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## RENEGOTIATION OF SELF AFTER A BRAIN INJURY USING IMMERSIVE VIRTUAL ENVIRONMENTS

A CONTRIBUTION TO TECHNOLOGY-MEDIATED SPEECH THERAPY

#### BY ULLA KONNERUP

**DISSERTATION SUBMITTED 2015** 



# RENEGOTIATION OF SELF AFTER A BRAIN INJURY USING IMMERSIVE VIRTUAL ENVIRONMENTS

## A CONTRIBUTION TO TECHNOLOGY-MEDIATED SPEECH THERAPY

by

Ulla Konnerup



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PhD supervisor: Professor Ann Bygholm

Aalborg University

Assistant PhD supervisor: Professor Lene Tanggaard

Aalborg University

PhD committee: Professor Lone Dirckinck-Holmfeld

Aalborg University (chairman), Denmark

MD, Adjunct Professor Kjeld Fredens

Aalborg University, Denmark

Ph.D. Per-Olof Hedvall

Lunds Tekniska Högskola, Sverige

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Not only Does the Brain Shape Culture,

Culture Shapes the Brain

(Doidge, 2007)

I



#### CV

Ulla Konnerup has a professional background as a speech therapist specialising in people suffering from aphasia. She earned her Master's degree in ICT and Learning from Aalborg University in 2006. Since 2008, she has been affiliated as a Teaching Associate Professor with the eLearning Lab in the Department of Communication and Psychology, Aalborg University. Ulla Konnerup has been the network coordinator for The Network for eLearning (NoEL) and has been educationally responsible for the Master programme, ICT and Learning (MIL). Her research interests are related to people with special needs and technology, especially adults with communication difficulties resulting from brain injury, technology-mediated learning, sociocultural learning, and qualitative methods. In her thesis, Ulla Konnerup researches the use of avatar-mediated rehabilitation in the context of people suffering from aphasia. In the autumn of 2012, Ulla Konnerup engaged in a research stay at H-star, Stanford.

#### **ENGLISH SUMMARY**

This thesis addresses the use of immersive virtual environments in the rehabilitation of persons suffering from aphasia. More specifically, it concerns how acting through a virtual representation—that is, a so-called "avatar"—might contribute to the renegotiation of identity and affect the re-establishing of lost communicative competencies following brain injury.

This research is theory- and data-driven. The theories used include brain, cognition, language, and learning theories; the theoretical perspective is sociocultural and is inspired by Luria, Vygotsky and later researchers with roots in the cultural historical school. The present research is a case study involving data collected through two pilot courses in an immersive virtual environment: Second Life. The first course is a pedagogical course for speech therapists, and the other is a rehabilitation course for persons suffering from aphasia. The courses were conducted by speech therapists at The Institute for Speech, Language, and Brain Disorders in Aalborg, DK, from 2011 to 2012. The data comprise interviews, video recordings and workshops. In addition, Ulla Konnerup's experiences as a speech therapist, as well as her research stay at H-star, Stanford, in the autumn of 2012, are included.

The research has demonstrated that avatar-mediated interaction in immersive virtual environments contributes to a strengthened renegotiation of identity through shared experiences, a joint repertoire, joint culture and heritage, narratives, and communication using multimodal tools. Through embodied interactions, persons with aphasia have been shown to be capable of immersing themselves in the interactions and scenarios of Second Life to great extent, leading them to experience a high degree of presence. Social and cultural activities and specific training practices, such as naming, categorization, selection, orientation and spatial activities have been shown to be suitable for avatar-mediated training. Furthermore, research has shown that persons with Anomic and Wernicke's aphasia tend to benefit the most from the recommended approach.

However, due to technical obstacles and the speech therapists' lack of didactic competencies in information and communication technology (ICT), among other issues, the interactions in Second Life have also been marked by frustration. Despite these difficulties, there are good indications that the illustrated method has significant benefits; moreover, recommendations for the development of future avatar- mediated rehabilitations for persons with aphasia are given.

The approach of this study is qualitative and phenomenological, with the intention of giving a voice to persons with aphasia.

#### **DANSK RESUME**

Denne afhandling handler om at bruge immersive virtuelle miljøer i rehabilitering af personer, der har afasi. Mere specifikt, handler den om, hvordan handlinger gennem en virtuel repræsentation af en selv, en såkaldt avatar, kan bidrage til genforhandling af identitet og påvirke gendannelse af tabte kommunikative kompetencer efter en hjerneskade.

Forskningen er teori- og data drevet. Teorien omfatter hjerne-, kognitions-, sprogog læringsteorier. Det teoretiske perspektiv er sociokulturelt, inspireret af Luria, Vygotsky og andre forskere med rødder i den kulturhistoriske skole. Det er et casestudie med data indsamlet i forbindelse med to pilotkurser i et immersivt virtuelt miljø, Second Life. Det første kursus er et pædagogisk/didaktisk kursus for talepædagoger, det andet en et rehabiliteringskursus for afasiramte. Kurserne blev gennemført af talepædagoger på Taleinstituttet, Aalborg, DK i 2011-2012. Dataene omfatter interviews, videooptagelse, og workshops.

Herudover inddrages Ulla Konnerups erfaringer som en talepædagog og fra hendes forskningsophold ved H-star, Stanford i efteråret 2012.

Forskningen viser, at avatar-medieret interaktion i immersive virtuelle miljøer bidrager til at styrke genforhandling af identitet gennem fælles oplevelser, et fælles repertoire, fælles kulturarv, fortællinger og kommunikation ved hjælp af multimodale værktøjer.

Gennem interaktion og embodiment har afasiramte vist, at det er muligt at fordybe sig i sociale samspil og scenarier i Second Life i en sådan grad, at de føler, at de faktisk er tilstede. Udover sociale og kulturelle aktiviteter, har konkrete opgaver, der indeholder elementer som navngivning, kategorisering, selektion, rum-retnings opgaver vist sig at være egnet til avatar-medieret undervisning. Desuden er der en tendens til, at personer med Logisk semantisk og Wernickes afasi har mest udbytte af metoden.

På grund af tekniske problemstillinger og talepædagogernes manglende itdidaktiske kompetencer har pilotkurserne også været præget af frustration. Talepædagogernes har et ønske om at blive opkvalificeret indenfor feltet.

På trods vanskelighederne, er der indikationer på, at afasiramte kan profitere af metoden og der motiveres til at udvikle avatar- medierede rehabilitations for personer med afasi.

#### **ACKNOWLEDGEMENTS**

I began this thesis in 2009; however, my interest in and work with the realms of aphasia and rehabilitation started long before. Thanks go to Villy Nesgaard to introducing me to this field 20 years ago; thank you for involving me in the Ansigt til Ansigt (ATA) project. Professionally, it was a turning point for me.

Thank you to my colleagues and to the persons with aphasia at The Institute of Speech, Language, and Brain Disorders; to Anette Krusborg, for making the present project possible; and to the project group, for making it come alive. Thanks to Pia Høgh, especially, for collaboration and discussions, and to Hanne Lisbeth Kristensen; our sessions have taught me more about aphasia than anything else.

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## **TABLE OF CONTENTS**

Chapter 1. The story of how this work became important to me	•••••	13
1.1. Why ICT became a leading player in my practise	15	
1.2. Objective and research questions	17	
1.3. Glossary	18	
Chapter 2. State of the art	•••••	21
2.1. Qualitative Research Within Speech-Language therapy	21	
2.2. Social Aspects of suffering from a Communication Disorder	24	
2.3. Technology-mediated Rehabilitation	28	
2.4. Virtual Rehabilitation	30	
2.5. Related Work	37	
2.6. Summary	42	
Chapter 3. Methodology and Research design	•••••	43
3.1. Methodological Considerations	43	
3.2. Researching with People	45	
3.3. Case studying	47	
3.4. Virtual ethnography and video analysing	48	
3.5. Summery	51	
3.6. Ethics	52	
Chapter 4. The case	•••••	53
4.1. Preparations and Choice of technology	54	
4.2. Pilots	54	
Chapter 5. Theoretical Framework	•••••	55
5.1. The Brain	55	
5.1.1. Cognition	59	
5.1.2. Attention	61	
5.1.3. Memory	61	
5.1.4. Pattern Recognition	63	
5.1.5. Wisdom and Competence	63	
5.1.6. Executive functions	64	

	5.1.7. Recent brain research	65
	5.1.8. From Neuropsychology to Neuropedagogy	66
	5.1.9. Mirror systems	67
5.	2. Doppelgänger	68
5.	3. Language and its Impact on identity	69
	5.3.1. Language	69
	5.3.2. Language, cognition, and thinking	71
	5.3.3. Language, cognition and culture	71
	5.3.4. Language, communication and communities	73
	5.3.5. Language, Communication, and Identity	73
5.	4. Aphasia	76
	5.4.1. Tests and Diagnoses	76
	5.4.2. Labelling Disorders	79
	5.4.3. Aphasia's Impact on Identity and Life Participation	80
	5.4.4. Defectology and special needs	81
	5.4.5. Rehabilitation.	82
	5.4.6. ICT in Rehabilitation	86
	5.4.7. The Role of the Speech therapist	87
5.	5. Learning and didactics in immersive virtual environments	88
	5.5.1. A Socio-cultural Understanding of Learning	88
5.	6. Immersive Virtual Environments	90
	5.6.1. Second Life	95
	5.6.2. Avatar and agents	96
5.	7. Avatar-Mediated Learning	98
	5.7.1. Embodiment	99
	5.7.2. Embodied Cognition	99
	5.7.3. The Self	102
	5.7.4. The virtual self	102
	5.7.5. Immersiveness	103
	5.7.6. Presence	103
	5.7.7. Multimodality	104

	5.7.8. Proteus Effect	4
	5.8. Concepts of Interest	5
2	Chapter 6. Empirical work	107
	6.1. Data collection 10	7
	6.2. Processing data	0
	6.3. Interviews with PWAs	4
	6.4. Workshop with PWAs, social others and speech therapists11	6
	6.5. Pilot 1 – Course for Speech Therapists	1
	6.6. Interviews with speech therapists	2
	6.7. Workshop for Speech Therapists	2
	6.8. Pilot 2 – course for PWAs	3
	6.9. Guided tour and interview with Peter	5
	6.10. Interviews with PWAs—evaluation	6
	6.11. Guided Tour and interview with Inge	8
	6.12. Additional data 2014	9
	6.13. Units of interest	0
	6.14. analysis	0
	6.14.1. Locale	1
	6.14.2. Units of analysis	1
	6.14.3. Hell no, I ain't looking like that	3
	6.14.4. Me, my, Mine, I or it	8
	6.14.5. Watch out for the tram	3
	6.14.6. Finding my way home	0
	6.14.7. Proud to solve problems on my own	1
	6.14.8. Renegotiation of identity	2
	6.14.9. Between men	5
	6.14.10. Peter's rehabilitation cabin	1
	6.14.11. Narratives and autobiographical memory	3
	6.14.12. Locale	4
	6.14.13. Dancing with Misse Møghe	5
	6 14 14 And we did also have a good laugh	6

6.14.15. And when it is not working	167	
6.14.16. Couldn't we just as easily google it?	168	
6.14.17. The speech therapist as avatar	171	
6.15. Summing up the findings	173	
6.16. Doing virtual ethnography in SL	174	
Chapter 7. A Framework for Avatar-Mediated rehabilitation		177
7.1. Pedagogical considerations	180	
Chapter 8. Conclusions		183
Chapter 9. Further research		185
Appendix		187
Ribliography		189

## **TABLE OF FIGURES**

Figure 1 Glossary	19
Figure 2 Qulitative research within speech-language therapy	23
Figure 3 Identity formation and social aspects in research	27
Figure 4 Computers and technology in aphasia therapy	30
Figure 5 Virtual rehabilitation in aphasia therapy	34
Figure 6 Web-ORLA	
Figure 7 Basecube, a virtual community for PWA	36
Figure 8 Stress Resilience in Virtual Environments	38
Figure 9 Scenarios from the Coming Home Project	39
Figure 10 VHIL's multi-sensory room	40
Figure 11 Jeremy Bailenson with a visitor crossing a virtual plank	41
Figure 12 Brain research dependent on culture and tools	44
Figure 14 The brain is formed by the lived life	72
Figure 15 Virtual street art (permission granted by Edgar Mueller)	91
Figure 16 2D VLE for students and teachers at AAU	
Figure 17 Avatars in Second Life	93
Figure 18 Infografic SL	95
Figure 19 The distinction between agent and avatar	
(Bailenson & Blascovich, 64-68)	97
Figure 20 Concept of interest	
Figure 21 Participants with aphasia (PWAs)	108
Figure 22 Overview of data	109
Figure 23 Processing video in Final Cut Pro	111
Figure 24 Processing video and audio in Transana	112
Figure 25 Structuring in Transana	113
Figure 26 John's book	115
Figure 27 Group discussion	117
Figure 28 Workshop on scenarios, activities and training	117
Figure 29 Ideas for scenarios in an IVE	
Figure 30 Dysfunctions and technology	120
Figure 31 Roundtable discussion in SL	122
Figure 32 Course plan for PWAs	124
Figure 33 Interviewing Peter in front of his home in SL	125
Figure 34 Peter in his language-training cabin	126
Figure 35 Handwritten notes from Helen	127
Figure 36 Inge's learning cabin	128
Figure 37 Holodeck; at the interactive security check	
Figure 38 Unit of interest	130
Figure 39 Units of Analysis	
Figure 40 Helen 2012 Figure 41 Helen 2014	134
Figure 42 Michael accidentally sitting on the floor	135

Figure 43 Helen standing on the table	137
Figure 44 Chris and Ian biking	
Figure 45 Different perspectives possible in SL	141
Figure 46 Object view	141
Figure 47 First-person mouse view	142
Figure 48 Michael	
Figure 49 Michael close to the tram	143
Figure 50 Janice is feeling cold	146
Figure 51 Janice really wanted that car	
Figure 52 Horseback riding	
Figure 53 Water sports resort	
Figure 54 Helen surfing	
Figure 55 Michael demonstrates how to jump	152
Figure 56 A hospital ward in SL	
Figure 57 Guided tour to the church	
Figure 58 Peter in his home	
Figure 59 Peter in his cabin	
Figure 60 The mobile display	
Figure 61 Dancing with Misse Møghe	
Figure 62 Gnom Island	

# CHAPTER 1. THE STORY OF HOW THIS WORK BECAME IMPORTANT TO ME

Many years of experience working as a speech therapist with persons with aphasia (PWAs) after a brain injury have given me first-hand stories and insights into the affected people's and their relatives' difficulties, feelings, needs, and rehabilitation possibilities. I have met more than 1,000 PWAs, and I have experienced that, for most, the most significant issue is that they no longer feel that they are themselves. Losing the ability to communicate makes people afraid to appear stupid and incapable of taking responsibility for themselves or others.

I was raised in a social and cultural educational context. Danish speech therapist Villy Nesgaard was my teacher—and, later on, my superior at The Institute of Speech, Language, and Brain Disorders in Aalborg. Since the seventies, Nesgaard has been strongly inspired by the Soviet psychologists—especially the neuropsychologist Luria<sup>1</sup>. One of the main reasons for this admiration stemmed from two Danish women—psychologist Anne-Lise Christensen and speech therapist Jytte Jordal—who visited Luria in Moscow in 1972. These women returned knowledgeable and inspired by Leontjev's, Vygotsky's, and especially Luria's thoughts. The journey ultimately influenced the development and debate within special education and rehabilitation in Denmark for many years.

Building on the principle of Luria's brain research, Nesgaard developed a qualitative test to examine the nature of aphasia and a method for aphasia treatment. The main idea was to restore a holistic functional language by restructuring the linguistic functional system (Vygotsky & Luria, 1993), with the goal of increasing communication abilities in the broadest sense.

Until 2005, all decisions regarding rehabilitation within processes of speech therapy in Denmark were determined on a professional basis by speech therapists themselves. Such approaches could vary from county to county. In general, the inspiration of Luria was so strong that it came to dominate a great part of Denmark. Some areas, though, were more dominated by American-inspired tests and cognitive psychological approaches. In these methods, language was considered to

<sup>&</sup>lt;sup>1</sup> Alexander Romanovich Luria (1902-1977), Soviet neuropsychologist and psychologist. Luria was one of the founders of Cultural-Historical Psychology and the leader of the Vygotsky Circle

be an individual phenomenon consisting of language systems, and the primary goal was to improve language production.

A thorough political structural reform in the Danish counties in 2006 led to a paradigm shift within the speech therapy realm. Service and economy were given high priority. Values, views of men and teaching methods were reviewed. To increase the degree of national and international comparability, there was a demand for standardisation (The Institute of Speech, Language, and Brain Disorders, 2006). The decision-making authority shifted from the speech therapists to the municipal social workers. The fact that people without any professional knowledge of language and communication became decision makers resulted in new demands for documentation and testing materials related to the character of the injury and the need for rehabilitation. From using the qualitative test (Nesgaard, 2007) and narratives about difficulties and lost functions to describe difficulties, the county of North Denmark switched to an American neuropsychological-based test battery: the Western Aphasia Battery (WAB). This approach presented quantitative output in graphs, provided an overview of progress, and offered an easier way of completing evidence-based work.

This shift led to, over a very short period, some crucial changes in pedagogical practices. It became critical for speech therapists to document progress, which could be read in the test materials. Otherwise, a municipality could refuse financial support for further rehabilitation. From a focus on functional communication skills, it became more common to attempt, for example, to name as many nouns as possible. In my opinion, these pedagogical changes deteriorated the rehabilitation process. The new methods differed from previous practise and theoretical foundations. Even worse, I allow myself to say, the changes occured in contradiction to the recommendations of the World Health Organization (WHO). The WHO had, in 2001, developed an international classification of brain impairments: the International Classification of Functioning, Disability and Health (ICF). The ICF is a concept of disability, within which a particular disability is considered to serve as the limitation of opportunities for participation in society ("WHO | International Classification of Functioning, Disability and Health (ICF)," 2015). Furthermore, the ICF offers a paradigm shift from illness and healing to everyday life problems and in relation to social others. The aim is to integrate the medical, scientific, psychosocial, and humanitarian perspectives in order to offer a common standardized language and a similar conceptual framework, "allowing all conditions to be compared using a common metric - the impact on the functioning of the individual" ("WHO | International Classification of Functioning, Disability and Health (ICF)," 2015). Denmark has officially endorsed the ICF terminology, but, in practise, economic and practical circumstances lead to difference in actions.

Thus, to meet the requirements set by the political system, The Institute of Speech, Language and Brain Disorders began to apply methods contrary to pedagogical convictions—and, not least, to WHO instructions. As a dedicated practitioner, I did not find it easy to simply obey orders and follow the new instructions. The changes conflicted with my professional pride. In frustration, I began to rethink the rehabilitation practice. How could the pedagogical practice be reformulated so that it was simultaneously true to our pedagogical beliefs, our vision of "the right" rehabilitation and today's knowledge about the brain and its ability to recover?

Qua the Luria-based rehabilitation, I have a great interest in brain research and how professionals can implement such knowledge in practise. New medical examination methods, such as neuroimaging, have contributed to new knowledge about, for example, the brain's activity in social interactions, the brain plasticity, and mirror neurons. This new knowledge is not a contradiction to Luria's brain research; rather, it can be considered as new layer, on which Chapter 5 will elaborate.

## 1.1. WHY ICT BECAME A LEADING PLAYER IN MY PRACTISE

For the last 15 years, I have been occupied with integrating ICT pedagogically to teach people with special needs. During the period between 2001 and 2004, I was project manager of the "Face to Face" (ATA) project, which was part of a large-scale project called The Digital North Denmark. The original purpose of this project was to establish video-conference-based distance learning services for PWAs to extend and improve their rehabilitation efficiency. The specific aims were to give PWAs the opportunity to learn or relearn ICT, to increase their overall communication skills, to strengthen their participation in public debates and to increase their self-reliance in relation to e-commerce and e-banking (Dirckinck-Holmfeld, Konnerup, & Petersen, 2004).

In addition to identifying concrete opportunities to use technology, the project revealed insights into PWAs' renewable drive to re-establish themselves as they were before the injury. This gave rise to change the focus, from considering rehabilitation as something specifically focused on optimizing language and communication to a process focused also on the patient's identity, quality of life, and ability to be a competent participant in society. All factors have communicative competence as their premise. Over the last 10 years, practice has reinforced the belief that computer-assisted rehabilitation and virtual learning can help to renegotiate the identities of people suffering from aphasia. PWAs who have inspired me include:

<sup>&</sup>lt;sup>2</sup> In Danish: Ansigt til Ansigt (ATA)

The man who is able to surf the Internet and check prices and quality—and thus, as he did before the injury, responsible for purchasing such things as washing machines and televisions for his family

The man who surprises his wife with lobster soup delivered from an Internet firm

The woman who buys new clothes and gifts for her grandchildren

The former director who became capable of continuing to buy and sell shares

The man who cannot physically go to the bank and verbally express his needs, but who may well be in charge of family finances via e-banking

The woman who actively plans major reconstructions at home and buys materials online

Those who, due expressive difficulties, cannot make calls, but, instead, send email, write on Facebook, add pictures to Instagram, etc. and, thus, are communicative social members

Those who can not read newspapers, either because they have lost their reading competence or because they can not turn over the pages in a newspaper, who can now have news read aloud or who can use a few simple shortcuts to access the news via electronic news feeds.

The above-mentioned are all examples of people who have increased their skills and opportunities to actively participate in "conversations at the dinner table". The skills are likely to have a positive impact on these people's rehabilitation of language and communication and, thus, their renegotiation of identity.

This thesis is, therefore, driven simultaneously by an urge to explore possibilities for practice that actually lives up to our view of rehabilitation and WHO recommendations and an interest to explore whether new technologies can provide an opportunity to challenge the brain's strategies for re-learning language. How can aphasia interventions be extended to involve a person's renegotiation of identity, quality of life, and competent participation in society?

#### 1.2. OBJECTIVE AND RESEARCH QUESTIONS

That the renegotiating of identity is a challenge for PWAs is substantiated by research (Duchan, Linda, Garcia, Lyon, & Simmons-Mackie, 2001; Shadden & Agan, 2004, p. 174). Communication and identity are strongly linked, and the multiple roles that define one's sense of identity within a larger society are modified by stroke and, consequently, aphasia (Shadden & Agan, 2004, p. 174). It is essential for the PWAs themselves and their significant others to regain their voices in dialogue with others, both privately and in society. Recent research from Australia about what people with aphasia want shows that their primary goals involve activity and participation components (Worrall et al., 2011, p. 309).

Although the focus of research on aphasia intervention and of the above-mentioned recommendations from WHO has shifted from a process of recreating and relearning language to incorporating communication acts, conversation, quality of life, and the regained feeling of belonging to society and family, practices are, as mentioned, not keeping up. There is still a need for concrete suggestions for new types of interventions. New approaches are needed to provide contexts in which identity and social belonging are consistent with actual research and knowledge.

This thesis concerns a virtual approach to practise. It is a suggestion for a reformulation of the aphasia pedagogic and rehabilitation methods. The focus is on the link between the ability to communicate and the formation of identity, without targeting linguistic aspects explicitly. Based on newer research on the brain and rehabilitation, the present case study addresses how we can combine knowledge of the brain, concrete rehabilitation practices, and the use of technology to assist persons with aphasia.

This background leads to the following research question:

How can avatar-mediated rehabilitation and social interaction in immersive virtual environments equip persons suffering from aphasia to renegotiate their identities and enable them to maintain knowledgeable and cultured persons?

