan for undervisning og projektarbejde

Sessions nr.	Dato	Indhold	Form	Udført
1	15.-16. februar 2015	Red samtykke. Introduktion til projektet. Projektarbejde med forberedelse af roller og øvelser.	Introduktion og øvelser og øvelser	
2	2-3. marts 2015	Hvad er et projekt og et projektsammenhæng? Formulering af et projektsammenhæng.	Præsentation og øvelser	
3	9-10. marts 2015	Ende deltagere og metoder til at indsamle og analysere fund.	Præsentation og øvelser	
4	16-17. marts 2015	De vigtigste metoder og bruge metoderne i projektet.	Øvelser og projektarbejde	
5	23-24. marts 2015	Lave projekt.	Projektarbejde	
6	27-28. april 2015	Lave projekt.	Projektarbejde	
7	4-5. maj 2015	Lave projekt.	Projektarbejde	
8	18-19. maj 2015	Præsentation af resultaterne.	Præsentation	
9	2-3. juni 2015	Præsentation af resultater.	Projektarbejde	
10	8-9. juni 2015	Præsentation af resultater.	Projektarbejde	
11	15-16. juni 2015	Evaluering af hele projektet.	Gruppe interview	

Der er et mandags- og et tirsdagshold (derfor to deltagere). Diana Schack Thoft har i samarbejde med VUK denne holdene. Man deltagere kun på et af holdene og arbejder kun med projektet, når man normalt er på VUK (enten mandag eller tirsdag). Der er ingen hjemmearbejde eller yderligere behov for at komme på VUK for at deltage i projektet.

Plan for the training and project work. Each session is described in Chapter 7



Agreed understanding:

Participated in other projects:

We have not

Like to participate because:

Find out of something. Benefit and help

Insight into the illness

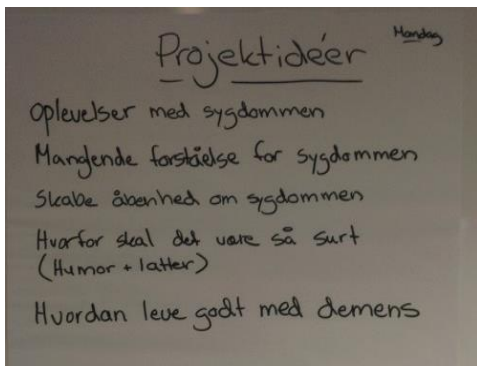
Get out of the project:

Come with and not be left behind

Not overlooked

Community – have it as good as possible

We help each other. Time



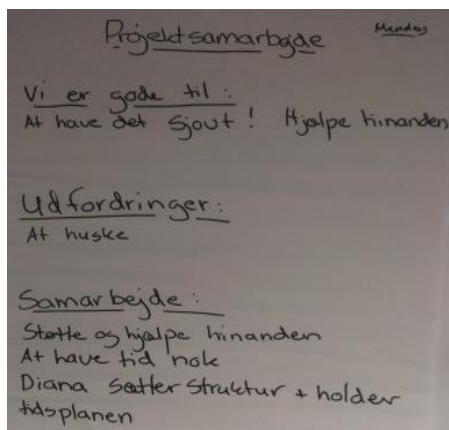
Project ideas:

Experiences with the illness

Missing understanding of the illness

Why does it have to be so negative? (humour and laughter)

How to live well with dementia



Project collaboration:

We are good at:

To have fun

To help each other

Challenges:

To remember

Collaboration:

Support and help each other

To have time enough

Diana sets the structure and keeps the time plan

Tuesday group



Title of the folder: Insight into the life with an early-stage dementia

Plan for undervisning og projektarbejde				
Sessions nr.	Dato	Indhold	Form	Udført
1	23-24. Februar 2015	Nyt samtykke, introduktion til projektet. Projektarbejde med forberedelse af noter og ansøjer	Introduktion og drøftelser og øvelser	
2	2-3. Marts 2015	Prædér et projekt og et projektopgørelse. Formulering af et projektopgørelse	Præsentation og øvelser	
3	9-10. Marts 2015	Fælles deltagere og metoder til at indsamle og analysere fund	Præsentation og øvelser	
4	16-17. Marts 2015	Øve nogle metoder og bruge metoderne i projektet	Øvelser og projektarbejde	
5	23-24. Marts 2015	Lave projekt	Projektarbejde	
6	27-28. April 2015	Lave projekt	Projektarbejde	
7	4-5. Maj 2015	Lave projekt	Projektarbejde	
8	18-19. Maj 2015	Præsentation af resultaterne	Præsentation	
9	1-2. Juni 2015	Præsentation af resultater	Projektarbejde	
10	8-9. Juni 2015	Præsentation af resultater	Projektarbejde	
11	15-16. Juni 2015	Evaluering af hele projektet	Gruppe interview	

Der er et mandags- og et tirsdagshold (derfor to deltagere). Diane Schack Thoft har i samarbejde med VUK dannet holdene. Man deltager kun på et af holdene og arbejder kun med projektet, når man normalt er på VUK (enten mandag eller tirsdag). Der er ingen hjemmearbejde eller yderligere behov for at komme på VUK for at deltage i projektet.

Plan for the training and project work. Each session is described in Chapter 7

Fælles forståelse Torsdag

Deltager i tidligere projekter:
Ney - vi kan derfor bestemme hvordan vi gør.

Gerne deltage fordi:
Interessant + hvor langt en man + ikke kan huske - give denne viden videre.
Drages til andre grupper - vi er mange og der bliver flere
Metoder + engagement + træning

Få ud af projektet:
God frokost + resultater i det videre arbejde (Nationalt + internationalt)
Resultater der kan bruges på sigt

Agreed understanding:

Participated in other projects:

No we can therefore decide how we do it

Like to participate because:

Interesting and how far are you + cannot remember – give this knowledge to others

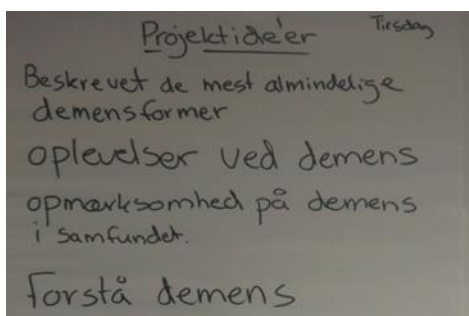
Use for other groups – we are many and more will come

Methods, engagement and training

Get out of the project:

A good lunch + results in the further work (national and international)

Results that can be used in the future



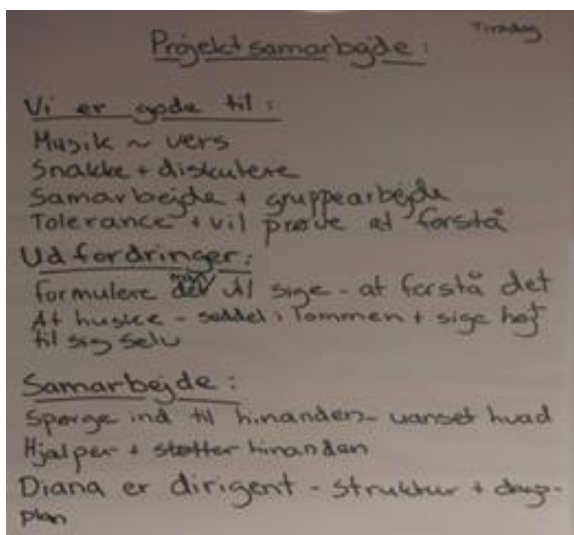
Project ideas:

Described the most common dementia types

Experiences with dementia

Awareness about dementia in society

Understand dementia



Project collaboration:

We are good at:

Music – verse

To talk and discuss

Collaborate and groupwork

Tolerance + try to understand

Challenges:

Formulate what you want to say – to understand it

To remember – a note in the pocket + say it aloud to yourself

Collaboration:

Ask about each other – no matter what

Help and support each other

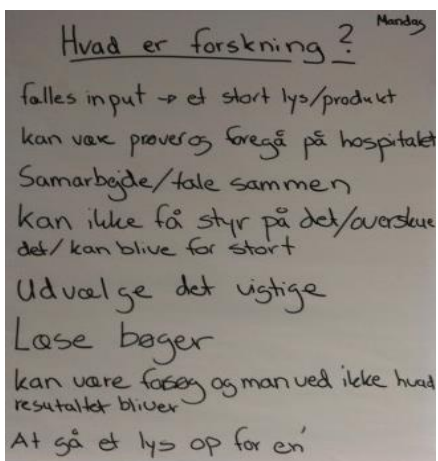
Diana is the conductor – structure + daily plan

Phase 3.1: The research question

Monday group



Pictures and drawings used for discussing what research is



What is research:

Common input – a big light/product

It can be samples and placed in a hospital

Collaboration/talk together

Can't get control of it/overview it/ it can be too big

Chose the most important things

Read books

Can be samples and you do not know what the result will be

Get an idea



The possible research topics:

Describe the most common dementia types

Tell about the experiences/problems you can have with dementia

To raise awareness and understanding of what dementia is

Why does it have to be so negative to live with dementia? The humour and the positive attitude's meaning

Tell about how you can live well with dementia. To stay active and be social

Tell about the experience of attending VUK

Tell about the changes of roles that can happen in a family when you get dementia

Tell about the losses you can experience in life with dementia

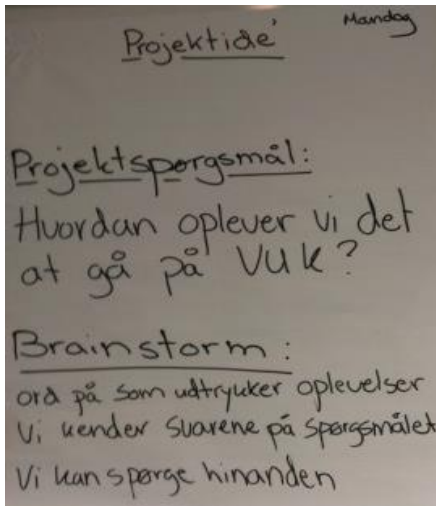
Ways to remember and learn in life with dementia

Practical advice when being together with and talking with a person with dementia



Chosen research topic:

Tell about the experience about attending VUK



Projectidea:

Project question:

How do we experience to attend VUK?

Brainstorm:

Words that express experiences

We know the answers to the question

We can ask each other

Tuesday group



Pictures and drawings used for discussing what research is

Tirsdag
Hvad er forskning?
 Skrive^{af} efter flere bøger / bruge bøgerne
 Øve sig + blandingsforsøg
 Finde svar på spørgsmål
 At finde svar (ikke alle kan)
 Mange ide'er kan blive løsningen
 Vælge den rigtige løsning/
 Samarbejde / snakke sammen
 Grundforskning (Biokemi)

What is research?

Writing after books/ use books

Practice + mixed experiences

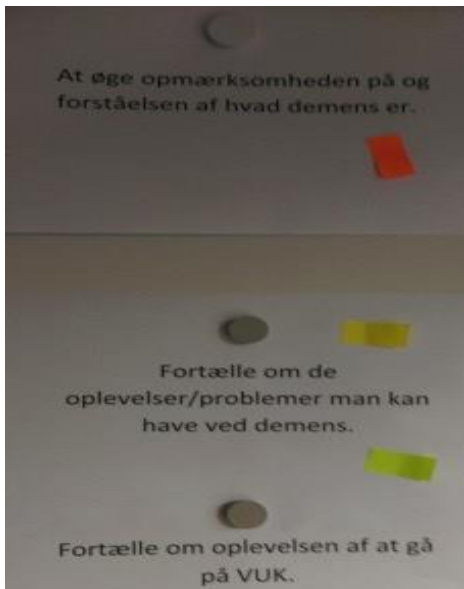
Find answers to questions

To find answers (not all can)

Many ideas can become the solution

Choose the right solution/ Collaboration/ talk together

Basic research (biochemistry)

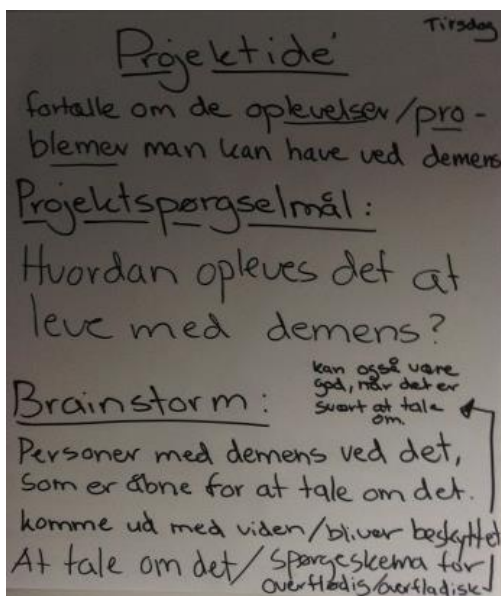


Project ideas the group voted for:

To raise awareness and understanding of what dementia is

Tell about the experiences/problems you can have with dementia

Tell about the experience of attending VUK



Project idea:

Tell about the experiences/problems you can have with dementia

Project question:

How is it experienced to live with dementia?

Brainstorm:

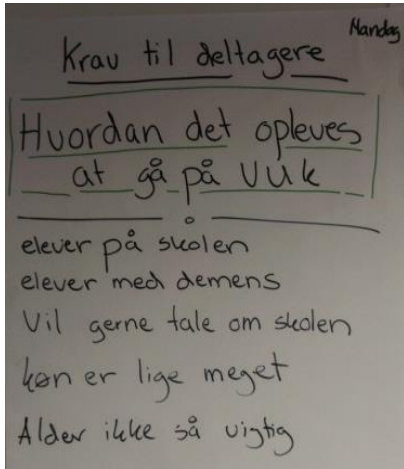
Persons with dementia know it

Who are open about talking about it

To talk about it/ questionnaire too redundant/superficially – can also be useful when something is difficult to talk about

Phase 3.2: The data collection methods

Monday group



Requirements for participants:

How it is experienced to attend VUK

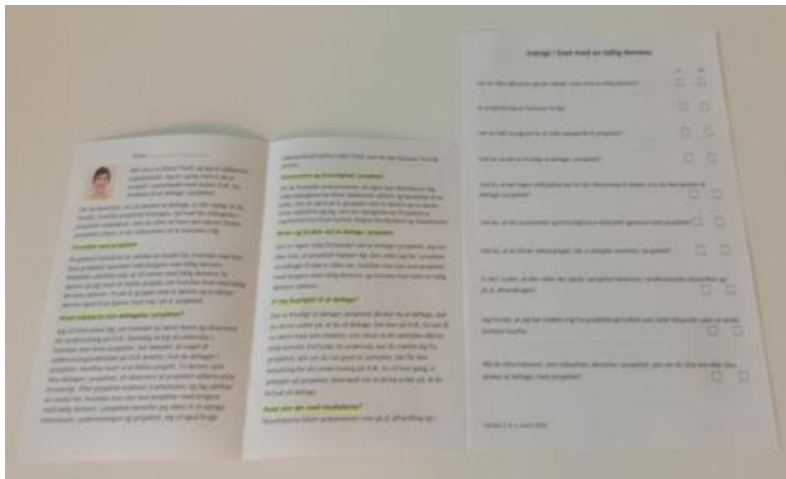
Students at the school

Students with dementia

Will like to talk about the school

Sex does not matter

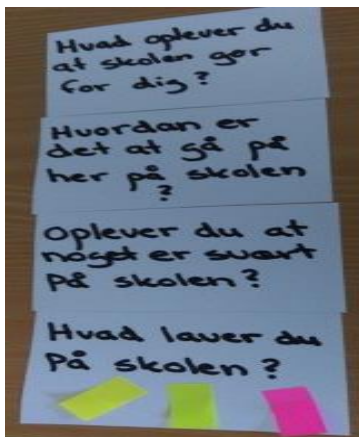
Age is not so important



Information leaflet and consent form from the PhD project for discussing research ethics. See appendix G and K for translation



The different data collection methods introduced to the student participants: Story with a gap, interview with question cards, storytelling with pictures and diary



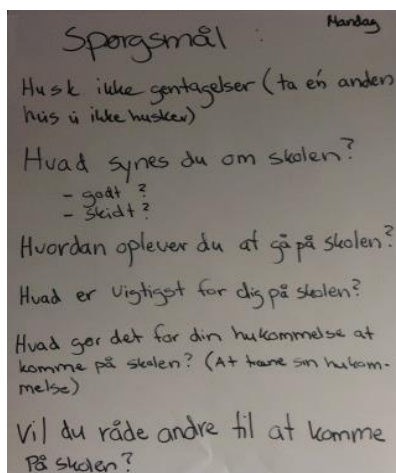
The chosen method: Interview with examples of question cards

What do you experience the school does for you?

How is it to attend the school?

Do you experience anything difficult at the school?

What do you do at the school?



Questions:

Remember no repetition (take another one if we cannot remember)

What do you think about the school? Good? Bad?

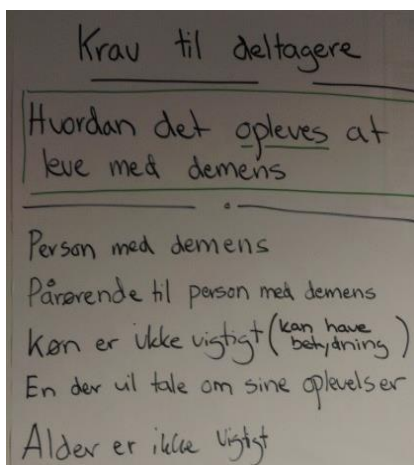
How do you experience to attend the school?