The emphasis here is on avatar-mediated actions and the assumption that social and embodied interactions will positively affect the brain's re-establishing process, thereby promoting cognitive and communicative functions.

In this context, it is neither possible nor intended for this research to prove any development of the brain through current and specific brain scans of the people involved. Brain research and theory are used to support the suggestion of remediated rehabilitation, not to serve as evidence.

#### 1.3. GLOSSARY

Term	Explanation
Agrammatism	A form of expressive aphasia; refers to the inability to speak grammatically. A person's speech may be telegraphic, with simplified sentences. Many or all function words (i.e., verbs) may be omitted.
Aphasic	A person with aphasia.
Aphasia	Greek; means the loss of language.
Cognitive fitness	Training the brain as one would train muscles.
E-learning:	All digital learning.
ICT	Short for Information and Communication Technologies
Functional language	Language in use; performance level
Holodeck	A feature in Second Life that a user can reload and close down
Immersive	Digital technologies, environments, or images that deeply involve one's senses and may create an altered mental state
IVE	Immersive virtual environment
Neologism	A newly coined word or term (created by the PWAs)
Onset	The date a PWA experienced his or her injury
Paraphrase	Originally the word means to reorganize an original thought/idea/text, here: An incorrect word substituted for an intended or target word
PWA(s)	Person(s) with aphasia
Rehabilitation	WHO has defined rehabilitation as a process that aims to enable persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychological, and social functional levels («WHO   Rehabilitation», n.d.).

### CHAPTER 1. THE STORY OF HOW THIS WORK BECAME IMPORTANT TO ME

	Rehabilitation is generally used to refer to the recovery of as many skills as possible after an injury. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination. In this thesis, it is specifically used to relate to the <b>restoration of language</b> , <b>communication</b> , and identity.	
SL	Second Life; a virtual environment	
Virtual learning	Internet-based learning; used synonymously with networked learning	
Virtual	Refers in general to something <i>imitated or simulated</i> , but it can be related to a variety of situations. Here, the term is related to digital simulations	

Figure 1 Glossary

# CHAPTER 2. STATE OF THE ART

The last 80 years have produced a large body of research addressing the field of aphasia and the consequences for communication, quality of life, and rehabilitation. This is a complex area involving knowledge about the brain, neuropsychology, speech, language, communication, learning, and behaviour. Also relevant to my study is research on ICT-mediated learning, which has experienced tremendous development over the last few decades. It would be too ambitious to provide an indepth state of the art of all the involved research areas. I have, therefore, chosen to provide an overview solely of the research that has inspired to conduct this thesis. These fields of interests are:

- Quality research within speech-language therapy
- Identity-formation and social aspects of suffering from a communication disorder
- Technology-mediated rehabilitation
- Virtual rehabilitation

In the following, each of these aspects will be addressed separately.

## 2.1. QUALITATIVE RESEARCH WITHIN SPEECH-LANGUAGE THERAPY

There are numerous competing understandings of aphasia and rehabilitation. In line with the above-described practise experiences, I will concentrate on research studies within the qualitative paradigm. Qualitative and interpretive research are relatively new to communicative disorders (Damico, Oelschlaeger, & Simmons-Mackie, 1999; Damico & Simmons-Mackie, 2003). In 2003, *The American Journal of Speech-Language Pathology* published a special forum on qualitative research consisting of five articles, each addressing qualitative research in relation to speech-language therapy.

The lead article by Damico and Simmons-Mackie (2003) argues generally about what qualitative research can bring to the field. The authors provide an operational definition of qualitative research and define a number of different approaches. The most frequently used are biological studies, case studies, conversation studies, ethnographies, grounded theories, and historical methodologies. All of these approaches have a long tradition in the social sciences, but are relatively new within the speech-language realm.

## Special Forum for Qualitative Research in Speech-Language Pathology

in

American Journal of Speech-Language Pathology (2 (12) May 2003)

Authors	Title	Main point
Brinton, B., &	Blending	Using a case study, the authors discuss
Fujiki, M.	quantitative and	how blending methods can be helpful in
	qualitative	bringing light to complex issues on
	methods in	language disorders. They focus on how
	language research	a qualitative approach fills a gap
	and intervention.	between research and practise.
Culatta, B.,	Quantitative and	Quantity procedures in a study on the
Kovarsky, D.,	qualitative	effectiveness of an instruction model for
Theadore, G.,	documentation of	children with language impairments are
Franklin, A., &	early literacy	supplemented by a qualitative
Timler, G.	instruction.	investigation of engagement and
		participation. Such approaches as
		ethnography of communication and
		communication analyses are used to
		provide valuable insights in the area.
Damasio, J. S.,	Qualitative	The lead article in this special forum.
& Simmons-	research and	The authors introduce an operational
Mackie N. N.	speech-language	definition of qualitative research and
	pathology: A	different qualitative traditions. Based on
	tutorial for the	specific cases, the article discusses what
	clinical realm.	qualitative methods have to offer the
		speech-language therapy realm.

continues on next page

Simmons-		By addressing cultural and societal
Mackie, N., &		factors, the article demonstrates that
Damico, J.		qualitative research significantly
		impacts the understanding of speech-
		language disorders. The article stresses
		how the qualitative realm brings
		knowledge to the field about, for
		example, the importance of
		communication for establishing social
		roles and identities and social
		constructions of competence and
		incompetence
Tetnowski, J.,	Qualitative	The authors discuss basic principles of
& Franklin, T.	research:	the complexity of research within the
	Implications for	field of speech-language and show how
	description and	qualitative research can be employed to
	assessment	provide effective and sufficient clinical
		communicative assessment.

Figure 2 Qulitative research within speech-language therapy

One characteristic shared by all these studies is that of being "analytic in nature; each involves data collection and the analysis aimes at description and explanation of behavioural patterns under scrutiny" (Janesick, 1994). Case studies are the most commonly used method with regard to qualitative research within the speech-language field. The case study methodology used in the present thesis, will be discussed in Chapter 3.

The other articles of the Special Issue provide a broader understanding to the method by describing concrete cases. Speech and language disorders represent a complex area, in which blended research-approaches can bring light to such issues as identities, engagement, participation, quality of life and social constructions (Brinton & Fujiki, 2003; Culatta, Kovarsky, Theadore, Franklin, & Timler, 2003; Damico & Simmons-Mackie, 2003; Tetnowski & Franklin, 2003)

Through the combination of these five articles, *The American Journal of Speech-Language Pathology*'s special forum provides an understanding of how qualitative research can be successfully employed within the speech-language realm.

## 2.2. SOCIAL ASPECTS OF SUFFERING FROM A COMMUNICATION DISORDER

Audrey L. Holland, retired professor at The University of Arizona, was one of the first to address the psychosocial and functional perspectives within the realm of aphasia (Holland, 1982, 1991; Holland & Beeson, 1993). Shelagh Brumfitt, professor at the University of Sheffield, UK, has also been researching the psychological aspect of aphasia—especially identity and self-esteem issues (Brumfitt, 1993, 2009).

Talking About Aphasia (Parr, Byng, Gilpin, & Ireland, 1997) is a unique work based on interviews with 50 people suffering from aphasia. By sharing first-hand stories about how it *feels* to live with aphasia and the impact that the impairment has on all dimensions of life, this study gives readers an in-depth understanding of this impairment. It also confirms my own first-hand experiences.

My interest in the field of the social aspects of aphasia and how it feels to live with this disorder has, from the beginning of the 21<sup>th</sup> century, been inspired by the work of researchers affiliated with the City University of London and the University College London. Additional research projects have been conducted in conjunction with the British communication disability network *Connect*. This network's focus is to equip people with aphasia and their social others to live with aphasia and to reconnect with life.

In the year 2000, Carole Pound, Susie Parr, Jayne Lindsey, and Celia Woolf, all affiliated with the City University of London, published the book *Beyond Aphasia* – *Therapies for Living with Communication Disability*. This book was an eye-opener for me. By addressing the psychosocial consequences of aphasia, the authors move away from the medical tradition of focusing on impairments, shifting instead towards a broader social and cultural understanding of the condition. Their model of rehabilitation describes how a reestablishment of individual identity as a collective identity is crucial for living with aphasia. Moreover, social approaches to aphasia management are presented without denying the importance of individual language training and a development of compensatory strategies.

#### CHAPTER 2. STATE OF THE ART

Identity Formation and the Social Aspects of Suffering from a Communication Disorder		
Author	Title	Main points
Holland, A. L., & Beeson, P. M. (1993)	Finding a new sense of self: What the clinician can do to help.  Aphasiology, 7(6), 581–584.	The article calls for concrete proposals for aphasia management that involve identity. It suggests that therapists assist by helping PWA work through associated personal losses.
Holland, A. L., Halper, A. S., & Cherney, L. R. (2010)	Tell me your story: Analysis of script topics selected by persons with aphasia. American Journal of Speech- Language Pathology, 19(3), 198–203.	With an aim to aid individuals in achieving a higher degree of selfesteem, a case study on PWAs in dialogue with a virtual therapist about topics of interest and importance to them is conducted. The results suggest that the PWAs focus on their life experiences, trying to reconnect with their families and social lives.
Parr, S. (2007)	Living with severe aphasia: Tracking social exclusion. <i>Aphasiology</i> , 21(1), 98–123.	Social exclusion is a common experience for PWAs, and it occurs at infrastructural, interpersonal, and personal levels. These perspectives should be addressed through training.

Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997)	Talking about aphasia: Living with loss of language after stroke. McGraw-Hill International	Drawing on interviews with PWAs, the book provides an understanding of living with aphasia.
Parr, S., Duchan, J., & Pound, C. (2003)	Aphasia inside out: Reflections on communication disability. McGraw-Hill International.	Through a number of articles, the book suggests new methods in aphasia management by providing insights into the lives of PWAs, their relatives, and therapist practises.
Pound, C. (2000)	Beyond aphasia: Therapies for living with communication disabilities. Bicester: Winslow.	The book describes a new social model of aphasia management that considers identity, disabling barriers, and competence in communication. The target group is long-term PWAs, and the model is developed by practitioners and researchers affiliated with <i>Connect</i> .
Shadden B., Hagstrom F. Koski P. (2008)	Neurogenic communication disorders: Life stories and the narrative self. San Diego: Plural Pub.	The book brings interdisciplinary perspectives together to facilitate an understanding of the social construction of self. The book investigates ideas for treatment that incorporate self-formation, pointing out that the sense of self should receive more focus in research on communication disorders.

#### CHAPTER 2.

Shadden, B. B., & Agan, J. P. (2004)	Renegotiation of identity: The social context of aphasia support groups. Topics in Language Disorders, 24(3), 174.	This article explores group sessions as a concrete approach to including identity and social issues in aphasia treatment.
Simmons-Mackie, N. (1998)	A solution to the discharge dilemma in aphasia: Social approaches to aphasia management.  Aphasiology, 12(3), 231–239	The study addresses the risk of isolation after the end of rehabilitation and suggests expanding the understanding of the responsibility of the speech therapist to deal with life-long social consequences.
Simmons-Mackie, N., & Damico, J. (2007)	Access and social inclusion in aphasia: Interactional principles and applications. <i>Aphasiology</i> , 21(1), 81–97.	Four principles concerning social interaction are discussed, and therapeutic strategies to improve social inclusion are suggested
Simmons-Mackie, N., & Elman, R. J. (2011)	Negotiation of identity in group therapy for aphasia: The Aphasia Café. International Journal of Language & Communication Disorders, 46(3), 312–323.	This article addresses identity as part of aphasia management by demonstrating the potential role of the group therapist in managing identity negotiation. It offers both a method of analysing identity negotiation in aphasia therapy and insight into behaviours occurring during social interaction that support robust identity development for PWAs.

Figure 3 Identity formation and social aspects in research

One of the world's leading researchers in qualitative research on aphasia, Nina Simmons-Mackie, Professor at Southeastern Louisiana University, addresses the risks of social exclusion for PWAs. Her research field falls within quality of life and social approaches to aphasia management (Simmons-Mackie, 1998; Simmons-Mackie & Damico, 2007; Simmons-Mackie & Elman, 2011). Simmons-Mackie (1998) shares her interest on social inclusion with Parr (2007). Specifically, within the psychosocial perspective, a sense of self and identity formation are central. Most of the researchers address identity issues to some degree in their work (e.g., Parr, Duchan and Pound, in their book *Aphasia Inside Out – Reflections on Communication Disability* (2003)). Shadden, Hagstrom and Koski (2008), though, with their book, *Neurogenic Communications Orders – Life Stories and the Narrative Self*, engage in a more in-depth exploration of the social construction of the self, the importance of language in self-formation and how to address the sense of self in communication disorder treatment.

Thus, there are a number of national and international trends in favour of a relational and context-sensitive approach to disability and rehabilitation.

#### 2.3. TECHNOLOGY-MEDIATED REHABILITATION

Research and projects within the field of technology-mediated rehabilitation have focused predominantly on technological options to improve speech and language production. In the 1990s and 2000s, pre-defined inflexible exercises were dominant, mainly as software programs (Petheram, 2004, p. 187). A special issue of *Aphasiology* concerning computers in aphasia therapy was published in 2004; Brian Petheram (2004) calls the issue a kind of state of the art in the field. Six articles provide a broad perspective of what computers and related technologies offers to existing aphasia treatment options.

According to the mentioned research (figure 3), the computer is the most beneficial tool in terms of such difficulties as naming, memory and attention. However, there seems to be a lack of transfer to verbal communication (Doesborgh et al., 2004). The PWA welcomes computerised home training, particularly with spouses, stressing the higher degree of independence (Mortley, Wade, & Enderby, 2004). Other articles ask for research within functional communication. To meet this dimension, Wallesch and Johannesen-Horbach suggest virtual reality in aphasia treatment:

In the case of aphasia therapy, virtual reality would constitute an interactive communicative environment. Although massive technological advances are occurring at a rapid pace, a breakthrough has yet to occur for man-computer communication

(Wallesch & Johannsen-Horbach, 2004, p. 233)

#### CHAPTER 2. STATE OF THE ART

## Computers and Related Technologies in Aphasia Therapy Aphasiology (18 (3) 2004)

Aphasiology (18 (3) 2004)			
Authors	Title	Main points	
Doesborgh, S., van de Sandt-Koenderman, M., Dippel, D., van Harskamp, F., Koudstaal, P., & Visch-Brink, E.	Cues on request: The efficacy of Multicue, a computer program for wordfinding therapy.	Investigation of the computer software Multicue and its effect on naming and verbal communication. Result: good effect on naming, but a lack of generalisation to verbal communication.	
Jennifer Egan, Linda Worrall & Dorothea Oxenham	Accessible Internet training package helps people with Aphasia cross the digital divide	By using aphasia-friendly Internet material, it is possible for PWAs to learn to use the Internet, when taught one-to- one. The Internet use provides the PWAs with independence.	
Mortley, J., Wade, J., & Enderby, P.	Superhighway to promoting a client-therapist partnership? Using the Internet to deliver word-retrieval computer therapy, monitored remotely with minimal speech and language therapy input.	Evaluation of a remote (Internet-based) therapy case with a focus on improving word retrieval and efficient therapist time. The conclusion is that, despite the use of little therapist time, PWAs achieved high degrees of independence with acceptable outcomes.	
Van de Sandt- Koenderman, M.	High-tech AAC and aphasia: Widening horizons?	Review of low- and high-tech applications for aphasia. Technology has a lot to offer, but there is a need for research on functional use.	

Petheram, B	Editorial: Computers and Aphasia: A means to delivery and a delivery of means	Special issue on the use of computers in rehabilitation; efficacy, critical appraisals and methods to ease daily activities
Wallesch, C., & Johannsen-Horbach, H.	Computers in aphasia therapy: Effects and side-effects	Review on published studies on computers and aphasia. More cases demonstrate improvement, but do not indicate which element of therapy has contributed to the effect. Computerised homework with spouses has an effect.
Wertz, R., & Katz, R	Outcomes of computer-provided treatment for aphasia	Applies definitions of computerised therapy. Computers have renewed recognition of aphasia therapy as multifaceted.

Figure 4 Computers and technology in aphasia therapy

#### 2.4. VIRTUAL REHABILITATION

In recent years, technology has evolved constantly and rapidly, leading to new features and possibilities. Reviews of the literature on virtual rehabilitation and aphasia results primarily in studies in which "virtual" is used as a synonym for "telerehabilitation" or "telehealth". Using health terminology shows that this issue is viewed more from a medical perspective than from a rehabilitation and relearning perspective.

In the early 2000s, projects established mainly for cost-effective purposes, due to the shortage of speech therapists (Mashima & Doarn, 2008, p. 1101). Telehealth is widespread today, especially in the USA, Canada, and Australia. American and Canadian associations for speech pathologists have since 2005 and 2006, respectively, issued policy statements and guidance for telerehabilitation as part of their practise (Brown, 2011).

### CHAPTER 2.

In 2008, Mashima and Doarn conducted a review of 40 telehealth activities in speech-language pathology. A broad group of patients were included: persons with aphasia, dysarthria, apraxia, cognitive communication disorders, dementia, traumatic brain injury (TBI), Parkinson's, cerebral palsy and multiple sclerosis (Mashima & Doarn, 2008, p. 1105). The results were, in general, positive. Both patients and speech therapists found the methods acceptable and interesting. Despite some initial sceptics, the authors report, "the absence of the clinician's physical presence does not compromise the 'human element' or reduce the effectiveness of services provided by telehealth" (Mashima & Doarn, 2008, p. 1105). The clinical efficacy outcome stresses the home setting, as follows:

Furthermore, telehealth meets the care needs of homebound patients with impaired mobility and allows for closer monitoring when additional or follow-up services are needed. Individualized home exercise programs can develop to facilitate carryover of learned skills to the functional home environment.

(Mashima & Doarn, 2008, p. 1106)

Cherney and van Vuuren (2012) have also reviewed a number of studies concerning videoconferencing in speech pathology. They compare training sessions performed face-to-face to those performed over videoconferences and conclude that telerehabilitation is, in general, valid, reliable and cost efficient. Furthermore, their studies demonstrate an equivalence between the face-to-face environment and telerehabilitation, though type and severity of the disorder might be an important factor in success (Cherney & van Vuuren, 2012, p. 250).

In sum, existing reviews are in consensus: both emphasize such technical and regulatory barriers as licensure, privacy, security, network latency, bandwidth, reimbursement, and privacy, which stressed as fundamental and hard to overcome (Cherney & van Vuuren, 2012, p. 243). In both reviews, the studies are primarily concerned with persons with motor-related disorders, such as dysarthria, apraxia of speech, Parkinson's, and physical disabilities. Case studies indicate that the improvements occur primarily in auditory comprehension, oral expression, and written expression (Cherney & van Vuuren, 2012, p. 250).

#### Tele-health and Virtual Rehabilitation in Aphasia Therapy (In chronological order) Ring, H. (1998). Is neurological There is much potential for rehabilitation ready for rehabilitation, but also many 'immersion' in the world technical obstacles. Virtual of virtual reality? reality (VR) is the future. Rizzo, A. A., Virtual environments for VR technologies offer new Buckwalter, J. G., assessing and options for tools in the McGee, J. S., rehabilitating rehabilitation of cognitive and Bowerly, T., Van cognitive/functional functional processes—in this Der Zaag, C., performance a review of case, patients with central Neumann, U., ... & projects at the USC nervous system dysfunction and Chua, C. (2001) Integrated Media visual-spatial disorders. Systems Center Potential use: The design and implementation illustrate a unique set of challenges and opportunities that will require interdisciplinary cooperation between usability specialists and scientists who have domainspecific knowledge of the range of impairments seen in clinical populations. Dirckinck-Evaluation of the distance Face-to-Face training of Holmfeld, L., participants with teaching project Face-to-Face. Konnerup, U., & aphasia through Rehabilitation of PWAs through Petersen, K. (2004) videoconferences. Positive distance learning

psychosocial side effects.

#### CHAPTER 2. STATE OF THE ART

Georgeadis, A., Brennan, D., Barker, L., & Baron, C. (2004)	Telerehabilitation and its effect on story retelling by adults with neurogenic communication disorders	Comparing how adults with brain injuries re-tell stories in face-to-face and videoconferencing settings. No significant difference was measured. The participants showed great interest in telerehabilitation.
Rizzo, A., & Kim, G. (2005)	A SWOT analysis of the field of virtual reality rehabilitation and therapy. Presence, 14(2), 119-146.	The analysis treats a general group of persons with disabilities. It concludes that there are several possibilities that need further development, but stresses personal independence training at home.
Rose, F. D., Brooks, B. M., & Rizzo, A. A. (2005)	Virtual reality in brain damage rehabilitation: Review	Explores studies that have used VR in the assessment and rehabilitation (brain injury, including executive dysfunction, memory impairments, spatial ability impairments, attention deficits, and unilateral visual neglect). It concludes that the use of VR in brain damage rehabilitation is expanding dramatically and will become an integral part of cognitive assessment and rehabilitation in the future.

Konnerup, U., & Schmidt, D. (2006)	Det virtuelle miljø - en mulighed for nye læreprocesser i rehabiliteringen af afasiramte. <sup>3</sup>	Master thesis on a virtual environment for PWA. It used a combination of home training in the web 2.0 environment and dialogues via Skype. The results were good: Subjects improved spoken and written language and their independency of social others. Participants were more up-to date with news and common knowledge using the Internet.
Mashima, P. A., & Doarn, C. R.	Overview of telehealth activities in speech-	Point of departure is the shortage of speech therapists
(2008)	language pathology	and the need for care and treatment. The review consists of 40 articles. All project involve videoconferences or are related to technology. Positive outcome are shown in relation to motor-related disabilities. Technical obstacles are dominant.
Cherney, L. R., & van Vuuren, S. (2012)	Telerehabilitation, virtual therapists, and acquired neurologic speech and language disorders	Review of evidence for the telerehabilitation of persons with neurological disorders between 2000 and 2012, from synchronous online sessions to virtual stand-in therapists.  Telerehabilitation might be costeffective, but there are still a lot of barriers in collaborating between private computers and clinical settings.

Figure 5 Virtual rehabilitation in aphasia therapy

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<sup>&</sup>lt;sup>3</sup> The Virtual Environment, new Methods in the Aphasia Rehabilitation

To meet existing technical barriers, Leora Cherney, a speech therapist at the Rehabilitation Institute of Chicago, created the Web-ORLA<sup>TM</sup> system. This system works mainly for persons lacking reading, articulatory and sentence formation skills. The training runs through the Internet using a virtual therapist.



Figure 6 Web-ORLA

As mentioned, I was in charge of a distance learning project, ATA, from 2001 to 2004 (Dirckinck-Holmfeld et al., 2004). The project and its evaluation were very similar to those in the studies mentioned above. The therapy was conducted via synchronous videoconferencing, and the assessments were sent by email beforehand. The object was to establish a distance learning service for persons suffering from aphasia, which could extend and improve their rehabilitation efficiency (Dirckinck-Holmfeld et al., 2004). The evaluation concluded that the training had a positive outcome. It especially stressed that the home training was flexible and that it promoted motivation and commitment. We experienced a high degree of involvement on the part of PWAs' relatives. A side effect was that the artefact—that is, the computer—facilitated a negotiation of the PWA's identity (Dirckinck-Holmfeld et al., 2004; Konnerup & Schmidt, 2006). The project developed over time. From using expensive videoconferences and email, we switched to using Internet-based Skype. We also designed a 2.0-based virtual community, in which PWAs could learn through interactions with speech therapists and peers. Making the interface simpler, with integrated and dynamic tools, made it easier to navigate among email, exercises, news, calendars, forays, etc.