What is most important for you at the school?

What does it do for your memory to attend the school? (to train the memory)

Would you advice others to attend the school?

Tuesday group



Requirements for the participants:

How is it experienced to live with dementia?

Person with dementia

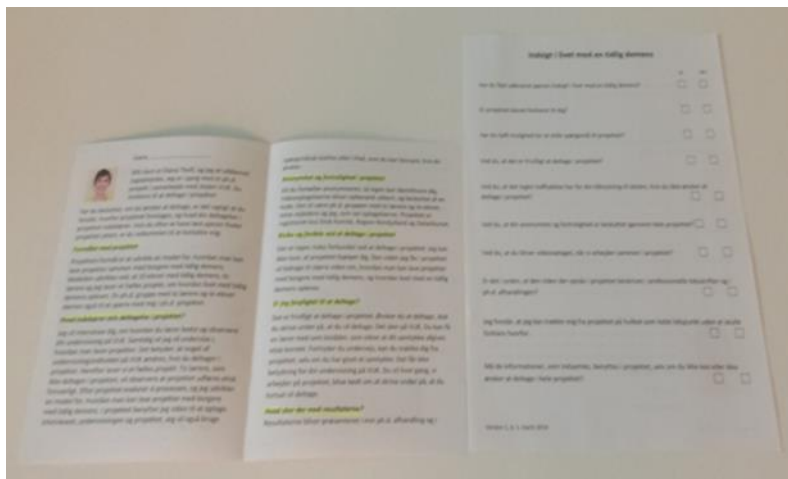
Relatives to a person with dementia

Sex is not important (can have an impact)

One who will talk about ones experiences

Age is not important

INVOLVING PEOPLE WITH EARLY-STAGE DEMENTIA IN QUALITATIVE RESEARCH ABOUT THEIR LIFEWORLD
PERSPECTIVES: DEVELOPMENT OF A PARTICIPATORY RESEARCH MODEL



Information leaflet and consent form from the PhD project to discuss research ethics. See appendix G and K for translation



The different data collection methods introduced to the student participants: Story with a gap, interview with question cards, storytelling with pictures and diary



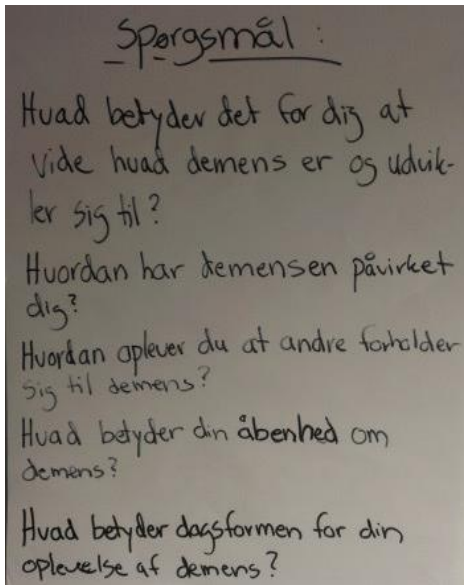
The chosen method: Interview with examples of question cards

Is there something that has changed for you after you got dementia?

How do you experience to live with dementia?

What is important for you now?

What does the dementia means for you?



Questions:

What does it mean for you to know what dementia is and develops to?

How has the dementia affected you?

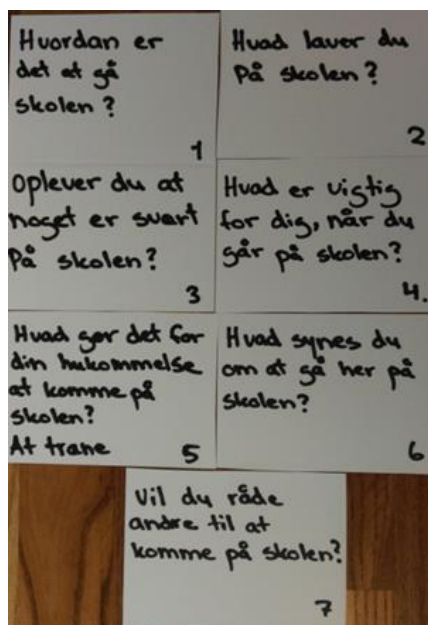
How do you experience others relate to the dementia?

What does your openness about the dementia mean?

What does the form of today means for your experience of dementia?

Phase 3.3: The data collection

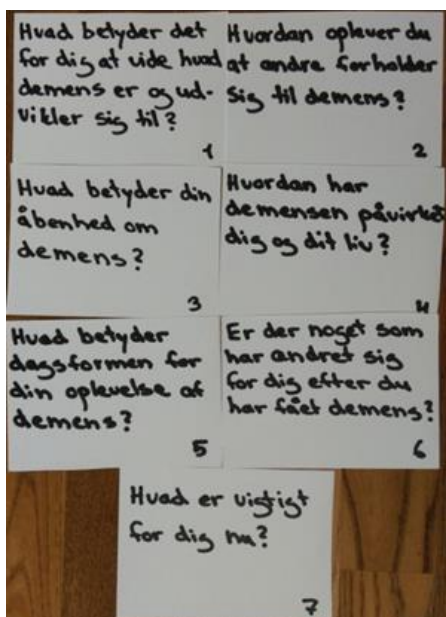
Monday group



Interview question cards:

1. How is it to attend the school?
2. What do you do at the school?
3. Do you experience anything difficult at the school?
4. What is important for you when you attend the school?
5. What does it do for your memory to attend the school? To train?
6. What do you think about attending the school?
7. Would you advice others to attend the school?

Tuesday group



Interview question cards:

1. What do it means for you to know about dementia and what it develops to?
2. How do you experience others relate to the dementia?
3. What does your openness about dementia mean?
4. How has the dementia affected you and your life?
5. What does the form of today mean for your experience of dementia?
6. Has something changed for you after you got the dementia?
7. What is important for you now?

Phase 3.4: The participatory analysis

Monday group



Data analysis:

Do like to attend the school

Positive to attend the school

Training is what it is about

Wait for the day you have to go

Get away from home and talk with someone

Camaraderie

Do not isolate at home

Do not stay at home in the same grind

Learn other people to know

To get some tools

Helps the memory

Good knowledge

Always looks forward to attend

Attend the woodcraft workshop – cutting board, rolling pin, knives

Creative

To get out among other people

Nice employees

Attend music

Things that expand your horizon

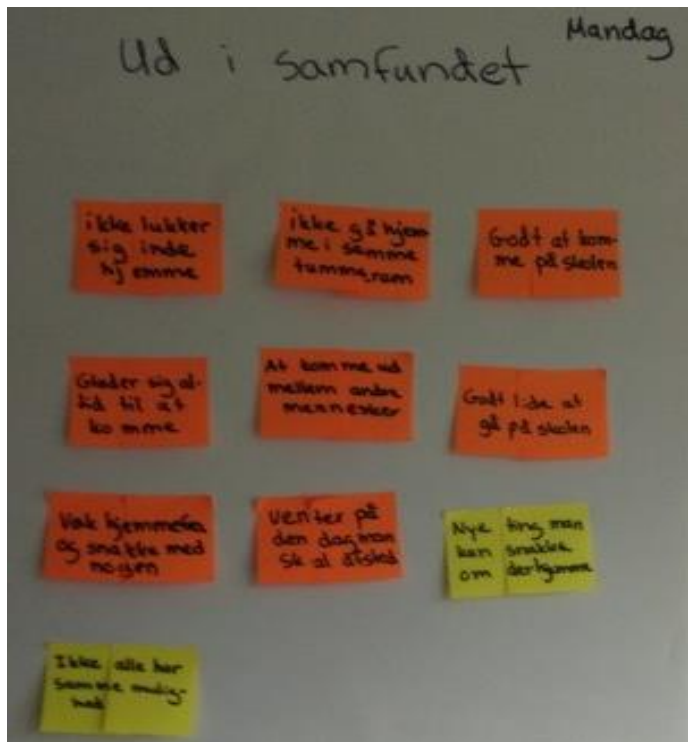
Nice people

Nothing difficult

Sing and laugh

To get a grip about things

To look at oneself to see that it works



A theme from the data analysis with the headline: To get out in society

Do not isolate at home

Do not stay at home in the same grind

Positive to attend the school

Always looks forward to attend

To get out among other people

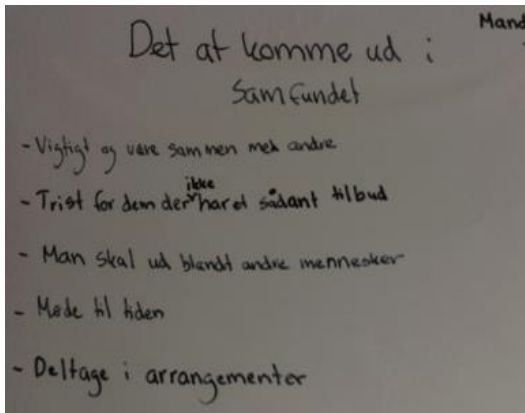
Do like to attend the school

Get away from home and talk with someone

Wait for the day you have to go

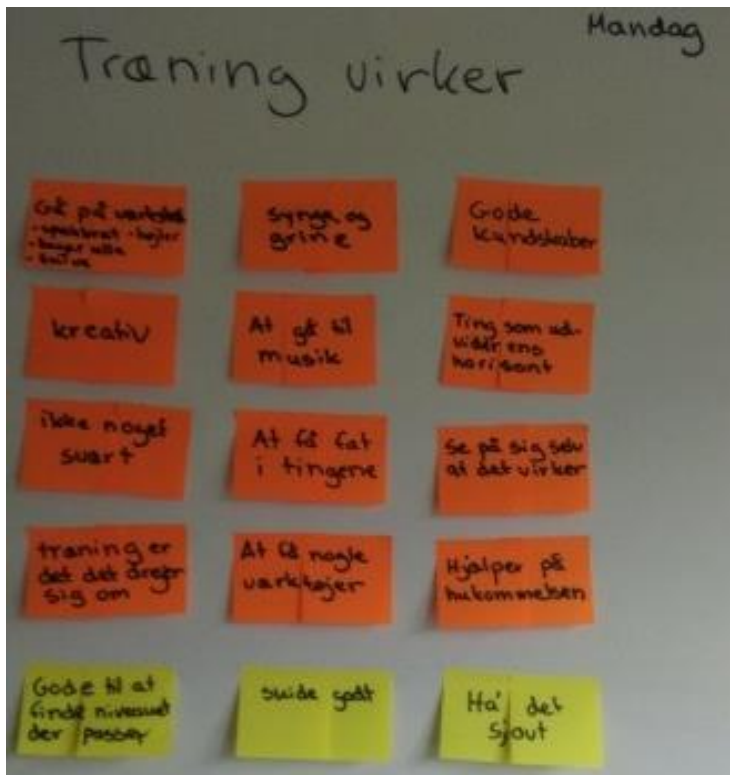
New things that you can talk about at home

Not all have the same opportunity



Interpretation of the theme: To get out in society

- Important and be together with others
- Sad for those who do not have the same service
- You have to get out between people
- Meet on time
- Participate in social arrangements



A theme from the data analysis with the headline: Training that works

Attend the woodcraft workshop – cutting board, rolling pin, knives.

Do like to attend the school

Sing and laugh

Good knowledge

Creative

Attend music

Things that expand your horizon

Nothing difficult

To get a grip about things

To look at oneself to see that it works

Training is what it is about

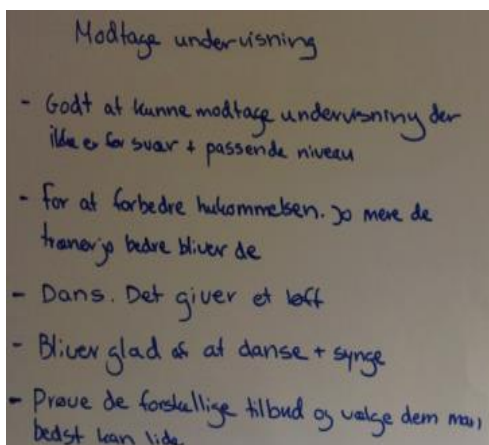
To get some tools

Helps the memory

Good to find the level that fits

Very good

To have fun



Interpretation of the theme: Training that works

- Good to receive teaching that is not too difficult + fits the level
- To improve the memory. The more they train the more better they become
- Dancing. It gives a boost
- Become happy by dancing and singing
- Try the different services and chose them you like the best



A theme from the data analysis with the headline: A positive camaraderie

Camarades that you can talk with

Nice people

Learn other people to know

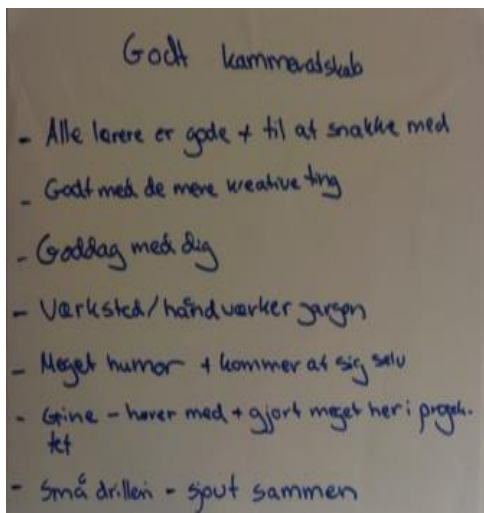
Very good

Camaraderie

Nice employees

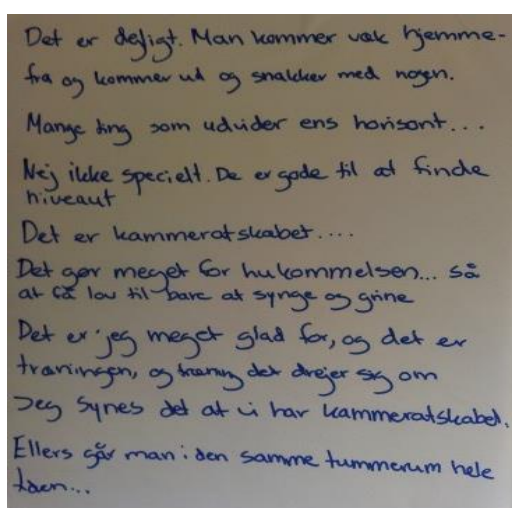
To have fun

We can say what ever we want



Interpretation of the theme: A positive camaraderie

- All teachers are nice and easy to talk with
- Positive with the more creative things
- Hello with you
- Woodcraft workshop/Woodcraft humour
- Much humour + comes by itself
- Laugh – is a part of it + done much in the project
- Tease – have fun together



Quotes chosen for the identified themes:

- It is nice. You get away from home and get out and talk with someone
- Many things that broadening your horison
- No not espesically. They are good in finding the niveau
- It is the camaraderie
- It does a lot for the memory... then to be aloud to just sing and laugh
- This I am very happy about and it is training and training it is about
- I think it is that we have the camaraderie
- Otherwise you stay in the same grind all the time

Tuesday group



The beginning of the data analysis:

I am positive about the dementia

To talk helps

The present is important

The Alzheimer's is in front of me and it bothers me

Aggressive

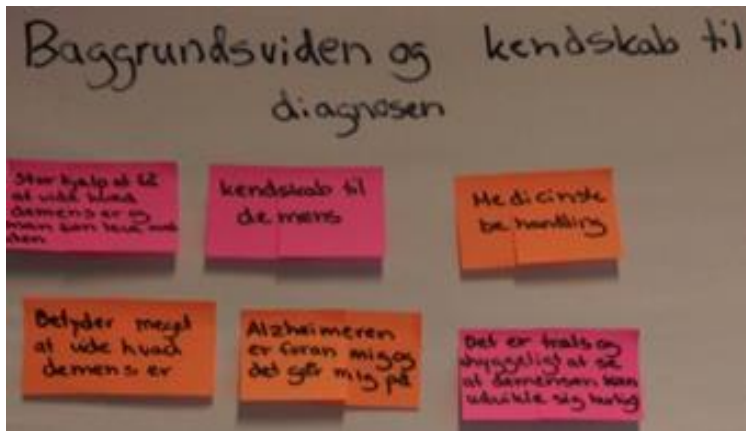
I am feeling better now and is not nervous

The short-term memory is affected

I need to get as much out of it as possible

Happy about it is progressing slowly

Means a lot to know what dementia is



A theme from the data analysis with the headline: Background knowledge and knowledge about the diagnosis

Great help to be informed what dementia is and you can live with it

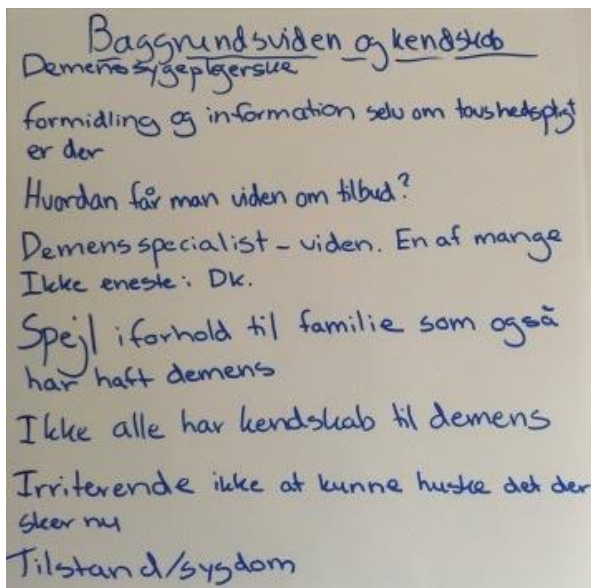
Knowledge about dementia

Medical treatment

Means much to know what dementia is

The Alzheimer is in front of me and it bothers me

It is negative and awful to see the dementia can progress quickly



Interpretation of the theme: Background knowledge and knowledge about the diagnosis

- Dementia nurse
- Communication and information even though the confidentiality is there
- How do you get knowledge about the services?
- Dementia specialist – knowledge. One of many. Not the only one in Denmark
- Mirror in relation to family who also have had dementia
- Not all have knowledge about dementia
- Irritating not to remember what is happening now
- Condition/disease



A theme from the data analysis with the headline: Consequences and impact of the dementia

Acknowledge that you can need help

Acknowledge that you have difficulties in remembering and this can be negative

It is negative with the short-term memory

I take it as it comes. I am happy and satisfied

Not able always to find what I need to use

Aggressive

Person names are difficult to remember

I need to get as much as possible out of it

The present is important

I feel better now and is not nervous

Happy that it progresses slowly

Take it easy and enjoy things

The family breaks a little

My experience with dementia has not been negative

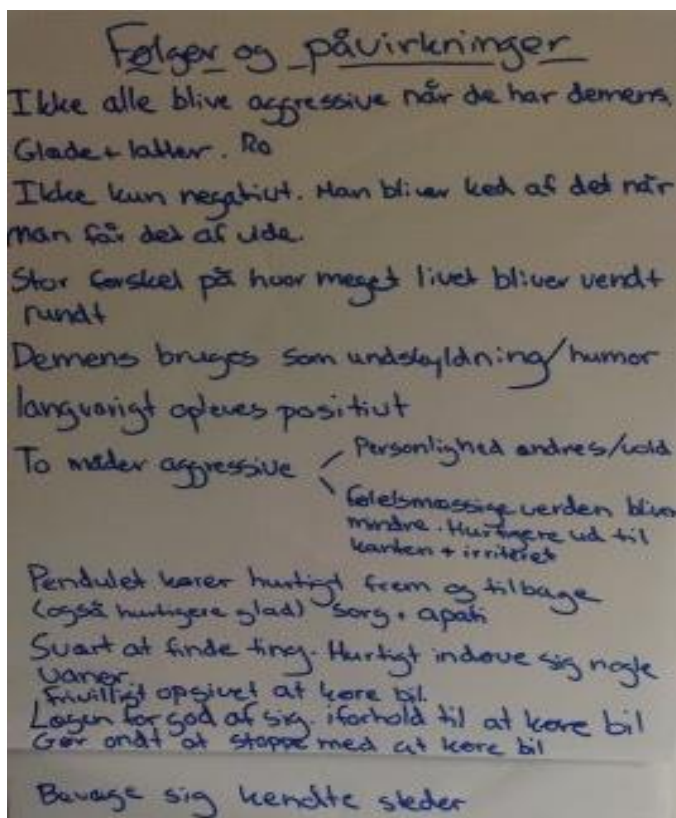
You have to be at the top but it is not possible all the time

Life has not stopped and is not broken

Different perceptions about dementia

I have it well with the dementia

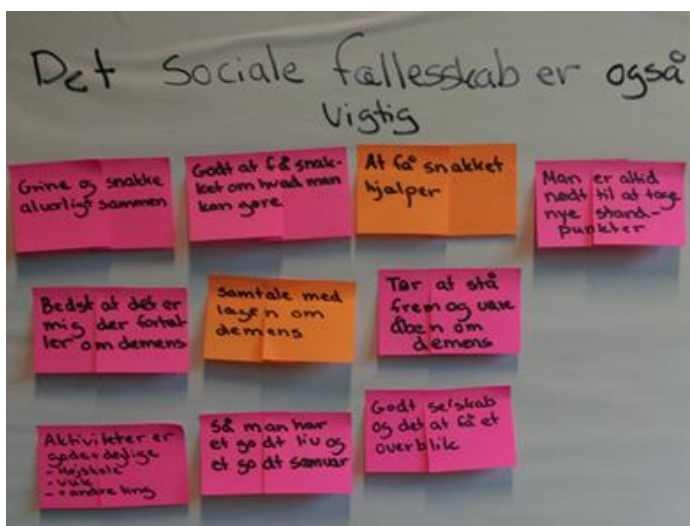
It is difficult to get into gear – insecurity in the traffic – no driving



Interpretation of the theme: Consequences and impact of the dementia

- Not all get aggressive when they have dementia
- Happiness and laughter. Peace
- Not only negative. You get sad when you get the information
- Big difference in how much life is turned around
- The dementia used as an excuse/humour
- Long term is experienced positive
- Two ways to be aggressive – the personality changes/violence – emotional world becomes smaller. Faster to the edge + irritated
- Pendulum fast forward and back (also faster happy) sadness and apathy

- Difficult to find thing – fast develop some habits
- Voluntarily given up driving
- The GP is too positive in relation to driving
- It hurts giving up driving
- Moves around in known areas



A theme from the data analysis with the headline: The social community is important

Laugh and talk seriously together

Nice to talk about what you can do

To talk helps

You always have to take new standpoints

It is best that it is me who is telling about dementia

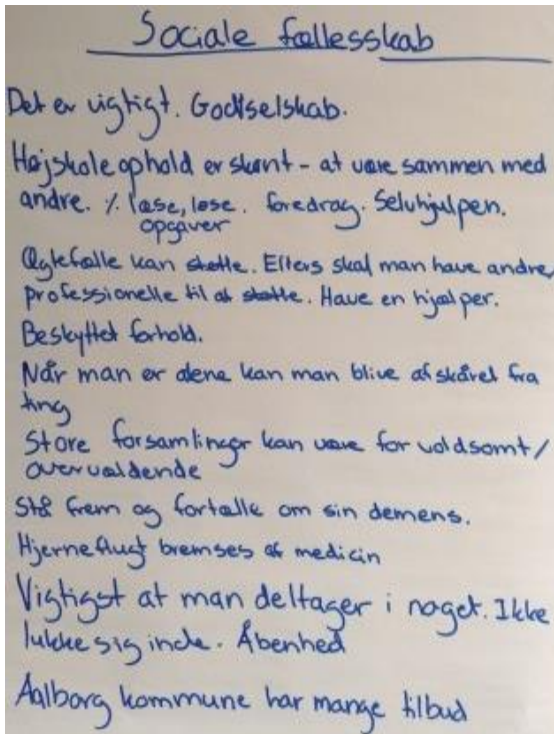
A talk with the GP

Dare to step forward and talk openly about dementia

Activities are good + nice – high school – VUK – Other things

So you have a good life and a good community

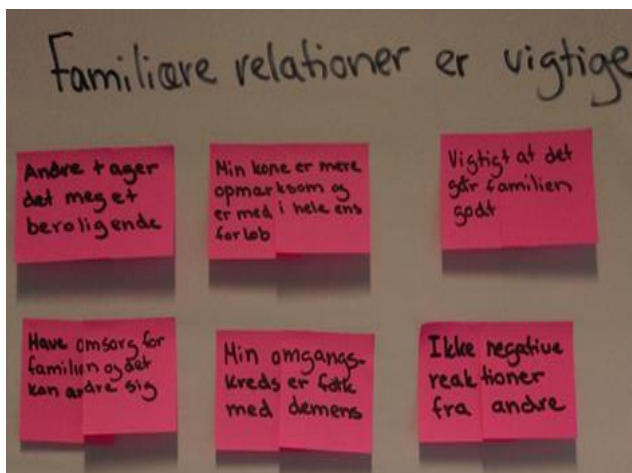
Good company and to get an overview



Interpretation of the theme: Social community is important

- It is important. Good company
- High school stay is lovely – to be together with others. % read, solve tasks. Lectures. Self-reliant
- Spouse can support. Otherwise you need others/professionals for support. To have a supporter.
- Protected conditions
- When you live alone you can be cut off things

- Big gatherings can be difficult/overwhelming
- Stand forward and tell about your dementia
- Brain drain slowed with medicine
- Most important to participate in something. Do not isolate. Openness
- Aalborg Municipality has many services



A theme from the data analysis with the headline: The family relations are still important

Others take it very calming

My wife has more attention and is with me in my process

Important that it goes the family well

To care for the family and it can change

My social circle is people with dementia

Not negative reactions from others

Familiære relationer Tirsdag

Oglefalle spørger til: Har du husket? skriver
meget ned eller fortæller det der skal huskes

Alfa og omega! Man kommer lettere igennem

Godt at omgangskredsen ved besked og forstår
hvorfor man kan sige noget urøvl.