Figure 7 Basecube, a virtual community for PWA

### CHAPTER 2.

Konnerup and Schmidt (2006) studied Basecube and its rehabilitation possibilities in a master thesis. Their work indicates that interacting and participating in mediarich web 2.0-based communities strengthens cognition, functional communication and, in a broader sense, personal and social mastery.

However, despite Haim Ring' (1998) article, which asked the question: "Is neurological rehabilitation ready for 'immersion' in the world of virtual reality?" there is still a need for research on immersive interactions in virtual environments and aphasia intervention. By discussing how persons with neurological disorders (e.g., motor disturbance, paralyses and other physical disabilities, Parkinson's disease, impaired cognitive functional disorders, visual defects, speech defects, and a need for occupational retraining) might benefit from interaction in virtual worlds, he concludes that he considers VR a feasible tool for any neurological disability:

VR almost certainly has a role as an assistive technology in neurological rehabilitation. It supports physicians in the diagnostic procedure by enabling three- dimensional manipulation of parameters and visualization of medical data. It gives patients access to navigable spatially complex environments within a broad time scale.

(Ring, 1998, p. 100)

Ring also stresses that several technical drawbacks, such as economics, access, adaption, ethics and safety, need to be addressed before virtual rehabilitation can be realised. Regarding my field of interest—the functional and the psychosocial—he touches only on memory and visual deficits.

In conclusion, these reviews suggest that there are mostly positive visions for content in telerehabilitation, although there still remain significant technical obstacles. Current research exists essentially from a health perspective. Research on learning outcomes, functional communication, and psychosocial issues as identity formation is still needed.

#### 2.5. RELATED WORK

Since there is no research specific to immersive virtual rehabilitation in relation to aphasia intervention, it is necessary to seek experiences and knowledge from other fields. At USC, researchers have been studying various patient groups interacting in virtual environments, and they argue that virtual reality appears to be an influential method for addressing behavioural and mental health within the domain of sociology and psychology (Rizzo, Difede, Rothbaum, Daughtry, & Reger, 2013, p. 2; Schultheis, Himelstein, & Rizzo, 2002, p. 378). In the following, I will describe some of the projects and research studies with which I have become acquainted and

which have inspired my work, primarily through visits to two Californian universities: Stanford and University of Southern California (USC).

At The Institute of Creative Technologies (ICT) at USC, researchers have conducting interesting research and developing projects concerning virtual humans and virtual worlds. Professor and psychologist Albert Rizzo, who is affiliated with the ICT at USC, has, for the last 20 years, conducted research within the field of VR for mental health therapy, motor skill rehabilitation, cognitive assessment and clinical skills training. Today, his primary research realm includes medical research dealing with Post-Traumatic Stress Disorders (PTSD), game-based rehabilitation and motor functioning, as well as how VR can be used to simulate real environments (e.g., war zones and virtual classrooms).

One of Rizzo's current projects (2011-present) is called Stress Resilience in Virtual Environments (STRIVE). Through a number of realistic emotional combat simulations, designed as narratives, soldiers are immersed in a virual warzone and interact with virtual humans before they actually go to war. By experiencing these narratives of chaos and stress before they experience the real battlefield, soldiers should be able to brace themselves with coping strategies and enhanced stress resilience—and, in the end, to prevent their potential risk for developing PTSD or other mental health difficulties (Rizzo et al., 2013)



Figure 8 Stress Resilience in Virtual Environments<sup>4</sup>

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<sup>&</sup>lt;sup>4</sup> From the project's website (http://ict.usc.edu/wp-content/uploads/2013/03/strive-3.jpg)

Another project, *Coming Home* (2007-2013), was directed by Jackie Morie and a portion of the ICT's U.S. Army Research Group. Within an online 3D virtual world designed in Second Life, veterans with post-deployment mental health issues were able to interact with peers and virtual agents, play games, find resources, and participate in therapeutic activities (Morie, Haynes, & Chance, 2011). The environment was designed as a social network in which persons with PTSD could interact. The research foci were how this environment could contribute to the psychological healing process and facilitate strong peer support, as well as on how an embodied component (in form of a personal avatar) could represent participants' inner feelings (USC, 2012). In one of the activities, "The Warrior Journey", the veterans are shown stories about the ideals of honourable warriors and then encouraged to tell their own stories. In this way, they reconstruct their life narratives and regain their self-esteem (Morie et al., 2011, p. 17).



Figure 9 Scenarios from the Coming Home Project<sup>5</sup>

In the fall of 2012, I was fortunate to be a visiting researcher at Stanford University. I was affiliated with the Human Interaction Lab (VHIL) in the Department of Communication, founded in 2003 by Associate Professor Jeremy Bailenson.

From USC's website (http://projects.ict.usc.edu/force/cominghome/public/images/4Photos.png)

Researchers at VHIL conduct research within the fields of psychology, sociology and communication, using empirical and behavioural science methodologies to explore social interactions and behaviours in immersive virtual worlds in an attempt to understand social presence. VHIL integrates technologies that feature equipment for tracking motion, rendering graphics, and displaying visual, aural, and haptic information. It includes a multi-sensory room that allows participants to explore a 20-by-20 ft space with specialized sounds, floor shakers, and a head-mounted display (HMD).



Figure 10 VHIL's multi-sensory room

### CHAPTER 2.







Figure 11 Jeremy Bailenson with a visitor crossing a virtual plank

Thus far, the research of the VHIL team has revealed that avatar-mediated interactions and digital identities can change the ways in which we see ourselves. Our real character can, so to speak, be transformed by mirroring our avatars. This phenomenon is called The Proteus Effect, and it was introduced by Bailenson and Yee in 2007 in the article "The Proteus effect: The effect of transformed self-representation on behaviour". The phenomenon is based on studies showing how short people might achieve more self-confidence by creating tall avatars, as well as how people who consider themselves unattractive might boost their confidence by using attractive avatars (Blascovich & Bailenson, 2011; Yee & Bailenson, 2007, pp. 102–108).

Additional, smaller studies have also been conducted at VHIL: For example, a project aiming to increase sustainable behaviour and environmental understanding by making an avatar cut trees in the wood showed that participants subsequently used less paper (Ahn, 2011, p. 36; 88). Another aimed to make people more altruistic and strengthen participants' sense of empathy towards others by having avatars search for a missing diabetic child in a big city (Rosenberg, Baughman, Bailenson, & Szolnoki, 2013). The results showed encouraging signs that there may be a spillover effect from the virtual environment to real life.

Other universities have also engaged in on-going research projects that aim to support the Proteus effect. I will briefly mention a few:

The Obesity Research Center at The University of Houston, Texas, is using Second Life in a project fighting obesity. One of the researchers' hypotheses is that "individuals with avatars who engage in physical activities in SL are more likely to engage in physical activities in real life" (Dean, Cook, Keating, & Murphy, 2009,

pp. 5–7). The participants were offered Linden \$6 if their avatars had healthy behaviours.

Sanchez-Vives and Slater, affiliated to Universitiet de Barcelona have conducted interesting studies on phobias and social anxiety. They have experienced that an Immersive Virtual Environment (IVE) can be successfully used to make people face their fears (Pertaub, Slater, & Barker, 2002; Sanchez-Vives & Slater, 2005).

Finally, I will mention that, in Europe—and, especially, in Italy and Spain—there are also many exciting projects. In 2009, *Technology and Informatics* published an issue devoted to advanced technologies in rehabilitation. This issue deals with projects that reflect the paradigm shift in rehabilitation, which has moved from focusing on deficit and dependence to assets and independence. The articles focus on rehabilitation as empowerment and on the development of social and communicative skills through VR (Gaggioli, Keshner, & Weiss, 2009)

The list of research studies and projects mentioned above is by no means exhaustible. Instead, these works must be considered an overview of what have been sources of inspiration for my research and the research tradition to which I contribute. I have been fortunate to see several of these projects first-hand during my research visits to California.

#### 2.6. SUMMARY

Qualitative research on the psychosocial aspects of the aphasia realm has been conducted for the last few decades, and there seems to be a consensus that a qualitative approach can add essential dimensions to quantitative research though, for example, insights into the participant engagement, degrees of participation, feelings, needs, social interactions, relationships, and renegotiations of identity. Mixed methods often broaden insights, and psychosocial problems seem to present a dominant problem after a brain injury. Thus, group therapy has been suggested to meet these psychosocial issues. A review of the research literature reveals a need rehabilitation is conducted further studies. Virtual primarily telecommunication from a telehealth perspective, not as avatar-mediated interactions in immersive virtual environments from a learning and functional communicative perspective. Thus, the aim of this thesis is to unite these issues, since experiences from other fields demonstrate that avatar-mediated interactions in virtual environments have impact how people see themselves in real life.

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<sup>&</sup>lt;sup>6</sup> Second Life has its own currency called Linden \$

# CHAPTER 3. METHODOLOGY AND RESEARCH DESIGN

#### 3.1. METHODOLOGICAL CONSIDERATIONS

As mentioned, aphasia treatment and research on aphasia are considered differently depending on the tradition in which they are viewed. This actual thesis consists of different aspects, such as learning, teaching, rehabilitation, brain research, technology, and psychology.

Brain injuries and rehabilitation exist in the area of tension between two research fields, each with their own traditions for research and the philosophy of science: 1) humanities (learning and communication) and 2) natural science (medical brain research and traditional speech pathology). These two traditional paradigms have contradictions. Specifically, the first has a collectively inclusive perspective, and the second has an individual-diagnostic perspective (Kirkebaek, 2010, p. 14).

The new medical technologies and communication testing methods developed in recent decades have revealed new knowledge in the field within rehabilitation, which gives rise to changing attitudes to "good practice". To stress that practice and research are changeable, the research in this thesis will be considered from a sociocultural perspective, in which knowledge and concepts are viewed as contextualized and produced from certain conditions that are related to the world in which we live and that are culturally and historically dependent. Reality is viewed as a social construct through which social phenomena and their meanings are created through social interactions.

Cultural-historical psychological theory and the social constructivism formed by Vygotsky and Luria (Luria, Teuber, Pribram, & Haigh, 1966; Vygotsky, 1986; Vygotsky & Luria, 1993) offer perspectives on both fields of interest mentioned first in this chapter. Brain research can be seen as a social construction that is determined and influenced by research and practices in a given time and in a given society.

Although knowledge about brain functions, physiological processes and brain injuries could be described as, with Wenneberg's words, "scientific knowledge" and "natural" (Wenneberg, 2000, p. 77), the understanding of this knowledge can be considered to be socially constructed.

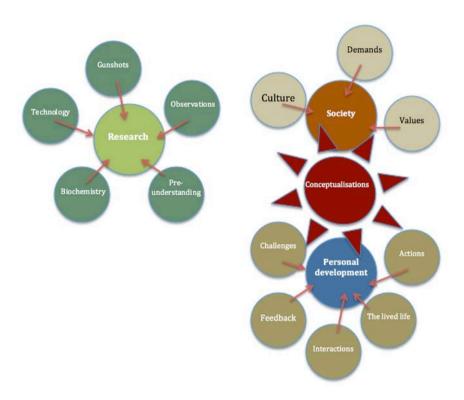


Figure 12 Brain research dependent on culture and tools

Brain functioning and the consequences of brain injuries must be seen in relation to social opportunities and requirements. By considering normality and disability—and, thus, people with brain injuries—as social constructs that are non-static, it becomes possible to highlight how new tools, such as technology-mediated communication, can affect and possibly change the learning and communication opportunities of this group.

Wenneberg (2000) stresses that science must create confidence-inspiring social mechanisms to ensure information that is as trustworthy as possible. With reference to Wenneberg (2000) and Rendtorff (2003), this thesis will show how even the ontological perspective and the so-called "true knowledge" of physical reality in

## CHAPTER 3. METHODOLOGY AND RESEARCH DESIGN

this context are context-dependent and relative from a historical-cultural perspective. Rendtorff (2003) denotes social constructivism as seeing "reality as a project and not a fact<sup>7</sup> and describes how social constructivism has roots in realizations based on the critical phenomenological and hermeneutical tradition.

#### 3.2. RESEARCHING WITH PEOPLE

In view of the above, the present research takes place in a social context, and each participant's social interactions, experiences and attitudes will be considered to have great importance in understanding the problem area. The research is not only *on* people, but also *with* people; thus, it is necessary to ensure a high degree of involvement of "the explored participants". Throughout the process, I have worked closely with a group of nine people suffering from aphasia, their relatives, and their speech therapists. The approach has been to seek access to knowledge about these people's experience of the phenomenon and related processes, including: aphasia, renegotiating identities and relearning to be knowlegeable and cultured citizens.

I am inspired by the phenomenology in which a phenomenon or an experience must be taken at face value. Edmund Husserl (1859-1938) is considered the founder of this phenomenology. Things are likely to be as they are experienced first-hand by the person, without necessarily being regarded as universal truths. As Zahavi (2003) states, "The phenomenon is as it appears to us, from our perspective, but not as the object is in itself<sup>8</sup>" (p. 13). Man is seen as intentional: that is, his consciousness is always directed toward something, and it is driven by values and goals. In phenomenological terminology, the first-hand perspective is emphasized, and the world is seen as experienced by actors (Zahavi, 2003, pp. 16–19). In the attempt to understand human social behaviour, the phenomenology largely makes use of qualitative methods. It is based on the subject and its relation to the world. Each human being should be able to articulate its own story and communicate it. The underlying basis of the phenomenology is the subject's being in the world. This means that we, as subjects, participate in the surrounding world.

Phenomenology is considered a prerequisite for many later theory formations, including hermeneutics (Zahavi, 2003, p. 7). Husserl's assistant, the philosopher Martin Heidegger (1889-1976), tried to bridge the gap between two seemingly contradictory systems of thought: hermeneutics and phenomenology. Heidegger (1927), breaks with Husserl in objectifying consciousness. To Heidegger it is essential that the reflexive recognition of subjectivity does *not* mean that consciousness lives its own life. We must recognize that human beings *are* in the world. When phenomenology insists on a first-hand perspective, based on the

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<sup>&</sup>lt;sup>7</sup> Translated by the author

<sup>&</sup>lt;sup>8</sup> All citations from Zahavi (2003) have been translated by the author

understanding that our *being in the world* is given in the horizon of meaning, we are situated in relation to. (Zahavi, 2003, pp. 16–18).

In this thesis, the phenomenon at hand (i.e., renegotiation of identity after a brain injury) will not stand alone, but will be interpreted in its historical-cultural context, according to the hermeneutical consideration that we, as subjects (here: researchers), do not have objective knowledge of the changeable; instead, we understand the subject through interpretation. Hermeneutics derives from the Greek "hermeneutikos", meaning "to interpret", and it originally reflected on the interpretations of texts and how these same texts could be understood differently in different epochs and milieus. Heidegger and Gadamer brought the hermeneutic idea into the understanding of human cognition (Winograd & Flores, 1987, pp. 27–30). Today, this is a common approach used in the humanities. Man is born into a particular culture, in which he is formed and developed through interactions with the world in which he lives in and the culture of which we, as humans, are products. The individual's interpretation of the world is determined either consciously or unconsciously by his pre-understanding (Gadamer, 2004; Winograd & Flores, 1987, pp. 27-30). This creates a circular argument, in which "what we understand is based on what we already know, and what we already know comes from being able to understand" (Winograd & Flores, 1987, p. 30). This understanding means that interpretation takes place in movements between the whole and parts and between what is to be interpreted and the context in which it occurs. The preunderstanding changes as the researcher is confronted with other parts or wholes.

Thus, this thesis may be viewed in light of the fact that the researcher is a carrier of Danish culture anno 2010 to 2015 and that the researcher has personal experiences working as a speech therapist and researcher. The tradition recognizes that the researcher has an understanding and an attitude that will impact the interpretation of this project. The methodology uses a method combination, in which the researcher—in a social context and with a hermeneutic-phenomenological approach—tends to interpret the involved participants' experiences and understandings. Social constructivism, phenomenology, and hermeneutics share the conception that man is intentional and that reality and meaning are created through human actions (Rendtorff, 2003). By considering the research area as a social construction that is context-sensitive, people, disabilities and technology become non-static entities, through which the rethinking and remediation of practises are possible. Through qualitative research methods and analyses of empirical data, the phenomenological-hermeneutic interpretation is positioned within a social constructivist perspective. The phenomenological analysis strategy emphasizes the subject's point of view (Kvale & Brinkmann, 2008, pp. 44-50). Finally, the approach acknowledges storytelling as part of science—and, thus, builds its assumptions on narratives from the participants and their experiences and on learning processes in the virtual environment.

#### 3.3. CASE STUDYING

The research design is inspired by the a case study approach as described by Robert Yin:

A case study is an empirical inquiry that investigate a contemporary phenomenon (the "case") in depth within its real-life context, especially when the boundaries between phenomenon and context may not be clearly evident...... A case study inquiry relies on multiple sources of evidence, with data needed to converge in a triangulating fashion, and as another result. Benefits from prior development of theoretical propositions to guide data collection and analysis.

(Yin, 2009, pp. 15–17)

This definition should be understood as a contradiction to experiments, laboratory test, and surveys. Yin (2009, p. 29) suggests five components to be used in the research design of a case study:

- A case study question
- Its propositions, if any
- Its unit(s) of analysis
- The logic linking the data to the proposition
- The criteria for interpreting the findings

The research question of this thesis is considered to be the *case study question*, and I have tried to identify *propositions* in the state of the art and the theory.

A case study allows a research study to be based on practices with high degrees of research group involvement in the natural environment. In the present case, the research group involves PWAs, their significant others and their speech therapists. The case is based on collaboration with The Institute of Speech, Language, and Brain Disorders in Denmark and relates to the Institute's practises with technology-mediated rehabilitation. The specific case, according to Yin's terminology regarding "units of analysis" is relevant for rehabilitation in IVEs. The case consists of three phases:

- 1. Development of the idea (pedagogically and practically)
- 2. Pilot course for speech therapists (learning to teach in an IVE)
- 3. Pilot for PWA (rehabilitation course)

The real-life context comprised the participants' homes (where the interviews were conducted), the university (where a workshop was held) and, finally, Second Life (SL), where the pilot courses took place. Since the perspectives of the PWAs, the professionals, their previous experiences and their theories are all included; the boundaries between case and context might not be evident. The features of the case rely on multiple sources of data, such as interviews, workshops, and participant observations. Theory and literature reviews of previous research have been fundamental for the research design.

The point is *not* to describe the frequencies and symptoms with of PWAs in general and their broad possibilities of technology-mediated rehabilitation. Neither is it interesting in this thesis to include representative cases related to managing ICT, injury, age, gender, or profession. The aim, instead, is to understand the rehabilitation potential of avatar-mediated learning in an IVE and to determine whether virtual communication and learning interactions might equip PWAs to renegotiate their identities, thereby enabling them to remain knowledgeable and cultured persons. The aim is not, as in some case studies, to develop theories; rather, based on my understanding and interpretation of the data, I seek to reformulate speech therapy and to develop a proposition for virtual aphasia pedagogy.

The case can be described as a homogeneous case consisting of a group of people who all have the same basic premise or motivation to describe a specific topic in depth: namely, they are all seeking to recreate themselves after a brain injury.

Since access to the participants' subjective experiences was desired, the case participants were not only selected based on established, stringent dimensions, but also on their similarities in relation to their enthusiasm and commitment to the use of IVEs in rehabilitation. This selected method was carried out in order to describe an optimal potential that could "manifest the phenomenon intensely" and that is based on theoretical knowledge of learning processes in IVE and research in rehabilitation after a brain injury.

#### 3.4. VIRTUAL ETHNOGRAPHY AND VIDEO ANALYSING

The advent of the Internet has opened new possibilities for such research methods as "Hyperlink analysis, web spheres, ethnographic explorations of online environments and web-linked fields, mapping and actively intervening in the construction of web geographies, and time-stretched and interactive electronic research interviews" (Hine, 2005, p. 245).

Since a significant part of the empirical data in this thesis is collected from the Internet (i.e., 1. recorded sessions from an online community, Second Life, and 2. interviews in online settings), some reflections on Internet-based research methods

# CHAPTER 3. METHODOLOGY AND RESEARCH DESIGN

are relevant. The approach chosen for this context has primarily been inspired by virtual ethnography, as described by Hine (2000, 2004, 2005, 2008), Schroeder and Bailenson (2008), Blascovich (2002), and Boellstorff (2008).

Virtual environments are a relatively new area of research, in which ethnographic approaches in particular have been used in social and psychological sciences since the 1990s. The understanding of virtual ethnography was initially developed in relation to text-based research. Today, the approach is also used in relation to research on virtual communities and worlds, like World of Warcraft and Second Life (Boellstorff, 2008, p. 61; Hine, 2008, p. 259).

Researchers recently begun discussing the extent to which it is possible to translate conventional ethnographic research methods into technological settings (Hammersley, 2006; Hine, 2004). Ethnography is defined as the first-hand study of "what people do and say in particular contexts. This usually involves lengthy contact, through participant observation in relevant settings, and/or through relatively open-ended interviews designed to understand people's perspectives" (Hammersley, 2006, p. 4). In the debate about virtual ethnography, there have been two subjects of special interest. The first concerns whether the short-term study of online sessions followed by video analysis can be defined as ethnography in the conventional understanding. The second concerns the setting: that is, whether observations in a virtual environment can be considered to be research on equal footing with observations in real settings. Hammersley asks:

Does ethnography depend upon the physical presence of the ethnographer in the midst of the people being studied? Or does the assumption that an ethnographer must be physically present involve an out-dated conception of what is required for ethnographic work?

(Hammersley, 2006, p. 8)

Hamersley's (2006) understanding of online research is build on the premise that the researchers and the participants have never met in "real life" and that the researchers, therefore, do not know who the participants really are. In other words:

We do not know who the writers of the online contributions are, what their purposes were, what their circumstances are, etc. beyond what they tell us. And we should perhaps be cautious about accepting what they say at face value.

(Hammersley, 2006, p. 8)

By this, Hammersley also reveals that he does not consider online settings to be *real*. However, according to Hine, the online setting *is* to be considered to be a social reality (Hine, 2008, p. 257). Comparing the principles in conventional

ethnography, as described by Hammersley and Atkinsons (1995), Hine concludes that the phenomena for *being* is the same in virtual ethnography as it is in conventional ethnography (Hine, 2004, p. 14). The research field is not necessarily a physical setting:

Of course, in all of this the question of where to locate the field, how it was that I understood myself as being in the field, brings home the point that "the field" is an epistemological rather than an ontological category: it is a state of mind

(Hine, 2004, p. 8)

Boellstorff, who considers himself an anthropologist, has conducted years of research as the avatar "Tom Budowski". He breaks the understanding that ethnographic research requires researcher and participants to meet in the physical world and argues that virtual worlds must be studied on their own terms (Boellstorff, 2008, p. 61). In an IVE as Second Life and with avatar-mediated research, a person actually *is* present in the culture he/she is studying. Moreover, the core of a phenomenological approach is taking a person's word for face value.

In an IVE, a researcher is given a vivid opportunity to experience a phenomenon in a first-hand way, observed from the outside. Schroeder and Bailenson (2008) have outlined research methods in online multi-user virtual environments and suggest a number of advantages for research. Specifically, subjects and researchers do not need to be co-located; interaction is possible in virtual environments (VE) that, for practical or ethical reasons, are not possible in the real world; all verbal and nonverbal aspects of the interaction can be captured accurately and in real time; and the social contexts and functional parameters of interactions can be manipulated in different ways (Schroeder & Bailenson, 2008, p. 327).