Ingen negative reaktioner og det er rart
oplever ikke at omsorgen for familien har
ændret sig

Man kan også vælge fra, fordi man ikke kan
leve med familielivet. Og fordi man har brug for
ro. Svært at tage hensyn hele tiden.

Interpretation of the theme: Family relations are still important

Spouse asks often. Have you remembered? Writes much down or tell this has to be remembered

Alpha and omega! You get easier through

Nice that the social circle knows and understands why you can say something nonsense

No negative reactions and that is nice

Does not experience that the care for the family has changed

You can also deselect because you cannot live a family life. And because you need peace around you. Difficult to take into account all the time.

Citater Tirsdag

Det er ikke livets frygtligste ting...

Jeg vil hellere have ruet....

Jeg skal have så meget ud af det som muligt

Jeg har ikke mødt nogen, som har taget afstand...

Så vi som har denne sygdom har et godt liv...

Jeg bider tænderne lidt sammen, når det bliver svært...

Dem jeg kender, har jeg sagt det direkte til

Jamen for mig betyder det alt. Jeg snakker om det...

Jeg synes, det er bedre det er mig, der fortæller om det...

Både lægen og spl. har spurgt om hun må være med...

At jeg vil blive ved med at have omsorg for min familie

Det er åbenheden...

At tage det roligt og nyde tingene..

Det at komme her det er jeg glad for...

Livet er jo ikke holdt op. Livet er jo godt
Da den kan godt svinge noget...
Man skal sørge for at være på toppen...
Jeg tager det som det kommer
Jeg synes, at det har været en stor
hjælp at få af vide at jeg har det...
Det er ikke livet dør gåv i stykker, det
at lære at sige...
Det med at køre bil...
Der er nogle ting man må opgive
Som man ikke kan mere
Personerne har jeg meget svært ved at
huske

Jeg lever godt med det, og det skyldes også
at jeg er parat til at snakke om det
Det har vendt op og ned på det hele
Vi har demens og vi har erkendt
hvad vi ikke kan finde ud af...
Man skal sige det som det er, så tror
jeg man har større chance for at få
hjælp
Det med ikke at kunne huske det
er træls
Der er nogen ting du ikke kan mere
men så kan du nogle andre ting

Quotes chosen for the identified themes:

It is not the worst thing in life...

I prefer the presence...

I need to get the most out of it...

I have not met someone who has taken a distance...

So we who have this illness have a good life...

I clench the teeth together a bit when it gets hard...

Those I know I have said it directly to...

But for me it means everything. I talk about it...

I think it is better that it is me who tell about it...

Both doctor and nurse have asked if she could join...

That I stay on caring for my family...

It is the openness...

Take it easy and enjoy things...

To come here I am happy about...

Life has not stopped. Life is positive...

Yes it can swing some... you need to be at the top...

I take it as it comes...

I think it has been a great help to get knowledge about I have it...

It is not life that is broken, it is to learn to say...

About driving...

There are some things you have to give up which you can't any longer...

Person names I have very difficult in remembering...

I live well with it but it also depends on that I am ready to talk about it...

It has turned up and down on everything...

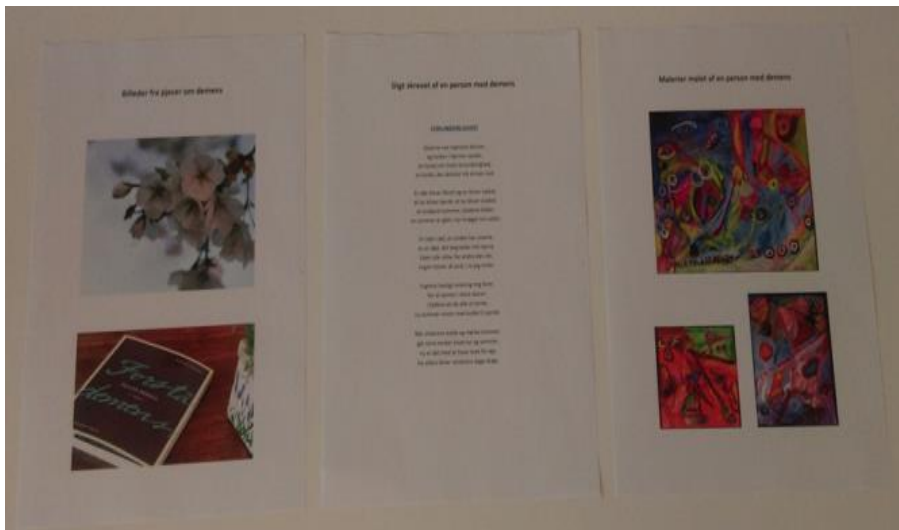
We have dementia and we have acknowledge what we can't do...

You have to say it as it is because I think then it is easier to get help...

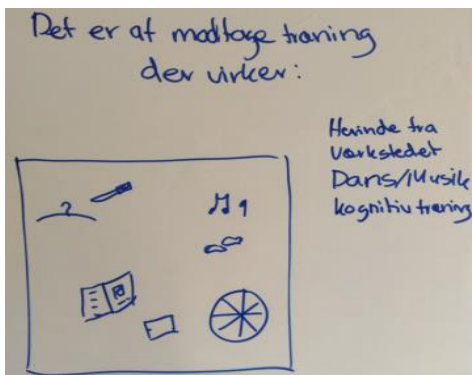
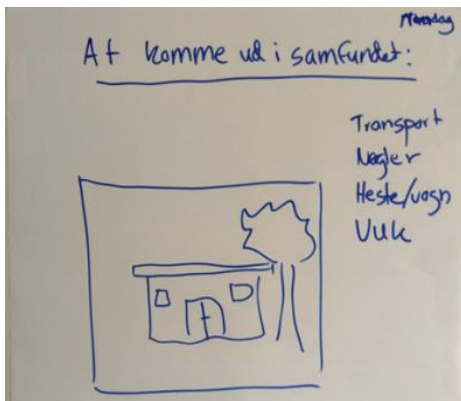
About not remembering is negative...

There are some things you cannot do any longer but then you can do some other things...

Phase 3.5: Plan the dissemination Monday group



Examples of creative methods to supplement the analysis: Pictures, poems and paintings



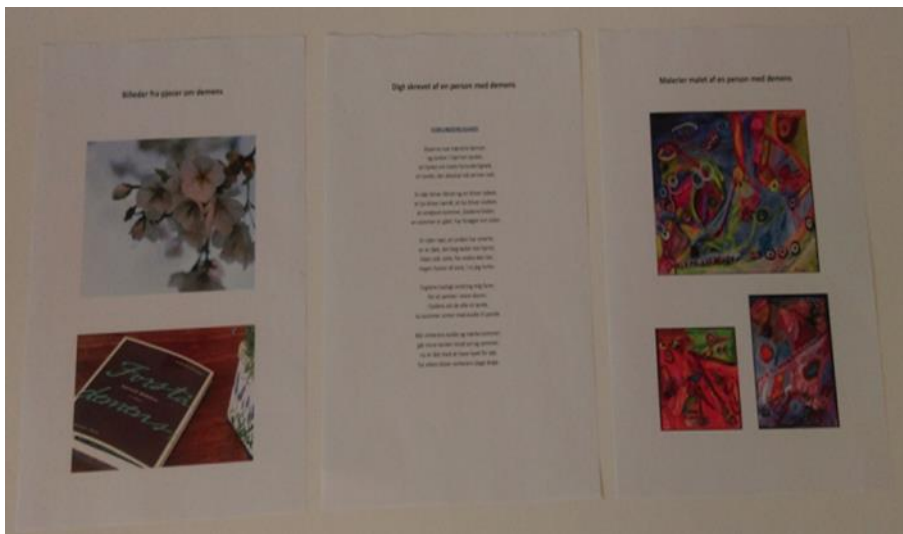
The chosen creative method: Pictures. The researcher drew how the student participants wanted the pictures to look like

1: To get out in society: A picture of VUK. Transport, keys, horses, car, VUK

2: To receive training that works: A picture of what they do in the woodcraft workshop. From the woodcraft workshop. Dancing and music. Cognitive training

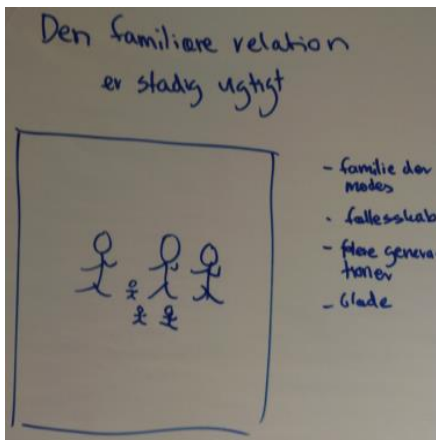
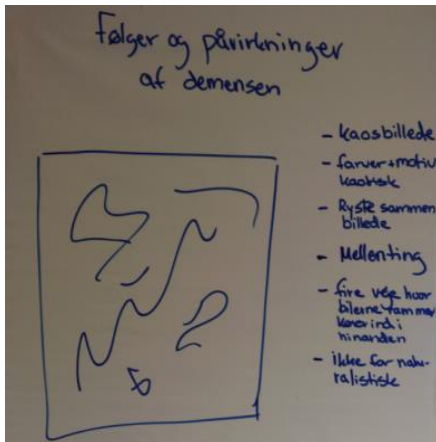
3: To have a positive camaraderie: A picture with people around a table having a good time. Have a photo of everyone. Sit together. Have a cosy time/laugh. Sandwiches. Chocolate.

Tuesday group



Examples of creative methods to supplement the analysis: Pictures, poems and paintings





The chosen creative method: Pictures. The researcher drew how the student participants wanted the pictures to look like

1: Background knowledge and knowledge about the diagnosis: A picture with a patient and a professional sitting at a table. Picture of a older person talking with a younger person. A doctor/ one you can talk with. % not to clinical a picture.

2: The social community is important: A picture with people sitting around a table. A group picture. Common tasks are solved. Gathering.

3: Consequences and impact of the dementia: A chaotic picture with coulers and a Chaotic motive. Shaken together picture. Something in between. Four roads hvor the cars hit/drive into eachother. Not to naturalistic.

4: The family relation is still important: Family that meets. Community. Several generations. Happiness.

Phase 4: Evaluation

Monday group

Interviewguide fokusgruppe interview

Oplevelse af projektet:

- Hvordan har det været at lave projektet?
- Hvad har betydet noget for jer igennem projektarbejdet?
- Hvad har gjort, at I har gennemført projektet?
- Hvordan har I oplevet jeres rolle i projektet?

Betydningen af projektet:

- Tager I noget med jer her bagefter projektet?
- Har det betydet noget for jer at være med i projektet?
- Har projektet ændret noget for jer?

Metoder i projektet:

- Hvad synes I om brugen af en projektmappe – en hjemme og en på VUK?
- Hvad synes I om det at få et program for hver gang med billeder og tekst af, hvad vi lavede sidste gang, og hvad vi skal lave denne gang?
- Hvad synes I om, at jeg har været den, som har skrevet og samlet jeres materiale på post ~~til~~, på papirer, videoer?
- Hvordan har I oplevet min rolle i projektet?

Vigtigt i et projekt:

- Hvad synes I er vigtigt at være opmærksom på, når man samarbejder med borgere med demens i et projekt?
- Er der noget man skal undgå, når man samarbejder med borgere med demens i et projekt?
- Hvad synes I en model for et projektarbejde skal indeholde, når man samarbejder med borgere med demens?

Mulige ændringer for fremtidige projektsamarbejder:

- Er der noget, I gerne ville have havde været anderledes i projektet?
- Er der noget I gerne ville have haft mere af i projektet?
- Har I nogen forslag til forbedringer til det at samarbejde om et projekt?

The focusgroup interview guide for the evaluation. See translation in appendix F

Tuesday group

Interviewguide fokusgruppe interview

Oplevelse af projektet:

- Hvordan har det været at lave projektet?
- Hvad har betydet noget for jer igennem projektarbejdet?
- Hvad har gjort, at I har gennemført projektet?
- Hvordan har I oplevet jeres rolle i projektet?

Betydningen af projektet:

- Tager I noget med jer her bagefter projektet?
- Har det betydet noget for jer at være med i projektet?
- Har projektet ændret noget for jer?

Metoder i projektet:

- Hvad synes I om brugen af en projektmappe – en hjemme og en på VUK?
- Hvad synes I om det at få et program for hver gang med billeder og tekst af, hvad vi lavede sidste gang, og hvad vi skal lave denne gang?
- Hvad synes I om, at jeg har været den, som har skrevet og samlet jeres materiale på post ~~til~~, på papirer, videoer?
- Hvordan har I oplevet min rolle i projektet?

Vigtigt i et projekt:

- Hvad synes I er vigtigt at være opmærksom på, når man samarbejder med borgere med demens i et projekt?
- Er der noget man skal undgå, når man samarbejder med borgere med demens i et projekt?
- Hvad synes I en model for et projektarbejde skal indeholde, når man samarbejder med borgere med demens?

Mulige ændringer for fremtidige projektsamarbejder:

- Er der noget, I gerne ville have havde været anderledes i projektet?
- Er der noget I gerne ville have haft mere af i projektet?
- Har I nogen forslag til forbedringer til det at samarbejde om et projekt?

The focusgroup interview guide for the evaluation. See translation in appendix F

Phase 5: Dissemination

Monday group

How is it experienced to attend VUK?

It is like getting out in society



By attending VUK, which is an adult school for teaching and communication in Aalborg Municipality, you as a citizen with an early-stage of dementia get the opportunity to get out, be a part of the society, and be together with other people. *"Otherwise you go in the same grind all the time. Therefore, I think it's great to get out among other people too"* Unfortunately, not all have this opportunity, as it depends on what services one's municipality offers. It is sad for those who do not have such a service in their municipality.

The good thing about attending VUK is to avoid isolating at home, which otherwise easily can happen after you have been diagnosed with dementia. Thus, it is important that you get out among other people and talk to someone. *"It's great. You get away from home and get out and talk with someone. I think that's great"*. It means that you afterwards can come home and have some new things to talk about at home with the spouse or the rest of the family. You have something you have to attend. *"It is about getting out and talk to other people. It helps some of the memory that you get away a bit from home and like that. I think"*.

To attend the school is associated with positive feelings, and you are looking forward to the day you go. One can even go and wait for the day you have to go. It is great to be able to participate in various events organised by VUK.

How is it experienced to attend VUK?

It is about receiving training that works



At VUK you experience as a citizen with an early stage of dementia to receive training that works. *"I am very happy and it's the training and training it is about"*. It is training that it concerns, but it is also important to have fun, laugh and have a good time together.

It is possible to receive very different training. You can work in a woodcraft workshop where you can make everything from cutting boards, hangers, rolling pins to knives. You also have the option to attend cognitive training, creative, dance and music. It is good with the creative things at school. To go to dancing seems to give a boost. You become happy by dancing and singing. *"It makes a lot for the memory. I also have the pleasure that we sing and when we have finished doing what we should. So then be able to just sing and laugh"*. You can try the different lessons and choose the ones you like best. It is good.

The teaching is perceived to be at an appropriate level, so that the teaching is not too difficult. *"No, not particularly. They are good at finding the level that fits"*. It is possible to get a grip of things. It is good to receive a training that is not too difficult. The teaching helps to broaden one's horizon and provides some useful tools. *"Many good things that expands one's horizons, and we also have many good employees at*

the school who give us some tools to move forward". You can feel in yourself that it helps the memory, and you can look at yourself to see it works. The training is done to improve the memory. The more you practice, the better you get.

How is it experienced to attend VUK?

It is about getting a positive relationship



To attend VUK is associated with building up, getting and being part of a positive camaraderie with other citizens with an early stage of dementia. Here you learn to know other people with dementia. People say hello to you when you come.

It is experienced positive that you can make new friends who you can talk to and who know about having dementia. *"It's the camaraderie. I think at least. I think you get some comrades who you can talk to. I think at least. That is is worth something"*. The other students with dementia are experienced as nice people. It is possible to say what you want, without causing problems. You feel really good and have fun in each other's company. *"I think that we have a camaraderie. It is great. We allow ourselves to say what we want, and we are just as good friends afterwards"*.

Much humour is used at the school, which occurs by itself. To laugh together belongs to go to school. Just as there has been laughed in the project that has been conducted. You tease each other, which is perceived as funny. Also in the woodcraft workshop at the school a certain kind of woodcraft humor exists.

Furthermore, the teachers at VUK are good in creating a great environment at the school. They are great and easy to talk with.

Tuesday group

How is it experienced to live with dementia?

You need background knowledge and knowledge about
the diagnosis



Being diagnosed with dementia means that you need to know what dementia is. It means a lot to know what the disease /condition is. It is a great help to gain knowledge about dementia and that you can live with dementia - also getting help from others if there is a need for this. *"I think it has been a great help to get knowledge about that I have it and that you can easily live with it with help"*. Some experience to have a mirror in terms of what dementia means because others in the family have had dementia. Others have not been aware of the disease/condition in advance.