According to Blascovich et al. (2002, p. 114) human representations do not have to be perfectly behaviourally and photographically realistic to represent human behaviours and interactions and to have a trade-off effect to real-life interactions.

Regarding the virtual part of this current research, I consider the approach to be a virtual ethnography. Although the setting was constructed and I, despite my role as researcher, was a co-designer, the natural setting was the IVE, Second Life. My role as a researcher was to observe the interactions, record the sessions, and finally analyse the recorded materials. The overall aim was to understand the participant's interactions and learning outcomes in their natural setting. My position was behind my computer, such that I was on equal terms with the other participants. I was online, and my avatar was visible to everybody. Most of the time, I was a silent observer; however, as in the real world, I said hello and goodbye, and if any circumstances required me to be more active and/or to participate verbally or

# CHAPTER 3. METHODOLOGY AND RESEARCH DESIGN

nonverbally, I did. Represented by my avatar as an ethnographer, being in the field helped the field became *a state of mind*. That said, the method used in this thesis was combined with research in the real world. I knew all of the participants beforehand from interviews and workshops. It was important for me to build trust amongst the participants before the online sessions, since the roles, as avatars were new to everyone. I also wanted to be clear about the purpose of my presence. Thus, I informed the participants about the project and what it would involve to be a participant in the project in speech and pictures at my home visits and at the workshop. Specific others were present to co-understand my research purpose.

Combining virtual ethnography with video analysis allows researchers access to be a part of interactions as they happen online and to explore details repeatedly afterwards. Video recording in qualitative research makes it possible to document social actions, since "video can form an archive, a corpus of data that can be subject to range of analytic interest and theoretical commitments, providing flexible resources for future research and collaboration" (Heath, Hindmarsh, & Luff, 2010, p. 2). Since the video material used in this thesis is not video of people and interactions in the physical world, there are some limitations with regard to facial and body expressions. In IVEs representations of people are recorded and thereby avatar mediated interactions and communicationare captured. Consequently, such recordings may not be as sensitive as real-life recordings in the physical world, since the person behind each avatar appears anonymously.

#### 3.5. SUMMERY

The methodology used is a combination of qualitative approaches. My understanding of reality is that it is a social construct that is culturally and historically dependent. Social phenomena and their meanings are created through social interactions. Thus, if a person wants to understand a phenomenon, he or she must study the phenomenon itself - in this case: the research case and its participants. The analysis and the conclusions will not be objective, since, in the research, I also served as a subject, interpreting hermeneutics with my experiences and lived life. I am aware that the research period was relatively short and that I played a double role (since as I was both co-designer and decision maker in relation to the choice of environment). I am also aware that there is a lack of replication and that one could argue a paucity of evidence. Nevertheless, through triangulating and analysing multiple sources of data, I have had the opportunity to study and understand a phenomenon: How PWAs learn, interact and renegotiate their identities in an IVE.

#### 3.6. ETHICS

Researching with and on people with disabilities poses some ethical challenges. These challenges do not grow less serious as we deal with people who are in the position of not being able to fully express themselves and who may have problems understanding the speech of others. How do we know if these people really want to participate? Do they understand what we are asking?

To meet this challenge, I selected participants who were (are) all former and present clients at The Institute of Speech, Language and Brain Disorders. The enquiries regarding whether the PWAs and their relatives wanted to participate were made by the participants' speech therapists, and both the speech therapists and the relatives were present at the first interviews. From former projects, my experiences are that being a part of a real research project engages and empowers tPWAs. Most PWAs deeply want to inform others about how it feels to have a communication disorder and to develop new rehabilitation methods. Thus, a research study makes them feel that they are being taken seriously. Finally, all of the partipants were offered to be anonymized.

# CHAPTER 4. THE CASE

The Institute for Speech, Language, and Brain Disorders in Aalborg, Denmark, has, since the beginning of this decade, focused on developing technology-mediated methods for rehabilitation treatments for PWAs. This focus has grown from the use of software and individual training programs in the 1990s to the use of social media in the 2000s—and to, today, the offering of avatar-mediated rehabilitation in Second Life (SL).

The present case comprises the development of a new initiative regarding avatarmediated rehabilitation, conceived through collaboration between The Institute for Speech, Language, and Brain Disorders and me. The initiative is based on previous experience with rehabilitation in web 2.0 technologies (e.g., the ATA project). Our finding from the ATA project was that, besides formalized teaching, the virtual environment provides many options for communication. The participants:

- 1. Communicate and learn by various forms of perception and modalities
- 2. Meet people at their same standing
- 3. Use preferred learning and communication strategies
- 4. Get an opportunity for self-reflection and self-presentation via profiles and weblogs
- 5. Get an increased extent of independence
- 6. Get a strengthening of cognitive functions
- 7. Become able to take responsibility for their own learning and the sense of being part of a community, as well as for the feeling of being "present"

(Konnerup & Schmidt, 2006)

Based on these results and knowledge about the plasticity of the brain (Bjarkam, 2004), mirror neurons (Rizzolatti & Sinigaglia, 2008) and embodiment, the idea for a new project emerged. Transforming the learning landscape from a two-dimensional learning environment to a three-dimensional one would allow bodily immersion and interaction through avatar mediating. Based on an assumption that the involvement of the body and of nonverbal activities will affect the brain, we expected a positively promotion of cognitive and communicative functions.

To involve different stakeholders in the development of the project, a project group consisting of therapists, PWAs, and relatives, was set up at an early stage.

#### 4.1. PREPARATIONS AND CHOICE OF TECHNOLOGY

Initially, we had the idea of designing a new virtual environment for the project, and a project proposal was given to students of Medialogy at AAU. However, none of the proposals we received were complex enough and suitable for our target group and objectives. The next step was to contact one of my friends at Stanford: Mette Terp Høybye. In collaboration with Stanford and Katalabs, Inc., Høybye had developed an environment for peer support for young people fighting cancer (Høybye, 2012). The environment was still a prototype, had only few scenarios and was not suitable for our project. However; further development would be too time consuming and expensive.

A workshop conducted for all participants made clear that the PWAs wanted an environment similar to that of a small Danish city. It came to our attention that some land in Second Life (SL) was for sale. The Institute for Speech, Language, and Brain Disorders decided to buy this land, since it would be an easy and inexpensive way to test some of our ideas. The fact that The Institute for Speech, Language, and Brain Disorders owned the land meant that we could make it private and, thereby, have a safe area in which to practice.

#### 4.2. PILOTS

Even though the involved therapists had experience with ICT in rehabilitation and distance training, they did not have any experiences in 3D platforms or avatar-mediated learning. A pilot course (pilot 1) for speech therapists was set up in SL. The primary goal was to develop a frame and a platform for pedagogical and didactic considerations and discussions. Pilot 2 was a six-week rehabilitation course for PWAs. In this pilot, the goal was to try out the avatar-mediated methods and to investigate who and how the different variations of PWAs could benefit.



Figure 13 Training session for PWA

The pilot courses were based on social interactions and activities in a community-centred perspective. Besides joining the group sessions, all participants were motivated to go online in SL more often.

# CHAPTER 5. THEORETICAL FRAMEWORK

Rehabilitation after brain injury is a complex field that can be viewed differently depending on the theoretical considerations behind the treatment and the interventions implemented. In order to answer the research questions, I will outline the theoretical framework in which this present research should be understood.

In Denmark, one can be trained as a speech therapist in two different ways. Either a person studies logopedics as full master degree at the university, or he or she combines a bachelor in learning science with a master's degree in logopedics at the teachers' colleges. My education came about through the latter method in the 1990s. The entirety of my education occurred through the lens of the Soviet cultural-historical model, referring to the psychologists LS Vygotsky, AR Luria, and AN Leontiev. From that perspective, knowledge of the brain and its higher mental functions was fundamental and considered a prerequisite for understanding brain injuries, language, and communications disorders. In this chapter, I will describe the brain, its mental functions, and recent research on these functions. The approach is not pathological (as if it were an illness); rather, it is functional in its understanding of the use of the language in social interactions. I will also elaborate on Vygotsky's (1934) research on thought and language, including how language is essential for identity formation and a prerequisite for learning and social relationships. Moreover, I will provide reflections on the consequences labelling people with disorders has and how rehabilitation and special education are framed. Since rehabilitation concerns re-learning, finally, I will describe my position within learning theories and the distinctive characteristics of IVEs and didactic potentials in avatar-mediated learning.

#### 5.1. THE BRAIN

It is, as mentioned, primarily the Soviet neuropsychologist Luria who formed and inspired me in my practice and research. Luria's work has inspired many neuropsychologists. Relevant to mention is his Latvian/Soviet student Elkhonon Goldberg<sup>9</sup>, who was born in Riga and was Luria's student in Moscow. In 1973, he fled from the Soviet Union, and today, he is a professor and acknowledged scientist in New York in the field of the function of the frontal lobes, hemispheric

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<sup>&</sup>lt;sup>9</sup> Clinical Professor of Neurology at New York University School of Medicine, Diplomate of The American Board of Professionel Psychology in Clinical Neuropsychology, Co-founder and Chief Scientific Advisor of SharpBrains.

specialization, memory, cognitive aging, and the general theory of functional cortical organization. He is strongly inspired by Luria's and Vygotsky's views on the role language plays in human development and learning ability. His research combines Luria's theories with present-day studies of the brain. Goldberg's present research field—that is, how cognitive fitness might harness the effects of lifelong neuroplasticity in order to delay and even reverse the effects of cognitive aging—has given rise to my idea of cognitive fitness/training in relation to rehabilitation. If cognitive training can delay aging and malfunctions, it might as well harness neuroplasticity to rehabilitate and stimulate areas in the brain.

Danish medical doctor and brain researcher Kjeld Fredens has been a great source of inspiration as well. Fredens is a former member of the Danish Council of Ethics. His field of interest comprises, in particular, the processes of the context, actions, and thoughts underlying learning, creativity and collaboration. Fredens describes his method of understanding the brain as neuro-constructivistic, in the sense that cognitive functions are built through interaction with the challenges they face (Fredens, 2006, 24:48). Cognition is not limited to the brain; rather, it is to be understood in relation to the environment. The brain develops through challenges, and context and feedback play crucial roles in its ability to learn. In his book *Mennesket i hjernen*<sup>10</sup>, Fredens (2004) introduces the concept of neuropedagogy and describes how neuropsychology can be translated into learning and teaching practices. In doing so, he offers a useful link between the knowledge of the brain and rehabilitation (Fredens, 2004).

According to my interest in whether interactions that are mediated and embodied by avatars can stimulate and rehabilitate language, I have tried to find answers in brain research, within the field of mirror neurons and embodiment. Specifically, the research of Rizzolatti (2005, 2008), Ramachandran & Altschuler (2009), and Damasio & Meyer (2008) offers some suggestions for how imitation and observation might stimulate conceptual representations of actions, which might lead to the re-learning of concepts and words.

To facilitate an understanding of the limitations and opportunities for learning and renegotiating identity after a brain injury, the brain functions and working methods will be described in the following.

First, let us explore a brief history of brain research.

Brain scientists have, since medieval times, tried to demonstrate how mental processes take place. The French physician Franz Joseph Gall (1758-1828) believed that human abilities, behaviours, and feelings were located as innate faculties in

<sup>&</sup>lt;sup>10</sup> Man in the Brain (author's translation)

#### CHAPTER 5. THEORETICAL FRAMEWORK

defined areas of the brain. This way of thinking was called phrenology, and it holds, despite its unscientific basis, importance in contemporary treatments (e.g., insanity) and in certain developments in brain research (Gade, Gerlach, Starrfelt, & Møller Pedersen, 2009, pp. 2–3).

The French anatomist Pierre Paul Brocca (1824-1880) and the German neurologist Carl Wernicke (1848-1904) were, at the end of the 19th century, the first scientists to demonstrate that language disorders (i.e., expressive and impressive character, respectively) were localized in certain areas in the brain. These findings were based on such scientific work as the observation and dissection of brains. Today, two kinds of language disorders are still named after these two men. Brocca expressive disabilities, and Wernicke refers to one related to impressive disabilities (Gade et al., 2009, p. 5)

A wave of attempts to find "localisations" of the brain's functions followed Brocca and Wernicke. There was no consensus among neurologists regarding the existence of limited localisations. Some were advocates of a holistic view, in which psychological processes are distributed throughout the brain, while others held the theory that human mental activities were more complex in nature (Luria, 1977, pp. 17–18).

Luria's epochal brain research (1970) is based on soldiers' head wounds from World War II. Through analyses of the changes that occur in human mental processes using local lesions, Luria studied the contributions of psychological processes at different areas and levels in the brain. Luria's (1973) work revealed that mental function cannot be localized to isolated areas in the cortex, "but is organized in systems of concertedly working zones, each of which perform its role in the complex functional system, and which may be located in completely different and often far distant areas of the brain" (p. 31). He considers the brain as a dynamic, functioning whole, consisting of cooperating functional systems. Specifically, the brain consists of general functions—which, in turn, consist of essential functions. This means that the brain has a surplus capacity, such that the same task can be solved in several ways. Thus, there is potential from which to draw. When some areas are damaged, intact areas take over. Thus, human behaviour is seen as a complex interaction of the different areas and levels in the brain, such that each makes its contribution to the development of psychological processes. Luria's research (1970, 1973) has been influential internationally for subsequent brain research—and, in Denmark, his thoughts have also been important for the context of special education.

Today, the general understanding of the brain among researchers is that it consists of a complex network of nerve cells, neurons, and glial cells that are connected by nerve lanes. Adipose tissue (myelin) facilitates the passage of the electrical signals produced in the neurons. The communication among neurons is made possible by

biochemical substances called neurotransmitters. The transfer from neuron to neuron is gradually facilitated by inputs from the outside world (Goldberg, 2009, pp. 25–27). Recent brain research has shown that, if they are stimulated, nerve cells can proliferate throughout life, damaged nerve cells can form new offshoots based on stem cells (if the body of the nerve cell is intact) and nerve cells can divide (Bjarkam, 2004, pp. 25–39; Buonomano & Merzenich, 1998; Doidge, 2007; Fredens, 2004, pp. 80–86).

In the early 1990s, an Italian research experiment using monkeys showed that the same specific areas in a monkey's brain are activated during action execution and action observation (Di Pellegrino, Fadiga, Fogassi, Gallese, & Rizzolatti, 1992, pp. 177-179). Further research conducted by others, including Rizzolatti & Sinigaglia (Rizzolatti, 2005a; Rizzolatti & Sinigaglia, 2008), Ramachandran & Altschuler (Ramachandran & Altschuler, 2009), and Damasio & Meyer (Damasio & Meyer, 2008), has revealed that mirror neurons respond actively to other people's goaldirected actions in the same way as if they themselves had performed the action. This means that the brain is activated through the notions of actions (Rizzolatti, 2005a, pp. 64–71; Rizzolatti & Sinigaglia, 2008). These findings have prompted further research on mirror neurons and their importance for understanding social skills. Damasio, a professor at the Brain and Creativity Institute at USC, is a neuroscientist with a special interest in the neurobiology of the mind and behaviour, who has written about aphasia and its impact on communication. Damasio also has an interest in embodied semantics for actions, which add interesting findings to the research on mirror neurons. He specifies that the sensory motor in the areas of the brain used to produce an action are also used for the conceptual representation of he same action. (Aziz-Zadeh & Damasio, 2008; Damasio, 1989). These findings might lead to some very interesting possibilities for language rehabilitation, especially with regard to action words (verbs).

With the development of new biotechnological registration options, it is now possible to see the structures of the brain, to study brain activity and to gain insight into electrical and chemical processes. The understanding of brain processes, damage localizations, and the knowledge of which areas of the brain play together is, accordingly, extended. Human brain imaging shows that language is not related to limited areas in the brain; rather, it is distributed throughout the neocortex. Language can be described as an emergent phenomena, "made possible when the brain's neural circuits have reached a certain degree of complexity" (Goldberg, 2005, p. 95). In Goldberg's understanding, language is shaped not only by the specifics of neural organization, but also (to a high degree) by socio-cultural factors (Goldberg, 2005, pp. 89–97).

Today, many brain researchers within both clinical and biotechnological fields have a shared understanding of the dynamic brain. The system of the brain consists of a

#### CHAPTER 5. THEORETICAL FRAMEWORK

mosaic of areas that are closely linked together (Goldberg, 2009; Rizzolatti & Sinigaglia, 2008).

In this context, I will not engage in a detailed description of the brain's architecture; instead, I will simply mention that the brain anatomically consists of several parts, as follows: 1) The brainstem regulates wakefulness and transfers energy to the neocortex (cerebrum) 2) The limbic system controls a number of body functions (e.g., body temperature, blood pressure and heartbeat). 3) The cerebellum's primary task is muscle interaction and balance and 4) Neocortex, which consists of overlapping areas, each with its own functional systems in a left and a right brain (Hansen, 1997, pp. 11–28). The higher mental functions addressed by this thesis exist primarily in the neocortex. However, the brain must be seen as a whole in any mental activity in which several functions occur in close interaction, each with its own special contribution. An injury in one area can affect other areas. The brain is a component of what makes learning possible, but the skills are not localized to the brain.

Luria (1976) was one of the first to interconnect brain research and psychology. Today, this discipline is called "cognitive neuroscience". However, knowledge about the architecture of the brain is not sufficient to understand human thinking and learning. In the following paragraphs, I will explicate some of the cognitive functions that are prerequisites for being able to learn and relearn. In so doing, I seek to provide insights into the fundamental fields of brain rehabilitation and to ease the understanding of the pedagogical approaches that are later recommended.

#### 5.1.1. COGNITION

Cognition is an expression of the active mental processes that are related to knowledge, such as: perception, action, emotion, attention, memory, and higher cognitive functions (e.g., language and thinking). In line with the described view on knowledge and learning, cognition covers both unconscious and conscious processes and should be seen in a socio-cultural context as an interactive life-process (Fredens, 2004, p. 9).

Within cognitive science, one differs between three different generations. The first generation was inextricably linked with information technology, since the brain was regarded as a mental processor of information. Seeing the human brain as a computer—and, thus, ignoring the body's impact on thinking and cognition, was criticized in the 1970s. Another generation of cognitive science inspired by, for example, the French phenomenologist Merleau-Ponty arose with the concept of the *embodied mind* in focus. The bodily experience and linguistic and conceptual cognitions were considered to be fundamental, as expressed by Gallagher and Zahavi as follows:

.... it is certain that our cognitive experience is shaped by an embodied brain. Indeed, it is increasingly accepted that the brains we have are shaped by the bodies we have, and by our real world actions. Cognition is not only embodied, it is situated and, of course, it is situated because it is embodied.

(Gallagher & Zahavi, 2012, p. 132)

Besides being anchored in the body, cognition is also situated and socially related. Within the humanities and linguistics, there has been a paradigm shift. Specifically, the focus has moved from generative grammar as defined by Chomsky (1964, p. 32), with an understanding of syntax as an autonomous and innate module in the brain, to a cognitive linguistic understanding, "where the focus now is meaning formation and its relation to our general perception and bodily perception of the world (Jensen, 2011, p. 39). Proponents of this understanding argue that cognition is based on bodily and social experience. For example, in their book *Philosopher in the Flesh*, Lakoff and Johnson describe that, according to the second generation of cognitive science, language is considered from the broadest perspective:

It includes, for starts all those things you would learn if you were to learn a foreign language: the meanings, the pragmatic, the speech-act constructions, constraints on processing...Second-generation cognitive science is committed to studying much more of the language than is Chomskyan linguistics. From such a perspective, Chomskyan linguistics studies only a tiny part of language.

(Lakoff & Johnson, 1999, p. 482)

The latest understanding of cognitive science, the third generation, is called the "social turn". In many ways, this generation is similar to the second, but it focuses on the fact that cognition, besides being socially and culturally based, is also action-based and mediated by artefacts. With reference to Vygotsky's (1978) notion of the social origins of higher mental functions, Hutchins stresses (1995, p. 283) that cognition is not an individual mental process, but a process that experiences an external stage. In Hutchins' terminology, the third generation is called "distributed cognition":

...communication among individuals in a socially distributed system is always conducted in terms of a set of mediating artefacts (linguistic or other), and this places severe limits on the bandwidth of communication among parts of the socially distributed system. Systems composed of interacting individuals have a pattern of connectivity that is characterized by dense interconnection within mind and sparser interconnection between them. A cognitive process that is distributed

#### CHAPTER 5. THEORETICAL FRAMEWORK

across a network of people has to deal with the limitations on the communication between people.

(Hutchins, 1995, p. 285)

This perspective of cognition is very interesting to include in designing rehabilitation in IVEs. Specifically, what are the limitations, and where are the potentials among participants?

#### **5.1.2. ATTENTION**

Fredens defines attention as "orientation towards something sudden and new; it also means attentive, energetic, thoughtful, concentrated, focused and conscious (Fredens, 2004, p. 116)" One can distinguish among several other kinds of attention, as well: a global attention (arousal and a selective attention. These allow us to focus on something specific and to select or deselect the relevant; sustained attention involves the ability to concentrate over time, and shifting attention suggests divided attention. One could compare this to "keeping several balls in the air" but also being able to switch among different strategies (Fredens, 2004, pp. 128–129). Perceptual processing of sensory input requires attention to move from, for example, hearing to listening. Attention plays a crucial role in the object-oriented consciousness and in all other cognitive functions. It is, thus, a prerequisite to learn and be rehabilitated after a brain injury.

#### **5.1.3. MEMORY**

Attention is a prerequisite to memory, and memory is the ability to create, store, and recall stored experience and information; that is, it is not an end in itself:

Most real-life acts of memory recall involve deciding what type of information is useful to me at the moment, and then selecting this information out of the huge totality of all the knowledge available.

(Goldberg, 2009, p. 93)

Memory is one of the most complex cognitive functions, and it draws on several different brain processes and brain areas. There is a distinction between anterograde amnesia (memory loss), which refers to a person's ability to learn new things after an injury, and retrograde amnesia, which affects memories from before the injury (Goldberg, 2005, pp. 126–132). In addition, there is a further distinction of memory

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<sup>&</sup>lt;sup>11</sup> All citations from Fredens are translatet by author

<sup>12</sup> Wakefulness

into memory for skills (procedural memory; e.g., riding a bike) and memory of facts (declarative memory). These, again, are divided into episodic memory (stored with the context in which it is recalled) and semantic memory (independent of context). A brain injury can affect all aspects of memory functions, but global memory impairment is rare. For rehabilitation purposes, it is important to distinguish among the different types of memory.

Goldberg (2005) breaks with the notion that the brain is made of short-term and long-term memory systems. Instead, he states that they are two stages of the same process and include the same brain structures. Memories are formed in and involve the same neural network that processes them, and:

When changes in the network become lasting and robust, the information becomes firmly ensconced in long-term storage. The changes that will have taken place in the network are chemical and structural. Synaptic contacts will have been altered and new receptors formed. The memories thus created will be robust and relatively invulnerable to any assault on the brain.

(Goldberg, 2005, pp. 111–112)

Before a memory becomes a robust structural representation, it has a more uncertain life as a so-called "repetitive loop" in the limbic system and the brain stem. Any new experience or piece of information that is similar to a previous one will breathe new life into the repetitive loops and increase the chance that the memory will become a long-term memory (Goldberg, 2005, p. 123). This means that many experiences with related common characteristics will form a common neural network involving overlap. Goldberg calls this generical memory and refers to the phenomenon of over-generalization. This process is why common aspects of situations are learned much faster than the aspects that separate them. The greater the total set of experiences is, the more resistant it will be facing a brain injury (Goldberg, 2005, pp. 124–125).