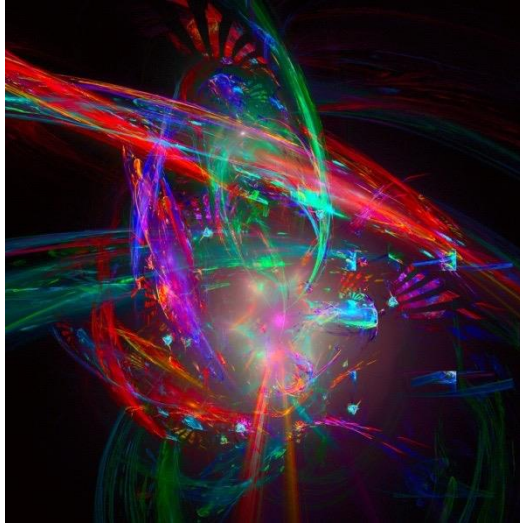
It is important to talk to your GP about what dementia is and about the medical treatment you can get. To get medicine is perceived as the progression of dementia can be slowed down. Also speaking with the dementia nurse or another dementia specialist can help. It helps knowing that you are not the only one in Denmark who have dementia. You are one of many.

To have knowledge about dementia and Alzheimer does not mean that you do not feel down because of the disease. You may find that the Alzheimer is in front of you, and

that it is difficult to overtake and overcome it. *"I bite the teeth a bit together when it gets hard. I have that from the sport"*. One can experience the disease/condition fluctuates. *"You just make sure to be on top, but you cannot be there forever"*. Likewise, it is tiresome and scary to see when the dementia progresses rapidly by acquaintances with dementia. To have knowledge of the services that exist in your municipality is also important, but you may find that it is difficult to get this knowledge, as one must be proactive towards the health professionals. It may require a lot of oneself. Important that the health professionals provide information of where to get help and services, after you have been diagnosed.

How is it experienced to live with dementia?

You experience consequences and impacts of the dementia



To live with dementia means that life is turned upside down, and you have to take some new positions in life with dementia, but that is also true about life in general. *"It has turned the whole thing upside down, but then one can get used to it, so it is always. Whether you're sick or not, you need always to take new positions"*. There are many different perceptions of dementia, and many are often associated with the losses that one with dementia may experience.

There are some things that are no longer possible or get harder. *"There are some things you cannot do more, but so you can do some other things. Otherwise you can also learn it or get others to do it"*. It is important to be honest about one's situation. *"You have to tell it like it is, I think, you have a greater chance to get help"*. It is also important to recognise one's situation. *"We have dementia and we have recognised what we cannot figure out, cannot remember and we have asked our close family for help"*.

A consequence of dementia may be that it is difficult to remember. *"This with not being able to remember it's negative"*. It is particularly the short-term memory, which is affected. Individual names may also be difficult to remember. *"Person names I have a hard time remembering. I know people and I say hello but struggling with the names,*

so I just say hello". It may also be that you cannot always find what you need, which mean you must learn some habits, so it is possible to find your things. Not being able to find what you need may mean it is easier to become irritated and "aggressive" when things are teasing. You may find that the pendulum is running fast forward and backward. You get easier angry, sorrowful and apathetic but also happy. There are two ways to be aggressive. It may be where the personality changes and one gets aggressive, but it may also be because the emotional world becomes smaller. Here you quickly come to the edge and get easier annoyed by things. However, it is also important to say that not all become aggressive when one gets dementia.

Also problems about uncertainty in relation to traffic exist and driving and cycling are for many no longer something they want to do because of the dementia influence. *"About driving"* is something some give up voluntarily, even though it may hurt if you have been very fond of cars. Some doctors may be too positive in relation to letting people with dementia continuing to drive, and it may be an idea that it was an independent physician who evaluated one's ability to continue to drive instead of your own GP. Often you choose to move around the areas you know.

It is of course sad, when you are diagnosed with dementia, but not everything is only negative in life with dementia. It is different, how much life is turned around with the diagnosis of dementia. The experience of living with dementia may also be associated with a more positive view, where it is the present that is important. *"I'd rather have the present. It is now the action is. This is where we feel good"*. Here it is not experienced as if life is kept or broken. *"Life is not stopped. Life's good"* and *"It is not life that is broken, it is learning to say, here I am, and I have dementia"*. The experience of dementia does not have to be negative, and it is possible to feel good with dementia. *"It's not life's most terrible thing it is how I feel. I'm fine with having dementia"*. It is important that *"... we, who have this disease have a good life, because I think that I have that"*. Here the focus is that you need to get as much out of life as possible, and that you want to be on top all the time, although you cannot always be there. It can also include taking it easy and enjoying the nearest things. *"To take it easy and enjoy things"* and that *"I take it as it comes"*. It can also help to create a more positive perception of dementia if you feel that it progresses slowly and you can therefore feel better now than right after the diagnosis, since you are no longer so afraid, that it will progress rapidly. You know the dementia may progress differently.

Similarly, one can relate humorous to the dementia and use it as a kind of a funny "excuse" when you sometimes cannot remember or do something wrong.

How is it experienced to live with dementia?

The social community is important



To live with dementia does not mean that people no longer care about being with other people. A positive social community is still very important, and be able to participate in various activities. It may be attending school, to receive teaching at VUK etc. *"To come here (VUK) I am happy"*. In "high schools", it is possible to be with others. It can be both people with or without dementia. Here you can get different inputs without being asked to solve problems. Some stay require that you are self-reliant and at others, a spouse or a professional can support. Some "high schools" operate under protected conditions. It is important to be aware that if you live alone you can be prevented from being involved in some of the social things. Further, larger gatherings may also be difficult for some because they are massive and overwhelming.

To have someone to laugh with is important but also to discuss serious matters is significantly. It is experienced positive when you can talk to others about what you can do when you experience difficulties living with dementia. It helps to talk about things. This also applies in many other contexts. The daring to stand up, be open about dementia and even take the initiative to talk about one's dementia is perceived as having a positive impact on the social life can continue despite the dementia. *"It is the openness"* about one's own situation, which is important. *"The ones I know, I've said it directly"*. *"But for me it means everything. I talk about it. I have never tried to hide it"*. One can continuously experience to have a good life with good fellowship and

company. Being with other people can also help to give a kind of overview. *"I think its better it's me who talk about it than they need to ask". "I have not met anyone who has distanced. Before they ever have asked me about it, I usually try to say that I have dementia".*

Most of all, it is important that you participate in something so you do not isolate yourself. In Aalborg municipality, it is perceived that there are many different services for citizens with dementia.

How is it experienced to live with dementia?

Family relations are still important



In life with dementia, the family and other close relationships are very important. They are alpha and omega! You get easier through the process with dementia with help from the family. You experience that the close relations do not react negatively due to dementia and that others can actually take it very calming in relation to the diagnosis. It is nice. *"I have not met anyone who has distanced"*. It is good that my social circle knows and understands why you can say some nonsense.

You may also find that your spouse is becoming more aware of what has to be remembered and is involved in your entire treatment. *"Both doctors and nurses have asked if she could join. She can. She must know what we're talking about"*. The spouse often asks if you have remembered this and that, begins to write much down and talks about what has to be remembered.

Living with dementia also means that you feel that it is important that it goes well with the family, and that you can stay on caring for the family as long as possible as you well know, this may not be possible in the future. *"That I will continue to care for my family and take care of them if there is a need for it"*. This means that caring for the family does not change after you get dementia. *"I need to get as much out of it as possible for me and my family"*.

You may also find that dementia can affect family life more negatively, and the family can break a little. You can choose to opt out of family, because you can no longer live

a family life because you need quiet space. It can be difficult having to take into account the family. It may also mean that you opt in a new social circle where others have dementia.

Appendix M. **Poem by one student at VUK**

The project in verse

When you get the diagnosis as DEMENTIA

Many maybe think: Does it threaten my existence?

No, no, no, the diagnosis dementia means to me
that I can get help, either by the doctor or by you.

The doctor starts with giving the medicine,
then I must follow the advices and pull in the line,
and informed, you can both live, have fun,
if you get a little help, when needed

Some experience to have a "mirror" in relation to,
what dementia means, with the doctor others speak.

To get the medication, is experienced as what we want,
to stop the brain's breakdown, it is good with agreements.

To have knowledge about dementia / Alzheimer means for the next,
that life will continue as before, but you hope for the best.

There are things that are no longer possible.

There are things for you that have become impossible.

Maybe you can learn it or get others to do it.

It is important, about your situation to be honest.

So there is a greater chance for help and it is glorious.

We must be open and recognise what we can find out.

Therefore, we have asked our closest for help, yes.

(Own translation)

ISSN (online): 2246-1256
ISBN (online): 978-87-7112-813-0

AALBORG UNIVERSITY PRESS