The opportunity to regain memory loss after a brain injury is individually determined. There is a tendency though that part of a retrograde amnesia can be reestablished. The newer and less consolidated a memory is, the weaker its chances of being recovered. Thus, a slower and less complete recovery of anterograde amnesia is often seen. Moreover, episodic memory is typically hit harder than semantic memory.

Knowledge of memory and a distinction between types can guide the learning strategies and the choice of technologies to be used in rehabilitation.

#### **5.1.4. PATTERN RECOGNITION**

Goldberg (2005) describes generic memories as patterns. Further, he describes the concept of pattern recognition as the human ability to form concepts about the world. Pattern recognition refers to the brain's generalization of memories, such that one does not meet every new object or challenge as if it were for the first time. Instead, neural networks allow pattern recognition, such that different experiences activate different neural networks. No network is identical, but they do overlap, and this overlap creates a network of common characteristics. The more experiences are similar, the more overlap. Humans are born with a brain that, to some extent, has pre-programmed schedules for pattern recognition; however, pattern recognition processes are also dependent on external stimuli and are, thus, a mixture of genetic and environmental factors. Goldberg describes how this ancestral experience is, to some extent, encoded in the human brain as part of a so-called "phylogenetic wisdom". This characteristic of human culture means that that collective knowledge can be transferred through generations by cultural means and symbol systems, including language (Goldberg, 2005, pp. 87-92). This view is consistent with the cultural-historical school's claim that human development is both historically and socio-culturally conditioned and that experience transfers through artefacts.

Fredens (2005) agrees that man is born with a number of transactions and strategies to learn and develop. However, with his neuro-constructivistic view of the brain, he has a more radical understanding of *how* big a role the outside world and the external factors play in the development of the individual brain (Fredens, 2006,. 24:48). That is, to Fredens, the physical world is also a social construction.

#### 5.1.5. WISDOM AND COMPETENCE

The phenomenon of wisdom is not easy to define. Through the ages, there have been several attempts, and leading scientists have often viewed wisdom as a psychological and social phenomenon. Overall, wisdom has often been correlated with intelligence and "has been understood as a fusion between the intellectual and moral, spiritual and practical dimension" (Goldberg, 2005, p. 74). However, how can one explain wisdom in relation to brain mechanisms? In his book *The Wisdom* Paradox Goldberg investigates this question, and he finds an answer that is closely related to pattern recognition described above. The patterns formed in the brain are, according to Goldberg (2005), characterized as wisdom, competence or expertise. The "ability to recognize a new object or a new problem as a member of an already familiar class of objects or problems" (Goldberg, 2005, p. 85) keeps us from considering every object or problem as new. Former experiences and knowledge can be used in the assimilation of new experiences. The wisdom of the species involves culturally coded and transferred categories; it contains human experience and particulars expressed through language. The wisdom of the group invovles skills and competences related to people with a common background. Finally, there is individual wisdom, in which language plays an important role in forming individual patterns, which can be described as a large stock of concepts (Goldberg, 2005, pp. 89–91).

When accumulated and stored patterns are broken due to brain injury and, thus, cannot draw on pattern recognition, several things have to be relearned. This requires a lot of energy on the part of the learner.

#### **5.1.6. EXECUTIVE FUNCTIONS**

The frontal lobes are particularly important for learning; therefore, the latest research on their function will be described shortly.

The front of the neocortex, the frontal lobes, were identified by Luria as the civilization of the organ (Goldberg, 2009, p. 4)—that is, the area in which the most advanced and complex functions are performed. In the human brain, the frontal lobes are associated with intention, purpose and decision-making. Even a minimal injury can cause apathy and indifference. In *The New Executive Brain*, Goldberg describes the frontal lobes and compares them to the CEO of a large company, as follows:

Like a large corporation, a large orchestra, or a large army the brain consists of distinct components serving distinct functions. And like these large-scale human organizations, the brain has its CEO, its general: the frontal lobes" CEO of a company.

(Goldberg, 2009, p. 21)

In addition to being the driving force in complex, targeted actions and thinking, the frontal lobes contribute foresight, impulse control, empathy, and the Theory of Mind<sup>13</sup>. The management function of the frontal lobes is also called an executive function. Neuroimaging has contributed new knowledge regarding the importance of the frontal lobes in novel or unfamiliar tasks (Goldberg, 2009, p. 89). The frontal area has the richest network of nerve pathways in the brain. It is associated with most other areas of the brain and is essential for motivation, memory and attention—and, thereby, learning processes. The executive functions also express metacognition and contribute to the recognition of their own difficulties and the development of conscious critical strategies.

 $<sup>^{13}</sup>$  The fact that you are able to perceive other individiuals as thinking, feeling, and acting subjects that are similar to yourself

#### CHAPTER 5. THEORETICAL FRAMEWORK

Based on the frontal lobes' impact on cognition, rehabilitation should work with self-reflection to the extent possible.

#### 5.1.7. RECENT BRAIN RESEARCH

Given the development of new biotechnological registration options, it is possible today to see brain structures, study brain activity and gain an insight into electrical and chemical processes. Our understanding of brain processes, damage localization and the areas of the brain that play together have, thus, been expanded.

The functional imaging of the brain confirms Luria's lesion studies (1970), which show that language is not related to specific areas, but is distributed throughout the neocortex and connected to different cortical regions, each representing certain aspects of physical reality. Goldberg believes that language should be considered an emergent property, made possible when the brain's neural circuitry has reached a certain degree of complexity (Goldberg, 2005, p. 95).

Based on clinical experiences and biotechnological potentials, brain researchers today have a shared understanding of a dynamic brain. The flexibility of the brain seems to be retained longer than formerly believed. It is known that new neurons develop via stem cells throughout life and that nerve cells can divide when stimulated. If the cellular interplay is altered, new features will emerge (Nudo, 2003). Rehabilitation is not only about the restructuring of the functional systems. If the nervous system is challenged, the neuroplasticity makes man capable of learning throughout his life, even after a brain injury, if there are nerve residues to build on (Fredens, 2004, p. 92). There are differences among the nerve lanes' regenerative capacities. It is easier to retrain defined functions (e.g., attention) than functions that involve the entire brain (e.g., memory) (Fredens, 2004, p. 19).

Treatment of brain injuries has been primarily a neuropsychological and therapeutic concern. Pharmacological research also exists in the development of medical products, with a focus on improving cognition. The medicaments we know today are primarily aimed at progressive diseases, such as as Alzheimer and Parkinson's, where the goal is to inhibit the degradation of neurotransmitters. Research, however, in Europe and the U.S. is also aiming to mitigate the symptoms of aphasia by improving, for example, understanding, time assessment, and planning. According to Small (2013), a professor in neurology at University of California, Irvine, current research has been generally unsuccessful. It is only in limited areas that drug use in aphasia treatment has shown promising results. Some results, however, suggest that pharmacological treatment (e.g., detro-amphetamines) might facilitate improvement in combination with speech therapy. Another method mentioned by Small (Small, 2013) though this approach is still in its infancy, is cell transplantation. The vision is that new cells might stimulate synaptic connectivity.

The controversy amongst brain researchers has been existed since medieval times. Discussion regarding whether psychological functions are innate localizations in the brain or a complex neural network developed over time is still on-going, though in a modern version. Fredens (2004) points out that one must be critical against unilateral biological information and that one needs to take care of simple solutions; that is, "The problem with a one-sided biological orientation is that it provides too simple solutions to very complex phenomena" (Fredens, 2004, p. 32). Brain scans and biochemical processes are interpreted by humans and put into context. Specific localizations of brain injuries can cause expectations of certain effects, but these should always be viewed with some caution. People with injuries with identical localizations cannot be expected to have the same symptoms or difficulties. Life before the injury will be an important factor in determining the degree of rehabilitation. Scientific results must sometimes yield to individual and personal nuances. In fact, "It is not uncommon in biomedical research that established theories and opinions are challenged and eventually overturned by unusual clinical cases, which cannot be explained by these theories" (Goldberg, 2005, p. 128). Neuroimaging must, nevertheless, be described as a revolution in neuropsychology research, since it provides visible and measurable results. These opportunities have helped to "graduate it from its tenuous position among 'soft' science wannabes to the rank of mature recognizes science" (Goldberg, 2005, p. 238). Fredens (2006) warns, however, only to relay on neuroimaging; he calls it "neo-phrenology". He believes that, in the eagerness to find eternal truths about the brain, one discovers a deterministic view of the brain and forgets to examine the person and the life he has lived (Fredens, 2006, 21:45). According to Fredens (2006), brains are not identical; they may have common transactions, but they are constructed through interactions with the outside world.

#### 5.1.8. FROM NEUROPSYCHOLOGY TO NEUROPEDAGOGY

The knowledge about brain injury, its architecture and its consequences achieved through testing, brain scans and observations must be translated into a pedagogical practice and rehabilitation interventions. The injury, its impact and its developmental potentials must be understood as an interaction between the biological damage and the psychological and social habitus. In Denmark, the first step of rehabilitation (i.e., diagnosing and the beginning of the interventions) will usually take place in the health system. Later on, the rehabilitation will move to a learning setting (i.e., rehabilitation). Thus, the process can be characterized by two different sets of knowledge: a scientific treatment system and a teaching system. Neuropedagogy is a collective term for interdisciplinary education and treatment that aims to promote the learning and development of people with disabilities due to injuries in the brain. Fredens defines it as follows:

Neuropedagogy is the pedagogical considerations, practices and treatment of persons with disabilities caused by illness, injury, or

disorders of the brain. The aim of neuropedagogy is to make the pupil as resourceful as possible via cognitive rehabilitation. Neuropedagogy is based on both cognitive sciences and pedagogy. The results of the education depend on the impairment; the pupil's personal resources and support in the community and the quality of the professional teamwork established to support and develop the student.

(Fredens, 2004, p. 26)

The concept of neuropedagogy brings the two perceptions of science together and reflects an overall rehabilitation intervention. The focus is on learning, and the person with the brain injury is seen as an active player, with regard to the neuropsychological, personal, and social aspects. One can say that neuropedagogy is teaching practice in terms of the brain. However, the brain is nothing in itself. Its overall function is linked to the body, its environment and the opportunities and limitations presented there. The philosopher John T. Bruer (1997) has been particularly critical about whether it is possible to bridge two such different paradigms of science as neuroscience and pedagogy. He states, "Currently, the span between brain and learning cannot support much of a load. Too many people marching in step across it could be dangerous" (Bruer, 1997, p. 15). Despite this perspective, neuropedagogy has gained ground in Denmark over the last two decades, especially in health and special education. The reason is that general pedagogy has struggled to embrace people with disabilities. From a constructivist and hermeneutic perspective, Thybo suggests this explanation: "Natural science offer important explanations of phenomena, including man and his brain. But man must be more than just explained, the community within humanities (and neuro pedagogy) would claim, man and his action must be understood." (Thybo, 2013, p. 32)

I will return to neuropedagogy in connection with the data analysis and practical proposals.

## 5.1.9. MIRROR SYSTEMS

As mentioned, Italian researchers' discovery of mirror neurons and their possible implications (Di Pellegrino et al., 1992, pp. 177–179) have given rise to research on mirror neurons and their impact on imitation and empathy (Damasio & Meyer, 2008; Ramachandran & Altschuler, 2009). According to these studies, some neurons become active by observing goal-directed motor acts (such as grasping, holdning, manipulating, etc.) (Rizzolatti & Sinigaglia, 2008). Research on mirror neurons in the human motor cortex has revealed that, when we are watching other persons move, "Our own brain becomes active in just those regions that would be active if we made the same movement ourselves. The major difference is, of course, is that we don't actually move" (Frith, 2007, p. 144)

Mirror neuron studies demonstrate how humans imitate other humans on an unconscious level. In addition, research in communication and social psychology has shown that people also imitate in a more visible and bodily way by mirroring/mimicking each other's speech patterns and postures (Van Baaren, Holland, Steenaert, & van Knippenberg, 2003).

Imitation also plays an important role in relation to learning. Adopting Thorndike's (1898) definition on imitation—that is, "Imitation is learning to do an act from seeing one do" Rizzolatti & Sinigaglia conclude two basic statements: "1) Imitation implies learning; and 2) during imitation the observer transforms an observed action into an executed action that is similar or even identical to the observed on" (Rizzolatti & Sinigaglia, 2008, p. 55). It is not possible, in this context, to explain the details of Rizzolatti's (2005) research on mirror neurons. However, it is important to stress that a large part of the brain—that is, the motor, sensory, and visual areas—is activated when a human observes another person's actions. There are some indications that it is necessary for the observer to understand the meaning of the observed's action (Rizzolatti, 2005b, pp. 60-68). Within the framework of this thesis, it has not been possible to examine participants' brain activity during interactions in SL. However, the knowledge that there actually is brain activity, even during observation, indicates the possibility of adding learning in immersive worlds. I will elaborate later on how knowledge about mirror neurons can be utilised in rehabilitation in IVEs.

# 5.2. DOPPELGÄNGER

Imitation is more likely when an observer can identify with the observed. Like studies on mirror neurons, research on avatar-mediated interactions in IVEs has suggested that people project themselves onto avatars so that a part of the brain is activated in the same way as if they, themselves, were active. Watching an avatar that resembles you even influence your thoughts, feelings, and actions.

... researches have demonstrated that the more similar the target is to the observer, the more likely, the observer is to mimic the target. For example, people are more likely to imitate the behaviours of others who are the same sex, race, age, and even those who share their opinion. The virtual doppelgänger demonstrates the ultimate power of virtual reality – the target it not merely similar to the observer, it *is* the observer

(Blascovich & Bailenson, 2011, p. 116).

This phenomenon is called the "doppelgänger effect", and it is a term for a lookalike of a person. At Stanford University, researchers have studied how this doppelgänger effect can be used to encourage people to live more healthily, be more environmentally conscious, gain higher self-efficacy and fight social phobias

(Blascovich & Bailenson, 2011, p. 116). Based on this background, we will later explore whether the phenomenon can be utilised in a pedagogical way with PWAs in SL.

# **5.3. LANGUAGE AND ITS IMPACT ON IDENTITY**

## 5.3.1. LANGUAGE

To achieve an understanding of the consequences of communication disorders and different rehabilitation approaches, it is essential to gain insight into different aspects of language, including linguistic processes, the brain organization of language and, finally, the impact language has on thinking and cognition—and, thus, on identity and learning.

Research on the development of language has a relatively short history. In the beginning of the 20<sup>th</sup> century, a German couple William and Clara Joseephy Stern kept a diary of the psychological development of their three children. Their first publication, from 1907 *Die Kindersprache*, is a classic in language acquisition literature. Over the last 100 years, the research field has reflected the changing views on language and cognition, which has grown from a normative and designative-instrumental perspective of language (Taylor, 1985) to the view this thesis follows: a more holistic perspective, in which language is socially and culturally closely related to an individual's lived life (Vygotsky, 1934).

According to the sociocultural view, language has many manifestations. It expresses itself as spoken language, written language, body language, and imagery. Language should not be seen as a goal in itself, but as a means of contact, communication, and learning; thus, it can be characterized as the bringing-into-speech of a person—and, therefore, of a part of identity and learning. With reference to discursive psychology, constructivist linguists consider the nature of language performance to be a social tool for interaction (Jensen, 2011, p. 148), which means that language takes place in a certain context. Language is an important element for learning, identity creation, and interaction in social communities. Through language, we present who we are and form the identities of both others and ourselves.

However, in order to define the concept of language, it is necessary to discuss both the linguistic dimension (i.e., form) and the functional dimension (i.e., use). Language content involves both a linguistic structure and an act with a specific purpose. Language is uttered by a sender and received by a recipient in a certain situation (Nicolaisen & Vejleskov, 1996, p. 12). Thus, the linguistic and functional dimensions are closely entangled, since the structure influences the message given.

The result is dependent on shape, function and communication within the community.

One example of the power of grammar (e.g., commas and intonation) shows how the same words can suggest different meaning, depending on the comma/intonation. For example, "Did your dog eat Kelly?" and "Did your dog eat, Kelly?" have quite different meanings. This is a simple example; however, much more than grammar has influence over meaning (e.g., body language, familiarity, etc.).

# Language involves:

- Form (phonology, morphology and syntax of linguistic expressions)
- Content (the utterance is about representing and symbolizing)
- Use (relationship between sender and receiver)

(Nicolaisen & Vejleskov, 1996, p. 18)

Speech is implied by an internal language, and it has an extensive cortical representation. The spoken language can be described as a signal system, which is articulated into sounds via speech organs. The individual phonemes are combined in different ways into words, which, then, are syntactically merged into meaningful phrases. The words represent content, opinions and emotions. One can roughly distinguish between expressive and impressive speech activity, as follows: Expressive speech is brought to execution by means of inner speech, which, based on a plan, is transcoded to verbal expression through narrative speech. By contrast, impressive speech, or language comprehension, is contingent upon one's ability to link a large number of sub-elements, namely: acoustic perception, excretion of phonemes, understanding of the meaning behind the words, ability to retain the phrase in memory and, finally, ability to understand the elements and shape them into a logical schema (Luria, 1973, pp. 306-309). In Luria's terminology, "a word is a complex multidimensional matrix of different cues and connotations" (Luria, 1973, p. 306). Thus, speech is described as a medium that uses language to transfer information. Luria refers to

"Modern psychology regards the speech as a special means of communication using language for the transmission of information. It regards speech as a complex and specifically organized form of conscious activity involving the participation of the subject formulation the spoken expression and the subject receiving it".

(Luria, 1973, p. 306).

Fredens (2006) also considers language to be an integral part of all cognitive processes. As in the understanding of cognition, there are two perspectives within the understanding of language: the generative grammar, as stated by Chomsky (1964) and the functional use of the language. The generative approach involves the language's form and rules, and the functional understanding concerns what language is used to—a kind of linguistic behaviour. In other words, "It is about how we share thoughts with each other and are interested in correlations between linguistic behaviour and cognitive functions" (Fredens, 2004, p. 204). Fredens characterizes language as an articulation of a person—and, thus, a part of that person's identity. (2006, 26:08, 58:02)

Generative grammar became the "established" linguistic theory in the U.S. and has had huge influence on the way in which aphasia testing is designed, which will be elaborated later in this chapter. However, in this thesis, I am primarily interested in functional language, and I consider language to be widely regarded as an active social practice. Specifically, I want to explore which facets of language are possible to train through a functional, social-communicative approach.

## 5.3.2. LANGUAGE, COGNITION, AND THINKING

In addition to being a means of communication, language plays an important role in recognition. Vygotsky (1986) was concerned with the relationship between language and thought, and he attributed language a key role in both play and social interaction. Specifically, he was concerned with language's dual function, in which thinking evolves from an outer to an inner dialogue. The outer dialogue is a meaningful negotiation with the other persons, while the inner dialogue involves thinking.

Language is fundamental to perception, memory, and thinking—and, thus, it becomes a tool of intellectual activity. Language also has a regulatory function for the planning and management of behaviour (Luria, 1984, pp. 122–128). The acquisition of language is closely related to experience, acting, play, and practice. It manages our awareness, knowledge, and experience of the world throughout our lives. This relationship between thought and word is a living process: "Thought is born through words. A word devoid thought is a dead thing" (Vygotsky, 1986, p. 255).

In sum, the loss of language has far-reaching consequences for one's ability to communicate, learn, and maintain one's identity and social interactions.

## 5.3.3. LANGUAGE, COGNITION AND CULTURE

Cultural-historical psychology is based on Vygotsky and Luria's (1976) crosscultural study of people in remote Soviet republics. By analysing the cognitive functions of people from different cultures, including people in Uzbekistan, who had been exposed to societal changes in the transition from a feudal agriculture to modern collective farming, they demonstrated that even basic psychological processes are influenced by environment and culture. Luria (1977) described this finding in the studies in The Cognitive Development: Its Cultural and Social Foundations, in which he mentions that perception and the naming of colours are culture-dependent, stating: "The data shows that even relatively simple processes are involved in perception of colours, and geometric shapes depend to considerable extent on subjects' practical experience and their cultural milieu" (Luria, 1977, p. 45). He concludes: "The basic categories of human mental life can be understood as products of social history - they are subject to change when the basic forms of social practice are altered and thus are social in nature" (Luria, 1977, p. 164). The main idea of the cultural-historical approach to psychology and learning is that it is culture in general and language culture in particular, that shapes an individual's cognition. A person's cognitive operations develop largely through the internalization of various externally existing cultural schemas (Goldberg, 2005, p. 98). We use language to think, understand, and conceptualise to ourselves, as well as to express ourselves to others.

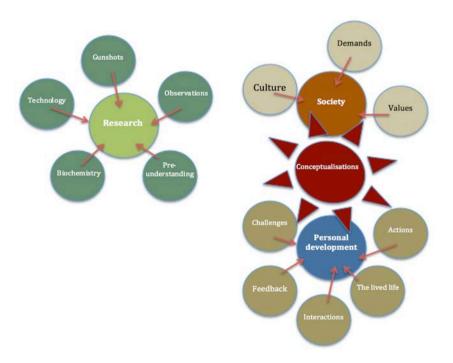


Figure 14 The brain is formed by the lived life

Vygotsky and Luria's (1976) studies on cognition demonstrate that the brain and mental processes are designed based on social and cultural contexts and that brains are likely to function differently depending on the interactions they have lived and the challenges they have been given. The studies, thus, substantiate the claims of Wenneberg (2000) (described in Chapter 3), who suggested that that even scientific knowledge could be understood as a social construct. In other words, there is no true knowledge of the physical brain.

# 5.3.4. LANGUAGE, COMMUNICATION AND COMMUNITIES

From a socio-cultural perspective, interpersonal communication is central to learning and development, and language can be considered a socio-cultural tool. Language mediates the world for us, and it is through communication that we become socio-cultural human beings. Lave and Wenger (1991) understand language in line with Vygotsky and Luria, but they also address the importance of being part of a community and how language and social competences are developed in meaningful groups.

Language is, at once, a means to think and understand and an opening to share experiences and make common knowledge of the society and the individual. In other words, communication fulfils two goals: exchanging information and fulfilling social needs (Holland, 1975).

It is through interaction with others that one learns a language, and it is through language that one becomes a participant in a community (Wenger, 1999, p. 203). Lave and Wenger (1991) see language as a means of action and of the negotiation of meaning. Language should not be considered separately; rather, it should be linked with cognition as an integral part of the social world and situated in on-going historical development (Lave & Wenger, 1991; Wenger, 1999, p. 48). Language is considered a social phenomenon through which the importance of participation and action in social communities is crucial and in which language is seen as a way to participate in social communities.

Thus, through narratives and social interactions in a community, language serves as a tool for identity formation.

# 5.3.5. LANGUAGE, COMMUNICATION, AND IDENTITY

In the book *Identitet*<sup>14</sup> by Brinkmann (2009), he refers to Erikson's (1971) understanding of identity as "the meeting point between what people wants to be, and the world allows them to be" (Brinkmann, 2009, p. 18). This is comparable to

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<sup>14</sup> Identity

the way in which I see identity; that is, identity is shaped not only by what you want, but also by the opportunities you are given.

Language is an important factor in the formation and maintenance of identity and the development of psychological processes and social relations. In social learning theories, learning and identity-formation are closely linked. Identity is created through communication in social communities, and it is something that must be maintained and sustained throughout a person's life, retold through language with narratives and images. Social connections are largely established and maintained through communication. In order to arrive at a coherent sense of self, individuals engage in communicative interactions, through which identities are established and modified. Language is used to shape our own experiences and to create images for others (Simmons-Mackie & Elman, 2011, p. 313). People acquire skills, attitudes and values, and this process of acquisition is reflected by the fact that each individual is a specific person-in-the-world. Thus, an individual identity is created and exists in the person's interaction with his or her surroundings, via meaningful exchanges of opinions, reflections, and mirroring.

Wenger (1999) attaches participation in communities of practice crucial importance in relation to identity formation. Our identity relates to social formation, as well as the ability to create a sense that defines our communities and evokes a feeling of belonging. Learning is viewed, beyond as a means of developing practice, as a means of developing and changing identities (Wenger, 1999, pp. 145–149). He considers identity formation to be a matter of either participation or nonparticipation in communities, as well as of the inclusion and exclusion of communities. Practice consists of a network of relationships among people with different functions and positions. The roles of individuals and their identifications are created through the practices in which they engage, regardless of the degree of participation. Lave and Wenger use the term "legitimate peripheral participation" (Lave & Wenger, 1991, pp. 34-37) to discuss the process through which newcomers become part of a community of practice. This term includes the activities, identities, artefacts, and communities of knowledge and practice. Participation is seen, not as something one can "turn on and off," but as something that becomes incorporated into one's whole life as a constituent part of his or her identity (Wenger, 1999, p. 57). The focus is on the reciprocal relationships between veterans and newcomers in communities of practice, in which learning and development serve as meaningful negotiations between actors. Man defines himself by what he is and what he is not (Wenger, 1999).

Practice consists of negotiations of ways to be a person in a specific context. Such negotiations may be tacit; however, regardless of whether individuals relate directly to the question of identity, they manage to accomplish their identities through the ways in which they act towards and relate to others. Thus, our practice is fundamental the question of how to be human.

The philosopher John Dewey (2004) describes identity as something non-static, which must be maintained and continuously renewed. He agrees with Wenger (1999), suggesting that identity is created through activity and participation; that is, "Life is a self-renewing process through action upon the environment" (Dewey, 2004, p. 1). Communication enables participation in communities and is a means of sharing of others' thoughts and feelings. Communication is not only an approach to social participation and a source of identity, but also concerns the formation of personality. In other words, "Not only is social life identical with communication, but all communication (and hence all genuine social life) is forming" (Wenger, 1999, p. 27). Thus, without communicative competence, it would be difficult to maintain and retell one's identity.

Eric Hodgins who suffered from aphasia, expressed how he felt about not having a fluent language anymore, as follows:

One's speech is very much part of one's personality. The fact that mine was once fluent and now was halting made me feel – conspicuous. I do not know the feelings of a person defaced by a burn or a scar, but I imagine them quite like the feelings I had, at first, about my tongue's new and unwelcome capacity.

(Hodgins, 1968, p. 94)

Self-efficacy, self-advocacy, and empowerment are all concepts that relate directly to issues of identity. Roles, values, and beliefs are acquired and maintained through social interaction and language-in-use (Shadden & Agan, 2004, p. 175).

## 5.4. APHASIA

Aphasia is an impairment of the language function due to a brain injury result from, for example, apoplexy<sup>15</sup> or another injury in which the blood vessels of the brain are damaged<sup>16</sup>. Aphasia takes many forms, depending on which areas of the brain have been injured and how deeply the patient has been affected. Aphasia leads to communication difficulties in varying degrees; however, a total loss of the ability to communicate is rare. Specifically, aphasia influences a person's ability to produce and understand speech/language. In addition, the ability to read, write, spell, and calculate can be affected. A PWA may experience problems recognizing the correct use of yes/no and recognizing and applying words to certain objects. Aphasia may also be accompanied by other disorders, such as paralysis, cognition problems, and a lack of concentration. PWAs often exist in worlds of chaos and confusion, in which language and interplay with surrounding environments are shattered.

Aphasia may affect anyone, regardless of gender, age, or social status; however, the risk increases with age. Often, long-term communication rehabilitation is required (Luria, 1970).

Due to the variety of conditions in aphasia disorders, it is difficult to provide exact numbers of incidences and prevalence (Code, 2010, p. 318). The number of incidences of new individuals with aphasia every year is estimated at five million worldwide, of which 80,000 are in the U.S (Shadden, Hagstrom, & Koski, 2008, p. 20) and 3,000 are in Denmark (Center for Hjerneskade, 2014).

## **5.4.1. TESTS AND DIAGNOSES**

Major advances in neuroimaging techniques over the last decades have, as mentioned, led to a wider understanding of brain injuries. In measuring the extent of a person's injury, neuroimaging plays an increasingly importent role. Neuroimaging is used differently in research and practise. Specifically, its practice has shifted from relying on an image as if the image, in itself, were a representation of a person and his/her abilities and disabilities to considering the image as one piece of a larger puzzle. Again, it is relevant to refer to the two competing factions within the linguistic understanding of language: linguistic competence (i.e., generative grammar, as understood by Chomsky) (1964) and linguistic performance. Competence refers to "the abstract system of mental representations and processes that constitutes the basis of language and the performance is the actual realisation of language through use" (Tesak & Code, 2008, p. 181). When it

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<sup>&</sup>lt;sup>15</sup> Common designation for cerebral hemorrhage or brain embolism

<sup>&</sup>lt;sup>16</sup> Head trauma (e.g., accidents: road, violence or work), illness (e.g., tumors, infections)

comes to the measurement of disabilities, the two factions each have their own strategies, such that the images of the brain are used differently.

One can imaging that Luria would have taking great interest in the window to the working brain that we can access today through brain scans (Cagigas & Bilder, 2009, p. 23). Recent research within cultural neuropsychology using neuroimaging has found "cultural differences at behavioural, structural, and functional levels that are being attributed to differences in highlighted experience within a particular skill set" (Cagigas & Bilder, 2009, p. 24), thereby confirming the cultural research Luria and Vygotsky (1977) conducted in Uzbekistan.

Neuroimaging research has, however, been criticised for its lack of explanatory theory (Cagigas & Bilder, 2009, p. 23). In a 2006 paper, "Can cognitive processes be inferred from neuroimaging data?" Poldrack discusses a common practise of 'reverse inference' and warns against inferring a particular cognitive process from the activation of a particular brain region. He does not consider such inferences to be deductively valid and stresses that one cannot conclude uniformity across contexts (Poldrack, 2006). Although neuroimaging needs to be interpreted in a social-historical context, it can still provide some information. Both biological and neuropsychological knowledge about the brain and the lived life of a person must be taken into consideration when you measure the person's achieved disabilities and design the interventions.

Although these methods may not have been available to him, Luria nevertheless accomplished something extraordinary with his neuropsychological assessment strategies and concepts that modern neuroimaging is often lacking: a theory-driven approach that elucidates the intimate interface between the nervous system and the cultural-historical world that finds its synthesis in every developing human.

(Cagigas & Bilder, 2009, p. 23)

As an example of the generative grammar and test practices inspired by Chomsky (1964), I will mention the tradition that developed in Boston in the 1960s and 1970s—a tradition that has since gained considerable influence in both the United States and Europe and that sits in contrast to Luria's (1970) ideas on aphasia intervention. When neuroimaging was still in its infancy, the Boston behavioural neurologist Norman Gerschwind re-introduced a neo-classical understanding of language as a centre located in the brain (Tesak & Code, 2008, p. 165). This approach received international recognition—and based on this understanding, the Boston researchers Herold Goodglass and Edith Kaplan developed a test battery in 1972 called The Boston Diagnostic Aphasia Examination (BDAE). In its classification of different types of aphasia, the test was based on the idea that certain aphasiac symptoms are related to certain locations in the brain (Tesak &

Code, 2008, p. 168). This test has since been translated and validated in a number of other languages. It has also inspired several offshoots and the development of new tests. One of the most-used offspring iterations in Europe is the Western Aphasia Battery (WAB), developed by Andrew Kertesz in 1982. Thus, the Boston understanding of aphasia has had significant impact on the clinical aphasiology development of tests and interventions in the Western world over the last four decades (Code, 2010, p. 321). Gerschwind was obviously inspired by Gall's phrenological understanding of the faculties in the brain and the classification of types of aphasia. The result was an easy method for describing the disabilities. At the same time, the test data can be used as evidence for deficits.

In 2001, WAB was translated and validated in Denmark by the neuropsychologists Palle Møller Pedersen and Kirsten Vinter. In the beginning, the approach was only used in some parts of Denmark. However, following the political reform in 2005, a national committee for best practices decided that all public institutes for speech and language disorders should use the WAB test as part of their diagnosing process. The argument was that we needed a shared fundament and research view. Furthermore, there was (and still is) a general lack of other validated and standardised tests in the Danish language (Hougaard, Mogensen, Porskjær, Lund, & Jensen, 2006). Finally, WAB is easy and fast to conduct.

My personal response to the best practice recommendations is that they show signs of creating a consensus between the two factions in Denmark. The result is a lack of stringency in the view of language and in the recommendations for using combinations of several tests—which, in practise, is time-consuming and fatiguing for PWAs. Test and diagnoses serve several purposes. In the early stages, the speech therapist's role is to explain the nature of a patient's damage and to provide information and guidance to the nursing staff, the relatives, and the PWAs themselves. This can be done via observations, conversations, and short bedside tests. At later stages, the test must provide suggestions for concrete intervention and possibilities for improvement and future development. From my perspective, the WAB offers a label, whereas Villy Nesgaaards Luria-test helps to plan rehabilitation by indicating specific interventions and activities.

In 2013, Audiologopædisk Forening<sup>17</sup> (ALF) published its recommendations on tests and diagnosing tools. In addition to the above-mentioned, there are other tests that assess the communicative competence; however, to my knowledge, these are only used as minor supplements. The psycholinguistic diagnosing test, PALPA (Kay, Lesser, & Coltheart, 2009), is also achieving relatively common use in Denmark. PALPA is, just as WAB, developed based on the assumption that mental processing systems "are organised and represented in the brain within a modular

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<sup>&</sup>lt;sup>17</sup> The association of audiologopedists in Denmark

architecture" (Tesak & Code, 2008, p. 193). Each module works independently of the others, unimpaired modules work normally (Tesak & Code, 2008, p. 193), and all brains are identical. This contrasts fundamentally with Luria's theory of functional and cooperative brain systems, which are socially and historically shaped. In reality, it appears that PWAs classified with the same type of aphasia exhibit major differences in their use of language, as well as in their ability and power to recover. Moreover, there is much more to language than its structure (i.e., syntax, morphology, and phonology). Pragmatics are important components as well, as are all the mentioned psychosocial circumstances.

The way in which a person views language, as well as his or her scientific belief, are closely linked to that person's professional traditions and the scientific milieu in which he or she is historically and culturally situated. This is a social construction more than it is a truth about a disorder.

## **5.4.2. LABELLING DISORDERS**

As practitioners and researchers, we have a need for labelling. We need a shared language about aphasia, and labels serve to generalise and to construct meaning about the disorder. However, labelling via diagnostic classifications has an impact on the persons concerned. Let me initially clarify that I find diagnoses very useful. They lead to opportunities and resources for PWAs, as well as to knowledge and guidelines for relatives and professionals. There are, however, some pros and cons that one needs to take into consideration as a professional. On the negative side, the most severe is that of a person being misdiagnosed or a label being inaccurate (Damico, Nicole, & Ball, 2010, p. 14). There is a tendency that it is the person who gets a stamp, instead of the symptoms that get a label. There is a huge difference between being an *aphasic* and a *person with aphasia*. On the positive side, a valid label might lead to interventions that help to overcome identified deficits. Furthermore, a person's disabilities might feel more legitimate, since the offers an explanation and provides access to legitimate illness behaviours and privileges.

What impact does labelling have on a person's identity? Research on the impact in labelling shows, on one hand, that labelling helps some individuals develop a self-image based upon identification. Then, a PWA can address his or her feelings and construct new identities. On the other hand, labelling might have negative consequences. For example, "...when individuals are labelled, the societal and cultural ideas associated with the disability in general and the label in particular become personally to that individual and often foster af negative self-feeling" (Damico et al., 2010, p. 17). Such a label might result in disempowerment or prevent the person from essential self-knowledge resources.

## 5.4.3. APHASIA'S IMPACT ON IDENTITY AND LIFE PARTICIPATION

Fredens (2004) and Shadden, Hagstrom & Koski (2008) argue that the self is created in communication with others through narratives and life stories. Thus, based on these fundamental considerations on the relationship between language, mental activity, and self-creation, it must be assumed that aphasia affects the sufferer's self-understanding and has implications for identity and thus might lead to psychological problems. Language difficulties make it hard to communicate with the surroundings, limit the opportunity to test ideas, tell one's life story, and consequently weaken one's ability to express his or her opinions and hamper his or her ability to continuously create the self. People suffering from aphasia face a significant disadvantages (Simmons-Mackie & Elman, 2011, p. 314).

Persons with language difficulties are likely to experience changes in the ways other people relate and react to them. They feel, they are seen as different person, with different identities. Thus, and as a result, PWAs may experience not being themselves any more (Brumfitt, 1993; Shadden et al., 2008; Vestberg, 2002). Social relationships can be difficult to maintain due to the communication disorder and it becomes difficult to interact socially. Thus, "Their greatest loss may be the reduction in the fluidity and flexibility with which communication allows navigation of the complex challenges of life's social actions and interactions. Their greatest challenge is to renegotiate identity" (Shadden & Agan, 2004, p. 174). In sum, aphasia leads to life-altering changes and can become a social problem.

Memory is a cognitive function related to many different areas of the brain, and many PWAs experience memory difficulties of various natures. Memory loss will also affect identity, since identity is shaped and constructed partly from autobiographical memories (i.e., memories about personal experiences and facts about oneself) (Hirst, 1994; Rubin, 1988) and partly of socially interactions and retelling one's life story to others. Professor of Psychology William Hirst has conducted extensive research in autobiographical memory, especially episodic memory, and its importance for the self. He claims that memory is organized as a narrative story, and that "it is not the memories per se, but the interpretation of the memories, or more specifically, the narrative told around the memories" (Hirst, Manier, & Apetroaia, 1997, p. 164) that have importance in shaping the self. Not being able to recognise oneself after a brain injury is aggravated by the fact of losing the ability to communicate, to remember one's past, or, thus, to continue telling one's story. (Fredens, 2006, pt. 41:13; Shadden et al., 2008). This shows how intrusive a language disorder might be in relation to a person's ability to evolve and continue to be him- or herself.

It has been previously mentioned that Wenger (1999) also considered participation to be a constituent part of identity, stating that it is meaningful negotiation and interpersonal relationships that encourage learning and development (Wenger,

1999, pp. 149–163). Qvortrup (2004) asserts that it is our ability to reflect and argue for clear values that help us to form as human beings (Qvortrup, 2004). In order to believe in themselves and to show the world that they are educated and informed persons, PWAs must keep finding new ways to participate, negotiate, argue, and reflex.

The loss of the communication competence has crucial implications for social life, identity, thinking, cognition and learning. The loss reduces intellectual activity, since the brain is used less, especially if a person has dropped out of the labour market. If it is not possible to find alternatives and compensation strategies for telling your story, presenting who you are, and participating in meaningful debates, it is likely that your intellectual level will gradually decrease: "It is often said that a person's language is at the level of his intelligence. It is probably largely correct. But the opposite also applies: Your intelligence is on par with your language" (Goldberg, 2005, p. 109).

Thus, rehabilitation must facilitate alternative ways of presenting oneself and develop new forms of actions.

## 5.4.4. DEFECTOLOGY AND SPECIAL NEEDS

Within the realm of special pedagogy, there have been, throughout history, roughly two paradigms: the collective inclusive perspective and the individual diagnosing perspective. Birgit Kirkebæk has been interested in the historical development of this area and how the methods and interventions at any given time depends on the changing understanding of "being human" (Kirkebaek, 2010, pp. 14–24). In our Western world, special pedagogical interventions stem from a medical model that considers disabilities as biological defects, deviations and abnormalities. Confer ICF, in which there has though been growing interest in involving social context in diagnosing and interventions.

Today, WHO, ICF, and the Danish school system are inspired by the work of Vygotsky. In his work as the scientific director of the Research Institute of Defectology, Vygotsky contributed to a new vision of people with disabilities. He developed the deterministic notion that a defect (i.e., disability) contributes to special conditions for development and the formation of personality. A disability should not be considered a static condition; rather, it is a condition depending on the surrounding environment and the potential social impact. Vygotsky argued that a disability should not subjectively feel like an abnormality before it becomes apparent that the environment takes a special attitude towards the condition (Danielsen, 1996, p. 24). Vygotsky also spoke against isolation and special schools, arguing for pedagogy involving full integration of people with disabilities. He believed that people with disabilities have the opportunty for full intellectual development, only they have the right tools available. Finally, he claimed that it

was possible to prevent the loss of functions through higher psychological functions and cultural processes (Danielsen, 1996, p. 25). To Vygotsky, social relations were of vital importance for the development of people with disabilities.

In guidelines for teaching people with special needs at The Institute of Speech, Language, and Brain Disorders, the aspect of social relationships is also emphasized. The concept of disabilities is defined as follows:

Disabilities are seen as a conflict between a person's qualifications, skills, desires and the demands and expectations of people in a concrete situation, and the target of special pedagogy is that: "Ease and reduce the effects of disabilities. Increase the possibility of active participation in society.

(The Institute of Speech, Language, and Brain Disorders, 2006)<sup>18</sup>

This is in line with Vygotsky and the socio-cultural perspective, and it demonstrates a concept of disability in which a disability is classified as a handicap whose degree varies according to requirements and the situation at hand. Such a disability can be addressed through the environment and through artefacts, and the overall goal of special education is participation.

## 5.4.5. REHABILITATION

Based on previous considerations, I will recapitulate regarding rehabilitation. Rehabilitation can be approached in different ways: for example, mechanical reductionist method, in which the teaching is designed based on the damage localization; or a constructivist method, in which the driving force for development lies in the ability to create meaning. In the first, the training moves from the individual against the social, and in the latter, the training moves from social interactions and negotiation of meaning to an individual person's learning. In the constructivist view, it is not the PWA alone who suffers from communication disabilities; rather, his or her social others and communication partners suffer as well.

From my perspective, rehabilitation must be seen in a sociocultural context, based on knowledge of the nature of the injury, the extent of the injury, the injury's location in the brain, and the personal/social context. Furthermore, it must be based on the individual, on who he/she was before the injury, and the opportunities

<sup>&</sup>lt;sup>18</sup> These guidelines are not available online anymore. Due to a reorganisation of the institutes for special needs in Aalborg, The Institute of Speech, Language and Brain Disorders no longer exists. Aphasia rehabilitation is currently addressed at the Center for Brain Injuries, Aalborg.

available after injury. Since PWAs are likely to be in existential crisis, psychological factors must also been taken into consideration. The overall objective is to provide an opportunity to restore meaning and maintain social relationships and identity.

Luria's understanding of language as a complex function composed of many subfunctions immediately suggests an optimistic view of the opportunities for rehabilitation and compensations. It means that various routes can perform a given cognitive task, depending on which strategy a person chooses. According to Luria, rehabilitation aims to restructure the system so that the damaged components are replaced with other, intact components (Goldberg, 2009, p. 244). The main principles of the approach are that lost or disturbed functions are rebuilt within their functional systems. This may be done by involving an intact function as compensation for an injured function (e.g., visual support for kinaesthetic damage) or by going moving from automated to deliberate execution of the same function (e.g., awareness of the articulatory process) (Nesgaard, 2007).

Goldberg (2009) has since been critical, though, of reorganization methods. He argues that there is little generalisation from the specific to the general use of reorganized and trained functions. Specifically, he says, "It is not that they showed no generalization at all, but this generalization tends to be "local" rather than "global<sup>19</sup>" (Goldberg, 2009, p. 245). This recognition and new knowledge on neuroplasticity led Goldberg to become even more interested in how more general cognitive exercises may help the brain redevelop and maintain its intellectual level throughout life. He compares brain activity with physical activity and uses a saying from sports: "use it or lose it" (Goldberg, 2009, p. 248). From research on animals with traumatic brain injury, it has been revealed "that immersion into an enriched environment facilitates recovery from the effects of brain damages in rats" (Goldberg, 2009, p. 246). Goldberg's new approach to training, thus, becomes "Rather than attempting to shape or reshape specific mental processes, try to reshape the brain itself' (Goldberg, 2009, pp. 246-247). Scientists at the Max Planck Institute in Germany and at Salk Institute for biological studies in Southern California substantiate this way of thinking about rehabilitation. Both places have demonstrated that cognitive exercises stimulate the brain. Specifically, functional imaging and neuro-stimulant medication, researchers at Max Planck have studied how the human brain physiology is improved through cognitive exercises. Similarly, Salk Institute has studied brainpower in adult mice exercising in enriched environments and has demonstrated that stem cells continue to proliferate throughout adulthood when stimulated. These findings demonstrate that damaged functions can be restored (Goldberg, 2009, p. 247). Furthermore, Goldberg refers to

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<sup>&</sup>lt;sup>19</sup> Goldberg explains Luria's findings with the suggestion that they ought to fit the politicied Soviet science (Goldberg, p. 245)

research showing that brain areas that are frequently activated have more neurons and brain lanes (e.g., the area that processes the sounds of musicians) (Goldberg, 2006; Schneider et al., 2002, p. 239).

Goldberg (2005) introduces the concept of *cognitive fitness* and develops a program for a target group of older people who are worried about their mental decline due to aging. The program consciously uses metaphors for physical exercise. Users are "trained and supervised" by a "personal cognitive fitness trainer" in a "gym", in which one of the training tools is a computer. The exercises include, for example, different aspects of memory, attention, language, reasoning and problem solving (Goldberg, 2005, pp. 270–274). Unlike Luria's idea of building on strengths, the cognitive fitness program trains weak functions.

This method stands in sharp contrast to the philosophy once swore followed in the cognitive rehabilitation of patients recovering from head injury. There an attempt has traditionally been made to teach the patient how to bypass, to circumvent, the impaired function rather to improve it. But in physical medicine, like brain science, there has been a growing appreciation of the body's natural plasticity and a consequent paradigm shift in the basic tenets of rehabilitation.

(Goldberg, 2005, pp. 274–275)

Even though the motivation behind the fitness program is cognitive training, Goldberg attaches great importance to the social aspect of connecting to people while training. The target group of the programme was originally elderly people seeking to prevent aging, but the programme has also shown positive experiences for people with dementia and Alzheimer's disease. Instead of focusing on cognitive helplessness, the programme focuses on reconnecting to cognitive abilities. Goldberg calls this "cognitive empowerment" (Goldberg, 2005, p. 279).

Goldberg's (2005) experiences with cognitive fitness reveal an assumption that cognitive training may also have an effect on people with brain injury. His model distinguishes between cognitive rehabilitation, which is rebuilding what is broken, and cognitive compensation, which develops new strategies or compensates through artificial compensation (i.e., assistive technology). Artificial compensation can both complement and promote existing strategies (Fredens, 2004, pp. 18–21). For example, Fredens refers to research that shows that the combination of cognitive rehabilitation and cognitive compensation leads to general improvement (Middleton, Lambert, & Seggar, 1991), which argues for concerted and general rehabilitation, thereby substantiating Goldberg's suggestion that rehabilitation must be based on more general cognitive exercises that reshape the whole brain. General cognitive training is difficult to measure with the test method used today, which measure only narrow specific functions. The effect of learning through a socio-

cultural approach is not measured strictly by measuring a single function; rather, it is always assessed relationally through functional interaction. When all is said and done, "the most important evidence of success, modest though it often is, is the impression of the program participants and their family members that they are retaining – or even regaining – their mental powers in real life" (Goldberg, 2005, p. 285).

As mentioned, the WHO has developed an International Classification (ICF). ("WHO | International Classification of Functioning, Disability and Health (ICF)," 2015), which demonstrates that disabilities must be related to limitations and opportunities regarding participation in society. The English speech therapists Carole Pound et al (2000, p. 6) supports this social constructivist point of view, which considers aphasia to be a social handicap:

The social model challenges the medical model by reconfiguring disability in terms of social oppression and by questioning the function and the nature of rehabilitation itself. According to this model, disability does not inevitably stem from the functional limitations of impaired individuals, but from the failure and the social and the psychical environment to take account of their needs.

(Pound, 2000, p. 6)

Focus shifts from teaching the individual—that is, the PWA—to focus also on his/her surrounding environment, with all its participants. Researchers argue that the general aim of authentic rehabilitation should be to prepare and assist people in integrating into a community and stressing the importance of social affiliation as a means of maintaining and developing self-identity (Pound, 2000; Simmons-Mackie, 1998; Simmons-Mackie & Elman, 2011; Wertsch, 1993, p. 13). Facilitating participation in the community entails passing responsibility to an individual over a gradual period in order to develop autonomy, enhance self-esteem and take greater ownership in the issues that face people (Code & Herrmann, 2003).

There are, thus, a number of national and international trends that favour a relational and context-dependent approach to disability and rehabilitation. At the same time, there is an increasing demand for evidence and documentation to get the economical funding for rehabilitation (Kirkebaek, 2010, p. 21). Therefore, there is a demand for evidence-based practice, even though research and practise document that a social-functional approach is likely to offer a better outcome. It is, however, difficult to prove this effect with scientific validity and reliability. Kirkebaek claims that the real aim of evidence-based practise is to avoid criticism and that evidence-based has become synonym for first quality. (Kirkebaek, 2010, p. 88).

In Denmark, speech therapy occurs in varying ways. In some places, the municipalities perform the rehabilitation; in others, counties, the health sector, or the social or educational sector performs it. The common objective of the rehabilitation though, is to facilitate the PWA to be able to regain the lost language, to avoid isolation, and, in general, to be capable of managing life through insight into the impairment and individual learning strategies. Furthermore, guidance to families is offered. Thus, there is an agreement on the goal, but not on the way to method to achieve it.

From a socio-cultural perspective, cognitive training is always seen in the context of social interaction, in which a community helps to re-create identity and recognition. Rehabilitation after brain injury is about restoring oneself, regaining skills and still being able to develop. In other words, "Identity is not something you have, but something you retell all the time" (Fredens, 2006, 41:43).

## **5.4.6. ICT IN REHABILITATION**

Through the 1990s and the 2000s, the main technologies used in rehabilitation have been tools for improving speech and language production through transmitting, sending, receiving, and reading. Technologies with communicative, participatory, and opinion-making dimensions have great potential, but are still in their infancy (Code & Petheram, 2011; Dirckinck-Holmfeld et al., 2004; Konnerup & Schmidt, 2006; Petheram, 2004). New social media, though, offers great opportunities for this group of participants, who are potentially marginalized in the communication and learning society. Research indicates that interacting with and participating in media-rich web-based communities of practice might strengthen cognition, communication, and—in a broader sense—personal and social mastering (Konnerup & Schmidt, 2006).

Another perspective is that research has suggested that intensive intervention (i.e., eight hours or more per week) is necessary to gain language improvement (Bhogal, Teasell, Foley, & Speechley, 2003; Cherney & van Vuuren, 2012). Unfortunately, it can be difficult for people to engage in that many sessions of interventions. At the Institute of Speech, Language, and Brain Disorder, researchers have addressed these needs through their web-based courses, ATA, and the avatar-mediated rehabilitation in SL. A focus interview with participants in ATA revealed that they used up to six hours a day through training communications via the Internet (Konnerup & Schmidt, 2006, p. 116). In addition, at the Rehabilitation Institute of Chicago's Center for Aphasia Research and Treatment, researchers seek to address these needs through treatment administered via a computer. The researchers have experienced that web-based treatment allows high-intensity practice. A study from 2011 found that participants who had received a Web-ORLA programme improved in oral expression, reading comprehension and writing on standardized aphasia tests, including the Western Aphasia Battery-Revised (Lee & Cherney, 2013).

In sum, from the above studies, it is clear that ICT has an unexplored potential for PWA.

## 5.4.7. THE ROLE OF THE SPEECH THERAPIST

In an ideal rehabilitation, a speech therapist uses his/her professional background to diagnose problems and plan interventions needed. He/she presents means that address both psychosocial and communicative goals and that seek to enhance interactions that facilitate identity formation as part of therapy. With a wide repertoire of didactic knowledge and learning strategies, a speech therapist should work in the zone of proximal development and guides, instruct and construct learning situations, builds scaffolds, establish a framework, motivate, support and counsel the PWA and his/her social others. Moreover, the responsibility for the rehabilitation should move gradually from the speech therapist to the PWA. The role of the PWA can, in Freden's words be described as that of a co-creator and/or co-actor in his/her own rehabilitation. Recognition must be achieved as narratives, which underline meaning, context, and memory processing. These narratives should be told in a social and cultural context, highlighting the importance of the outside world (Fredens, 2004, pp. 16-17). Rehabilitation is ideally a collaboration between the speech therapist, the PWA and significant others, such that each person contributes his or her own expertise and insight.

The above represents is an ideal picture of how I believe this process should work. In reality, such a process is, unfortunately, not realistic, most often due to economic constraints.

# 5.5. LEARNING AND DIDACTICS IN IMMERSIVE VIRTUAL ENVIRONMENTS

The approach to learning in immersive virtual environments is based on socio-constructivistic conceptions that learning and knowledge are culturally and historically interdependent. Furthermore, I am strongly influenced by Lave and Wenger's ideas about learning as participation in social contexts (Lave & Wenger, 1991; Wenger, 1999). These authors describe learning as being situated in communities of practice, in which learning extends beyond the pedagogical structuring context and involves the social world. According to Lave and Wenger (1991), social interaction is a critical feature; they describe learning as a process in which the learner becomes involved in a community of practice representing his/her beliefs and behaviours. The situated learning theory descended from Luria's and Vygotsky's social development theory (Luria, 1976; Vygotsky, 1997; Vygotsky & Luria, 1993), which claimed that social interaction plays a fundamental role in the development of cognition, such that language and communication are central to the learning process.

## 5.5.1. A SOCIO-CULTURAL UNDERSTANDING OF LEARNING

When one talks about learning in the process of rehabilitation after brain injury, it is important to involve cognitive learning in order to gain insight into how the individual PWA can restore strategies for their own learning. However, I do not believe that human cognition can be viewed in isolation; instead, cognitive processes must be seen as part of a wide range of social contexts. To clarify the distinctions between the two main directions within cognitive learning theories—a cognitive understanding arising from the Swiss psychologist Piaget and a social understanding rooted to Vygotsky (the cultural-historical school)—I will briefly outline the main differences.

Piaget is a proponent of an understanding of cognitive learning that can be described as a mental construction process in which the learner, through an active engagement, receives information, interprets it, and relates it to what he/she already knows. Piaget was preoccupied with internal mental processes and the development and learning through which individuals adjust to the society. Knowledge is created in in the encounter between what the individual know in advance and the new. Cognition is internalized through concrete physical actions. Problem solving and the ability to reflect on their own learning are central in cognitive learning theory (Dysthe, 2003, p. 44). Piaget believes, like Vygotsky, that a child's activities in relation to the outside world are essential to the development.

Piaget and Vygotsky (who, as a curious side note, was born the same year: 1896) engaged in a theoretical discussion over decades. Vygotsky's book, *Myshlenie in* 

rech<sup>20</sup>, was first published in 1934 and is, to great extent a polemic presentation of Piaget's theories on thought and language. Generally, Vygotsky's criticism was that Piaget considered the development of children to be egocentric—not in the meaning of self-centred, but in the understanding that the child only perceives events and objects from his or her own starting point. The development of language is one of the discussion's central issues (Vygotsky, 1986, pp. 12–57). The authors agree that language and thinking are interdependent; however, it is the order of the development that they disagree on. While Piaget considers the first step in the development of the child's language to be the egocentric speech, this is primordial and intrinsic. As the child becomes socialized, the egocentric speech fades out. Vygotsky argues exactly the opposite:

Egocentric speech is originally social. It does not fade away, but becomes *internal* speech. It is internalized. It is the most important means of thinking, which is born external, objective activity of the child. Verbal thinking develops insofar as activity is internalized.

(Vygotsky, 1997, p. 25)

Thus, Vygotsky's hypothesis was confirmed: the thinking that develops from practical activity is *mediated* by speech (i.e., by the word). In short, one could say that Piaget saw development as something that moves from the individual to the socialized, while Vygotsky considered development as something that moves from the social to the differentiated individual (Danielsen, 1996, p. 74).

Inspired by Vygotsky, Lave and Wenger (1991) introduced the concept of situated learning in their book *Situated Learning*. They emphasise that knowledge and skills must be contextualised and pedagogically structured as reflections of everyday situations. Lave and Wenger propose the term "legitimate peripheral participation" for the participants, indicating that participation can occur in varying forms, from newcomers to masters. By using the word *peripheral*, the authors make clear that being a participant does not depend on the degree of activity. Rather, it relates to the feeling of belonging; that is, "The form that the legitimacy of participation takes is a defining characteristic of ways of belonging, and it is therefore not only a crucial condition for learning, but a constitutive element of its content" (Lave & Wenger, 1991, p. 35).

The sociocultural learning perspective is preoccupied with how individuals interact with other people and tools in their learning processes. Tools are called artefacts, and they might be tools (e.g., computers) or representation systems (e.g., language or math symbols) (Vygotsky, 1999). The learning can, thus, be mediated in different ways, either through practical resources (physical tools/artefact) or

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<sup>&</sup>lt;sup>20</sup> Thought and Language

through intellectual resources (physiological tools/artefacts). Artefacts and behaviour patterns are developed over time and can be understood from a historical and cultural perspective, exploiting previous experiences of generations. Language serves as the primary mediating tool for man.

Being part of a community, both with peers and with family and friends, has important implications for learning, identity, and self-esteem. One of the characteristics of a community of practice is mutual engagement and participation (Wenger, 1999). Another focal point of a community is a common goal. Each participant comes with his own repertoire and his own history to be distributed.

When you talk about injury, it is relevant to include cognitive learning in order to gain insight into how each PWA can restore strategies for learning. In discussing learning in relation to the rehabilitation of language, a cognitive understanding of learning focuses on language production, while a social constructivist understanding of learning focuses on language function and social interaction.

## 5.6. IMMERSIVE VIRTUAL ENVIRONMENTS

In the following, I will specify why I have chosen to use the term *immersive virtual environment* to address the learning and communication environment in this thesis. I believe that the language and the terms that we, as professionals, choose to use, reflect our attitudes and approaches to learning and rehabilitation. My choice is based on surveying and interpreting the various definitions and terms that have been used to describe computer-mediated communities over the last 35 years. By summarizing some of the core concepts mentioned in the definition, I will outline a number of core concepts, which I later will use as an analytic lens for the empirical data.

Many different terms have been used to describe computer-mediated communities. The terms cyberspace, virtual reality, virtual communities, online learning environments, online world-like environments, metaverses and 3D virtual worlds are just some examples of community descriptions that, in all their diversity, represent the same thing: namely, a conceptual space (most often Internet-driven), in which data, language and interactions are manifested by humans using technology.

Within the field of virtual environments, virtual communities or virtual reality, the term "virtual" has been used for decades. Researchers, artists and journalists have tried to define the word, sometimes in inconsistent ways, which has led to some confusion in the literature. According to Merriam-Webster dictionary, virtual means, "very close to being something without actually being it"; however, it can

be related to a variety of situations. Virtual can be defined as something that looks like, feels like or is experienced as real. It can also be said to describe something that is merely conceptual (not physical). Most often, the term is related to simulations in a computer or online; however, in its literal meaning, it is not (Wiktionary, 2015). 3D street art is one example of a non-digital virtual space. Others are dream or hallucinations.



Figure 15 Virtual street art (permission granted by Edgar Mueller)

In this paper, however, I will concentrate on the digital environments when using the term virtual.

Virtual is often linked to Virtual Reality (VR) and associated with science fiction and cyberspace. Within the literature, the concept of cyberpunk arose in the beginning of the 1980s. Cyber refers to Internet-mediated or virtual. William Gibson coined the concept of cyberspace in his 1984 science fiction/cyberpunk novel, *Neuromancer*. To explain the original understanding of cyberspace and the virtual world, the research literature refers to a frequently used quotation from this novel:

Cyberspace. A consensual hallucination experienced daily by billions of legitimate operators, in every nation, by children being taught mathematical concepts... A graphic representation of data abstracted from the banks of every computer in the human system. Unthinkable

complexity. Lines of light ranged in the nonspace of the mind, clusters and constellations of data. Like city lights, receding.

(Gibson, 1995, p. 51)

Implying envisions of reality TV, Internet addiction, behaviour tracking and computer simulations, *Neuromancer* has had great influence on our subsequent understanding of cyberspace and virtual worlds as futuristic communities (Baym, 2010, p. 151; Gibson, 1995).

Reingold (1987) does not relate a virtual community to something futuristic. In his definition, cyberspace is more a place, a bulletin board, or a network than a space or an environment with inhabitants. It is used for the exchange of data and words—not actions. He defines a virtual community as simply as:

A virtual community is a group of people who may or may not meet on another face-to-face, and who exchange words and ideas through the mediation of computer bulletin boards and networks. Like any other community, it is also a collection of people, who adhere to certain (loose) social contact, and who share certain (eclectic) interest.

(Rheingold, 2012, p. 162)

The definition illustrates a 2D computer-mediated community, in which the written word is dominant.

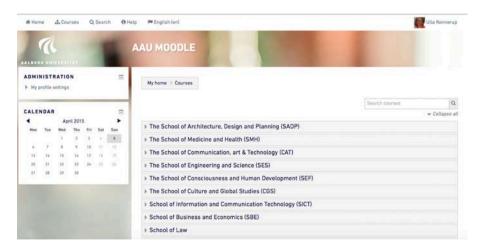


Figure 16 2D VLE for students and teachers at AAU

The next definition I have chosen derives from Bainbridge (2007). With his use of words like environment, world, and characters, we move back to the 3D understanding of the virtual community.

....an electronic environment that visually mimics complex physical spaces, where people can interact with each other and with virtual objects, and where people are represented by animated characters. The diversity of current virtual worlds can be represented by the creativity-oriented environment Second Life (SL), and the massively multiplayer online role-playing game World of Warcraft (WoW).

(Bainbridge, 2007, p. 472)

People interact in spaces and are visible, since they are represented as animated characters. The user perspective and the possibility to co-create content in communities are central.



Figure 17 Avatars in Second Life

Blascovich et al have debated some of the psychological senses involed in interacting in virtual communities. In particular, they discuss immersive virtual environments as technology-mediated communities that allow a user to be absorbed in their environments:

An immersive virtual environment (IVE) is one that perceptually surrounds an individual. Immersion in such an environment is characterized as a psychological state in which the individual perceives himself or herself to be enveloped by, included in, and interacting with an environment that provides a continuous stream of stimuli.

(Blascovich et al., 2002, p. 105)

With his publication *Being There Together*, Schroeder stresses the feeling of presence and of social interactions with others, describing a virtual community as a environment "in which users experience other participants as being present in the same environment and interacting with them – or *being there together*" (Schroeder, 2010, p. 4).

The roots in science fiction and cyberpunk have contributed to a view of technology-mediated communication as unreal and different from physically embodied communication and interaction. This is not always the case, however. Today, communication technologies and virtual communities are tools that are taken for granted to be on an equal footing as physically embodied communication channels. Virtual communities and virtual identities might be built on the platform of fantasy, but such fantasy is not the norm:

There may be fantasy realms where people use the Internet to create selves with no bearing on their offline selves, though, on close examination, even there the lines bleed. People do use the Internet to create false identities. But these are expectations, not the norm. Taken as a whole, mediated communication is not a space, it is an additional tool people use to connect, one which can only be understood as deeply embedded and influenced by the daily realities of embodied life.

(Baym, 2010, p. 152)

Inspired by Blascowich et al., I have chosen to use the term *immersive virtual environment* in this thesis. *Immersive* is used in the understanding of absorbing oneself and forgetting the surrounding world. *Virtual* is used to mean computer-mediated, and *environment* is used synonymously with a community, milieu, or space.

Are these virtual communities just for fun, or do they offer cultural experience? Are they suitable for learning? Yes. From a socio-cultural learning point of view, virtual communities contain a unique set of characteristics. As early as 1994, Hedberg and Alexander pointed out that a very important feature of virtual worlds was their "transparent interface with which the user directly controls the objects in the context of the virtual world" (Hedberg & Alexander, 1994, p. 215). Hedberg & Alexander mention three aspects of virtual worlds that contribute to this transparency and through which such environments have "the potential to offer a superior learning experience" (Hedberg & Alexander, 1994, p. 218): increased immersion, increased fidelity, and a higher levels of active learner participation. In Chapter 6 and 7, I will return to how IVEs facilitates learner experiences and identity-forming activities.

## 5.6.1. SECOND LIFE

SL is, without comparison, the IVE with the most users and the most frequently referenced IVE in research. It was founded by Linden Lab in San Francisco in 2003. By 2014, there were more than one million regular users ("residents", as they are called) ("Second Life," 2015). It has been essential for Linden Lab to stress that SL is not a game, but a society (Carr & Pond, 2007, p. 21). On the occasion of SL's 10-year anniversary, Linden Lab published a press release with an 'infographic' of facts and figures, illustrating SL's widespread use and popularity.

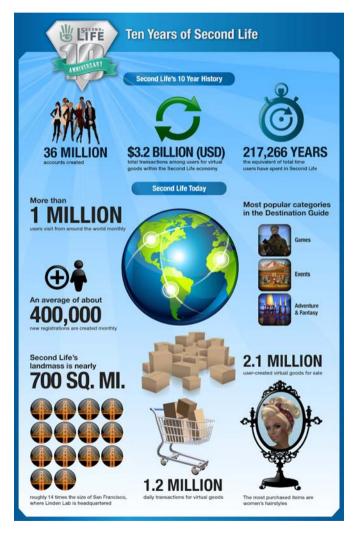


Figure 18 Infografic SL

SL is a free online world that people can enter, explore, and interact in by logging in on the Internet. Using a keyboard and mouse, users control graphical digital representation of theirselves: that is, so-called "avatars" (Carr & Pond, 2007, p. 34). A person who controls an avatar can decide its behaviour and personalize its appearance. Age, gender, race, height, and weight can be changed with a few mouse-clicks. It is possible to rent or buy land, build houses, buy spaceships and much more. Avatars can fly and teleport, giving the user a degree of self-control and self-representation.

The easy web-based access from home computers makes SL fit for rehabilitation. SL is, in many ways, a virtual replica of the real world. It is possible to personalize a user's environment with a small amount of money. Some would argue that the graphical appearance could be more realistic; however, research has shown that a photographically real display does not increase users' feelings of social presence more than other parameters, such as minimal cues (Sanchez-Vives & Slater, 2005, p. 337).

Environments like SL offer such features as embodiment, presence, collaboration, user-centeredness, context-awareness, and cross-real interactions to enhance users' learning experiences. Through avatar mediation, IVEs opens up bodily immersion and interaction, affording users the semantics of place, including deixis, indexical language, and body orientation. Compared to many other technologies, the critical characteristics of IVEs include the presence of avatars, a shared space, and shared activities (Rehm & Konnerup, 2012).

In the following, the concepts of importance related to rehabilitation in IVE will be outlined and explained.

## **5.6.2. AVATAR AND AGENTS**

With reference to the former definition of the virtual concept, one could say that a virtual person can take the form of a variety of representations, from a character in a videogame, to people writing blogs, to a Facebook account, and many more. To be more precise, one can differ among the following dimensions:

- Form (biological, mechanical, fictional, digital)
- Controlling force (person, algorithm)
- Realism dimensions (photographic, behavioural, anthropomorphic)

In this context, it is relevant to explore the personalised representations, in computer-mediated communities: that is, agents and avatars. Both are digital

representations, but the controlling force is, respectively, an algorithm and a person. An agent is an algorithm driven by a computer program, and each avatar is represented and controlled by a real person. I will use the notion *embodied agent* to indicate that an agent takes the appearance of a person.

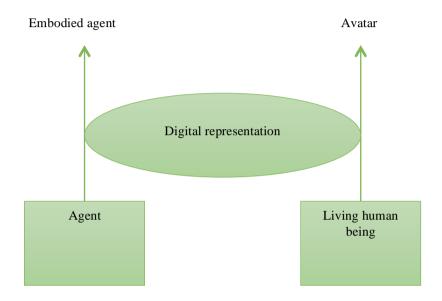


Figure 19 The distinction between agent and avatar (Bailenson & Blascovich, 64-68)

Central for embodied agents is the use of multiple input and output channels in order to realise a user's communicative experience that resembles his natural communicative behaviour. Agents follow their own agenda, and they have preprogrammed tasks and goals (Rehm & Konnerup, 2012).

An avatar is a digital representation of a human being, whose behaviour reflects those executed by the controller, typically in real time. Avatars can communicate via text, symbols, verbal and nonverbal channels. Thus, the user experience the actions of the avatar in first person, thereby supporting the feeling of "being there".

Currently, the degree of behavioural resemblance is relatively low. "The key challenge, though, is designing faces and bodies in high enough detail to allow for the realistic rendering of behaviour" (Bailenson & Blascovich, 2004, pp. 64–68).

From a Cartesian mind/body dualistic point of view, it has been argued that interacting in the virtual world involves leaving an inert body behind, such that the avatar is to be considered as a disembodied subjectivity that inhabits the virtual realm (Jones, 2006, pp. 12–13). However, as Hayles argued in her book, *How we became Posthuman from 2008*, this is not how the concept should be considered; rather:

...it is not a question of leaving the body behind but rather of extending embodied awareness in highly specific, local, and material ways that would be impossible without electronic prosthesis

(Hayles, 2008, p. 291)

According to the phenomenological expression *the corporeal schema*, the body is extendible through artefacts. The schema of the body is not limited to the psychical body; instead, it includes phenomenological experiences through interactions with the surrounding environment. Merleau-Ponty (1996) explains this conception by providing the metaphor of a blind man's stick, as follows:

The blind man's stick has ceased to be an object for him, and is no longer perceived for itself; its point has become an area of sensitivity, extending the scope and active radius of touch, and providing a parallel to sight.... To get used to a hat, a car, or a stick to be transplanted into them, or conversely to incorporate them into the bulk of our own body...

(Merleau-Ponty, 1996, p. 143)

The blind man's stick is an example of an embodied tool that prolongs a man's bodily perception and tactile world. Since the stick is automated by the body and is, thus, embodied, it becomes part of the man's own bodily experience: a perceptual extension or prosthesis. Technology or virtual experiences can be considered to be similar.

### 5.7. AVATAR-MEDIATED LEARNING

Embodied personal representation constitutes the potential for having a strong effect on people. In the following, I will outline some of the aspects suggesting that the learning experience differs between tradition physical learning environment and e-learning using 2-dimensional user interfaces.

## 5.7.1. EMBODIMENT

The term embodiment is defined in a number of different ways in the research literature on psychology, cognition, and learning (Rohrer, 2007, p. 348). In this context, the understanding is very similar to the phenomenological understanding, as stated by Merleau-Ponty. The phenomenological body and its role in perception and learning were central in Merleau-Ponty's research. In Phenomenology of the Perception (1945) he emphasis "the critical role of the body in mediating between internal and external experiences" (Dourish, 2001, p. 116). Through the perspectives of a computer scientist and human-computer-interaction (HCI) Dourish argues that the phenomenological understanding of perception and the concept of embodiment are relevant to understanding how technology mediates communication—and, thus, is crucial to the design of technology. With a focus on the community as a mediator of situated learning, users will be enrolled in what Dourish (2001) defines as embodied interaction. He defines embodiment as: "the property of our engagement with the world that allows us to make it meaningful". Further, he continues: "Embodies interactions is the creation, manipulation, and sharing of meaning through engaged interaction with artefacts" (Dourish, 2001, p. 126). Embodiment is a participative status and a way of being; thus, it can be considered a source intentionality (Dourish, 2001, pp. 125-126). The phenomenological understanding that embodied interactions turn actions into meaning corresponds with Luria's and Vygotsky's basic ideas:

Meaning is not located in the brain but only in the interaction between living human being and his natural social environment: "The neurocognitive system exits enmeshed in the world, in which we move, behave and live with others through our bodily existence".

(Christensen & Prigatano, 2009, p. 175)

## 5.7.2. EMBODIED COGNITION

I have previously stressed that cognition cannot be understood separately. I have also explained the different generations within cognitive science. The first generation neglected the body; the second generation was inspired by the phenomenological philosophers, with the embodied mind in focus, arguing that cognition is bodily and situated; and, finally, the third generation considered cognition, besides being socially and culturally shaped, to also be mediated, action-based and distributed across a network of persons. With reference to Fredens, I introduced that the concept of *neuroconstructivism*, meaning that cognitive functions are built through interactions with the challenges the person meets and thus are to be considered to involve interconnectivity between body and mind.

According to the ancient Greek philosophers, the relationship between body and mind has been discussed within philosophy, psychology and learning science. The dualistic method of thinking has even permeated our language: We do not have one exact word for the connection between mind and body; instead, different terms have been used over the years. In 1927, Dewey made a speech to the New York Academy of Medicine, "Preoccupation with the Disconnected", where he addresses the paradox, and how the dualism has influenced science and medicine.

The division in question is so deep-seated that it has affected even our language. We have no word by which to name mind-body in a unified wholeness of operation. For if we said "human life" few would recognize that it is precisely the unity of mind and body in action to which we were referring. Consequently, when we discuss the matter, when we talk of the relations of mind and body and endeavour to establish their unity in human conduct, we still speak of body and mind and thus unconsciously perpetuate the very division we are striving to deny.

(Dewey, 1928, p. 6)

This paradox still exists to some extent. However, with the concept of *embodied cognition*, which has been commonly used since the beginning of the 21<sup>st</sup> century (Johnson, 2013, p. 234), we are approaching something more comprehensive. By using an adjective form of body in the concept of *embodied cognition* (rather than body *and* cognition), we indicate that cognition and body are closely linked. This is a way of characterising the cognition and of stressing the inherent ties between cognitive processes and a body's action.

Though the understanding of embodied cognition is not quite consistent in the research literature, there seems to be agreement on two fundamental claims:

(1) There is no mind or mental activity (and hence no perception, feeling, thought, communication, valuing, or action) without a body and (2) the body plays an indispensable role both in what has meaning for us and in how we experience and make that meaning. In other words, the body does not just provide representational content for mental operations. Rather, it shapes the ways we conceptualize, reason, and communicate.

(Johnson, 2013, pp. 234–235)

As mentioned, higher cognitive function is not limited to specific areas in the brain, but distributed throughout neocortex in an overlapping and collaborative network. Nor is conceptualization separated from the areas responsible for perception and

motor functions (Johnson, 2008, p. 162). Research shows that areas in the brain that are used for producing an action are the same areas used for the conceptual representation of the same action: the so-called motor cortex.

Our bodies shape fundamental human concepts and brains, arise from sensorimotor experiences, and are neurally realized as sensorimotor schemas/patterns in a close relationship between perception and action (Johnson, 2008, p. 162; Lakoff & Johnson, 1999, p. 77). Once the body knows to interact with the environment in a certain way, similar experiences will evoke the most suitable motor program in new interactions (Gallese, 2000, p. 31). Furthermore, the multimodal system (i.e., hearing, vision, touch, and action) provides an interconnected experience that contributes to people's perception of the world. Moreover, concepts are conceived and developed differently, depending on individual experiences and socio-cultural and historical situations (Shapiro, 2010, pp. 70–71). Moreover, according to Merleau-Ponty's words from 1945/1996:

That the life of consciousness - cognitive life, the life of desire or perceptual life - is subtended by an "intentional arc" which projects round about us our past, our future, our human setting, our physical, ideological and moral situation, or rather which results in our being situated in all these respects.

(Merleau-Ponty, 1996, p. 136)

This approach brings us back to the concept of mirror neurons, which provide a biological explanation for the link between action and perception and a "relationship between *control* of action and *representation* of action" (Garbarini & Adenzato, 2004, p. 103). Gallese argues that object observation does not necessarily require the observer's active interaction to activate the motor program. Looking at an object can be sufficient to unconsciously simulate a potential action:

If this interpretation is correct, objects are not merely identified and recognized by virtue of their physical 'appearance', but in relation to the effects of the interaction with an agent. In such a context, the object acquires a meaningful value by means of its dynamic relation with the agent of this relation. This dynamic relation is multiple, as multiple are the ways in which we can interact with the world by acting within it. The object-representation ceases to exist by itself. The object phenomenally exists to the extent it represents the target of an action.

(Gallese, 2000, p. 31)

This suggests a strong presumption that computer-mediated sensorimotor stimuli and interactions in IVEs will evoke the motor program as if it were operating in a physical world.

With the concept of *embodied cognition*, we engage a larger understanding of cognition. The close connections among body, environment, and culture suggest added dimensions and possibilities in the design of aphasia intervention and rehabilitation.

# 5.7.3. THE SELF

I use the terms self and identity more or less interchangeably. There are, however, minor differences between their uses. Whereas *self* refers to the understanding that (as noted in *The Oxford Dictionary*, n.d.): "A person's being that distinguishes them from others", identity is used in the understanding described previously: the traits, characteristics, social relations, roles, and social group memberships that define who someone is.

Like Fredens (2006) and Shadden, Hagstrom & Koski (2008), I assume that the creation of the self occurs in communication with others through narratives and life stories. However, what if the self is created in a virtual environment? Will it still be the same person? How shall we describe this phenomenon?

## 5.7.4. THE VIRTUAL SELF

People have always presented themselves in a variety of manners, depending on the situations in which they find themselves. Goffman (1959) uses the theatre metaphor of *backstage* and *frontstage* to illustrate people's performances in their attempt to project a certain image. In his metaphor, the people are viewed as actors. When they are at front stage, they are conscious of their behaviour and are following social rules and conventions. In their private backstage, however, they act differently, since no performance is necessary (Goffman, 1959). With the advent of computer-mediated technologies, especially social media and virtual environments, we have been provided new platforms, with possibilities to play and try out new identities and new ways of presenting ourselves (Dourish, 2001, p. 61). Since avatars are created and controlled by users, creativity and fantasy are allowed to form people's "second self" as they wish. Research has shown, however, that this is not the norm. Most people consider the Internet to be an additional tool to connect that is deeply embedded in the daily realities of embodied life (Baym, 2010, p. 152)

#### 5.7.5. IMMERSIVENESS

Dede (2009) describes immersion in a virtual environment as the subjective impression that one is participating in a comprehensive and realistic experience. Such immersion involves the willing suspension of disbelief (Dede, 2009, p. 66). Sensory information causes users to forget that they are in a mediated environment, leading them to believe and behave as if they were in the real world (Sanchez-Vives & Slater, 2005, p. 332; Schroeder, 2010, p. 3; Slater, Usoh, & Steed, 1994).

The Dourish concept of technology being *present-at-hand* is a metaphor for forgetting that you are involved in interactions mediated through technology (e.g., a mouse); instead, you feel that you are immersed in acting through your avatar (Dourish, 2001, p. 109).

First-person experiences in an IVE might also enhance feelings of immersion.

#### 5.7.6. PRESENCE

Immersion can lead to *presence*, which is "a state of consciousness that may be concomitant with immersion, and is related to a sense of being in a place" (Slater & Wilbur, 1997, p. 1). Slater, Usoh, and Steed have conducted several studies attempting to define the concept of presence. They have developed three conditions, as follow:

- (1) The subject's sense of "being there" is a direct attempt to record the overall psychological state with respect to an environment;
- (2) The extent to which, while immersed in the VE, the VE becomes more "real or present" than everyday reality;
- (3) The "locality", which is the extent to which the VE is thought of as a "place" that was visited rather than as just as a set of images.

(Slater & Wilbur, 1997, p. 5)

In brief, one could say that presence is how immersion makes you feel. Schroeder (2010) noted that, in the context of virtual environments, "media richness is often called 'co-presence' and that the feeling of "being there" make users feel they are together in the same (virtual) space" (Schroeder, 2010).

In rehabilitation, such parameters as embodiment and a sense of presence have demonstrated creating positive effects for learning tasks (Phillips, Ries, Kaeding, & Interrante, 2010).

#### 5.7.7. MULTIMODALITY

Recent research on human communication in the physical world emphasize its inherently multimodal nature:

[T]he transition into referential or language-like expressions involved hands and body, face and voice and mouth, all together, as an integrated ensemble......[Human] *always* mobilise face and hands and voice together in complex orchestrations. .....Indeed, kinesic and audible expressions are so intimately intertwined in their employment in the creation of utterances, they must be seen as being produced under the guidance of a single project.

(Kendon, 2009, p. 363)

Within computer-mediated-communication and the design of computer interfaces, multimodality refers to multiple inputs and heterogeneous representations (Streeck, Goodwin, & LeBaron, 2011, p. 9)

#### 5.7.8. PROTEUS EFFECT

The phenomenon of the Proteus effect has already been introduced in Chapter 2. In short, the Proteus effect indicates that interactions in IVEs might change how people behave and consider themselves in the physical world. However, there is still a need for research that can give evidence of a spillover effect to conclude that the negotiation of identity in IVEs can induce identity in the real world.

#### CHAPTER 5. THEORETICAL FRAMEWORK

# **5.8. CONCEPTS OF INTEREST**

As mentioned, I have chosen various core concepts from the theoretical considerations that have relevance to the research question. These are listed below. They will also later be used to point out units of interest for the analysis.

Core concepts	Sub-points
Identity	<ul> <li>Gender</li> <li>Age</li> <li>Family</li> <li>Occupation</li> <li>Renegotiation</li> <li>Narrativity</li> </ul>
Presence	
Immersiveness	• Engrossment
Embodied cognition	<ul><li>Conceptualization</li><li>Mirror neurons</li><li>Motor</li></ul>
Learning	<ul><li>Situated</li><li>Social</li><li>Mediated</li><li>Meaningful</li></ul>
Rehabilitation	<ul><li>Communication</li><li>Language</li></ul>

Figure 20 Concept of interest

# CHAPTER 6. EMPIRICAL WORK

In this chapter, I will present the empirical data. Specifically, I will describe the practical steps and the processes in chronological order. Based on the theory outlined in Chapter 5 and on the collected data, I will analyse themes relevant to my research question. Finally, I will summarize my interpretation of what has emerged from this analysis.

### **6.1. DATA COLLECTION**

As I wanted to conduct this thesis with a high degree of involvement of "the explored participants", I addressed The Institute of Speech, Language, and Brain Disorders with a request for collaboration. We agreed to form a project group with the purpose of carrying out a pilot project related to rehabilitation in an immersive digital learning environment. The group consisted of four speech therapists—including the person responsible for the digital rehabilitation. All involved speech therapists had experiences in teaching digitally through the web-based ATA. The speech therapists were given the task of finding PWAs that, presumably, would be interested in joining the pilot project and that, at the same time, would participate in the interviews and the workshop. The point of involving PWAs was to gain first-hand knowledge of the phenomenon of aphasia and of renegotiating identity and relearning to be active citizens by interacting in an avatar-mediated immersive learning environment.

The criteria for PWAs were that they should:

- Have been diagnosed with aphasia after a brain injury based on a recognised test and a brain scan,
- Be current or former patients at The Institute of Speech, Language, and Brain Disorders.
- Have participated in web-based rehabilitation before,
- Have a computer at home with a newer graphic card and good bandwidth,
- Be interested and willing to try new and untested rehabilitation methods.

The idea was to put together a relatively diverse group of PWAs in relation to age, sex, severity of aphasia (i.e., mild, medium and severe), different degrees of mobility and varied post-onset. However, there was an overrepresentation of interested and motivated men. Since motivation, engagement and familiarity with technological tools had the greatest importance among the requirements, a group of seven men and two women aged 58 to 72 years were invited to participate—even

though I am aware from former projects that there may be significant differences in the activities that motivate men and women (Konnerup & Schmidt, 2006). The objective is to investigate the learning potential, which the case illustrates. All the PWAs had supporting relatives: either spouses or adult children.

Name	Born	Post- onset	Diagnose	Relative	Former Occupation
Allan	1951	2009	Anomic Aphasia	(Alone)	Pig Breeding Consultant
Brian	1948	2009	Broca's Aphasia ('non-fluent aphasia')	Children	Bricklayer
Chris	1944		Transcortical Motor	Wife	Sexton
Helen	1953	2002	Wernicke's Aphasia/Anomic ('fluent aphasia')	Husband	Nurse
Janice	1953	1984	Anomic Aphasia	Husband	Pedagogue
Ian	1945	2009	Anomic Aphasia	Wife	Carpenter
John	1945	2009	Wernicke's Aphasia ('fluent aphasia')	Daughter	Grocer
Michael	1946	2009	Wernicke's Aphasia ('fluent aphasia')	Wife	Electrician
William	1941	2008	Global Aphasia (severe)	Wife	Psychologist

Figure 21 Participants with aphasia (PWAs)

# CHAPTER 6.

Content	Method	Numbers	Type of documentation	Where and Who	Date
Preparation Information Mutual expectations Getting to know each other	Qualitative Interview	9 x 30 minutes	Notes	In the home of PWA Researcher interviewing (supported by their relatives and personal speech therapist)	October-November 2010
Information about IVE in general Generation ideas for scenarios and other content in a relevant IVE	Workshop	1	Note-its Posters Snapshots	At AAU 9 PWA and their relatives 4 speech therapists	12. March 2011
Pilot Course 1 (Training sessions for speech therapists)	Observation and video-taping of online courses in Second Life	6 hours	Camtasia recording, QuickTime Player	Speech therapists	September- October 2011
Experienced PWA - user in SL (Peter)	Qualitative Interview	1	Camtasia recording, QuickTime Player	Peter in SL	December 2011
Additional face-to-face training for Speech Therapist. Second Life	Workshop	1	Notes	At the institute of speech disorders	13. March 2012
Training courses	Observation of online courses in Second Life	30 hours	Camtasia recording, QuickTime Player	PWA in SL	April –June 2012
Evaluation – Speech Therapist	Qualitative interview	6 x 30 minutes	Audio Recordings Mp3 format	Speech Therapists	January-February 2012
Evaluation	Qualitative Interview	5	Audio Recordings Mp3 Reflections in writing	PWA - reflections and feedback	June 2012
Guided Tour in Media Lab, Danish Vision (SL) with experienced teacher and designer Expert interview	Qualitative Interview in Second Life	1 1/2 hour	Camtasia recording, QuickTime Player	Inge (expert) Her land and collaboration with Peter Holodecks	December 2013
Visions and Future Practices	Qualitative Interview	30 minutes	Mp3 format	Speech Therapist in charge (Pia)	March 2014

Figure 22 Overview of data

The empirical work was conducted from the autumn of 2010 to the spring of 2014. Above is an overview of the collected data. This overview illustrates different types of data. The collection consisted of varying kind of documentations that supplemented one another, including: audio-recorded interviews, video-recorded SL sessions, notes from interviews and workshops and written notes from PWAs and posters. The initial interviews with the PWAs and the workshop with the PWAs, relatives, and speech therapists were in the original data design, as were the two pilot courses. The guided tours with Peter and Inge Knudsen were opportunities that arose along the way. I had met Inge in another context, during which we discussed our mutual interest: SL. Inge introduced me to Peter, and both were very interested in sharing experiences. In this way, I gained the opportunity to

interview two experts who could shed light on long-term SL use. The interview with the speech therapist and the workshop for the speech therapists were established by necessity along the way. The pilot course for the speech therapist revealed that they needed significantly more time to become familiar with the IVE and its features. That is, they did not feel qualified to teach PWA in SL. To give each speech therapist an opportunity to describe their issues in detail, I decided to set individual interviews with them. To meet their sense of inadequate skills, it was decided that a workshop would be conducted with the aim to improving their SL literacy. Data from 2014 are to be considered to be additional, though informative.

#### 6.2. PROCESSING DATA

My intention with this research project—and, thus, with the data obtained—was to understand the phenomenon of avatar-mediated interaction and how it can equip PWAs to renegotiate their identities and maintain their roles as knowledgeable persons. Therefore, I sought examples of phenomena in the data that could shed light on this issue. At the same time, I was interested in whether there might be recurring themes to which I had not been alerted.

Collecting and processing of the data varied, depending on the situation and the goal, from informal talks with notes on papers and note-its to more advanced software used to capture and process information.

Inspired by Kvale's approach to processing qualitative interviews with a focus on "meaning" (Kvale & Brinkmann, 2008, pp. 201–219), I set up steps for working with the qualitative data, focusing on meaning in videos and audio-recorded interviews.

#### Video:

- 1. Online observation (in real time), while video-recording the screen
- 2. Watch the whole video to get a sense of the whole (sometimes repeatedly)
- 3. Divide the video into natural units with headlines
- 4. Choose central passages and name them after central themes
- 5. Clip the central themes into one video
- 6. Transcript of relevant passages
- 7. Choose recurring central themes for my units of analysis

#### Audio recordings:

- 1. Audio-recording
- 2. Listening (repeatedly) to the whole interview to get a sense of its intirety
- 3. Transcript (using the software Transana)
- 4. Marking natural meaning units
- 5. Putting these in the Collection (a feature in Transana) and creating express clips
- 6. Choosing recurring central themes for my units of analysis

To preserve the video data, I used the software Camtasia Studio, which allows the user to record the screen and to subsequently edit and save the recordings in different formats. For further processing, I used the software Final Cut Pro X, which is an advanced movie-editing tool for Mac. With Final Cut Pro, a user can edit video and audio in a very detailed way. All videos were saved in QuickTime Movie format to make them readable on the most possible devices. Selections of the video clips were transcribed in Transana, a software tool for processing qualitative data, in which a user can work with audio and video simultaneously, identify keywords, and create clips for analysis. I used Transana for both video and audio recordings. Since the videos already had been processed through in-depth editing in Final Cut Pro, Transana was primarily used to transcribe passages I already presumed to be interesting, while the interviews were transcribed in full length.



Figure 23 Processing video in Final Cut Pro



Figure 24 Processing video and audio in Transana

Transana was a great help in structuring the data. Everything is saved in a database, and the user can create series for each relevant topic. In the transcribed text, you can mark sequences of interest and save and name them as express clips in categorisations. It is very useful in the analysing process to have such easy access to the saved sequence themes, structured by units of interest.

I used my iPhone for all audio recordings. My iPhone is always ready at hand, the sound quality is okay, and the recording was always with me afterward. I listened to the recordings repeatedly on my many walks; thus, I really have the statements "under my skin". This made the transcription easier, and, again, I had a presumption of the units of interesting themes.

#### CHAPTER 6. EMPIRICAL WORK



Figure 25 Structuring in Transana

#### 6.3. INTERVIEWS WITH PWAS

In order to meet the PWAs in quiet surroundings, I chose to carry out the initial interviews in their own homes. My experience has shown that communication becomes more informative, when own artefacts, such as family photos, hobby tools, etc., can support the speech. It was also beneficial on this occasion to see the PWAs' private computers, to gain insight into their use of the computers, and to determine the computers' capacities.

The visit intended to: 1) get an impression of all PWAs and hear about how aphasia had influenced their lives, 2) interview them about their interests, skills and motivations in relation to the use of digital media, and, finally, 3) inform them about the project and what to expect, while letting them ask questions. The interviews took place over coffee tables, and both social others (mostly spouses) and speech therapists were present. This step was conducted as a qualitative semi-structured interview (App A), and, over more occasions, we engaged in discourses, visited the garden or a workshop, or looked up something at the computer.

Of the PWAs, William stood out. William suffers from severe global aphasia and has a sparse verbal language. He had never participated in any web-based course. His son had contacted me because the family desperately wanted to find a communication tool for William. William was eager to communicate, and he managed to tell much of his life story using gestures, facial mimicry, body language and, not least, a globe and an atlas.

Allan has been an active man all his life. As a local reporter for the local news, he was always up to date in the community. After his injury, his language was disabled, but not his physics. He had begun to take many photos, and he wanted to share them with others in a digital forum. Allan is interested in beautiful landscapes and fauna in his local area.

Helen and Janice have been participating in web-based rehabilitation since the beginning, in 2001. They have also participated in research before, and Helen has joined me in a conference, in which she talked about using web-based tools. They both have rich private social lives and supportive families. Their motivation for participating in another project was their eagerness to engage in and explore new rehabilitation possibilities. Helen is an experienced ICT user, whereas Janice has major difficulties remembering processes over time.

Michael is primarily a handyman, but he has used computers for several years. After his brain injury, he had to relearn to use the computer again; however, he now uses it frequently for ordering tickets, searching for travel information, and so on. He also, however, spends much time in his workshop doing different kind of

#### CHAPTER 6. EMPIRICAL WORK

handicraft. Michael was interested in the project mostly because he still needs to improve his writing and speech competence.

Chris and Ian have both been participating in SL activities with their speech therapist, Pia. They like group therapy and doing activities with peers. Chris has been using the computer for several years (he has two computers at his desk in the living room). Ian still needs to improve his reading and speech competences.

Brian suffers from severe non-fluent aphasia, which means that his expressive verbal language is insufficient. He lives alone and is physically disabled, so he uses a wheelchair. He has a grown-up daughter, who has promised to help him use the computer. He is minimally experienced with digital media, and he does not have much interest in the project. His favourite activity is taking a ride to the harbour, where he watches the boats and the people.



Figure 26 John's book

John has always been a very active person. He has just finished "writing a book", (in cooperation with a journalist) called 2 *gode liv*, which refers to his life before and after his brain injury. John has severe fluent aphasia, which means that his speech largely consists of empty words and content-lacking words. His competence in writing is severely impaired. He has been extremely proactive in engaging in compensation strategies, including recruiting help to make and save a huge collection of words and sentences both at his laptop and in paper on his desk. He has managed to communicate through social medias and in notes. Furthermore, he is a frequent user of a digital camera, which helps him support his memory.

All PWAs wanted to improve their communication abilities. Being a part of a research project—and, thus, using their "expertise" in suffering from aphasia to

help improving aphasia interventions was, however, a major part of their motivation.

The outcome of these informal visits was primarily to get an impression of a group of inspiring PWAs with a desire to communicate and to get better doing it. However, the PWAs also gave inputs regarding what content an IVE could have. Based on their hobbies and interests, the following ideas were developed for scenarios:

- Navigating a sailing ship
- Being a local reporter and sharing photos from various scenic areas
- With a globe, identifying and visiting places travelled in the world
- Creating a flower garden
- Creating a joint construction project

These were good suggestions for a 3D environment, showing that the PWAs had some understanding of the differences between two- and three-dimensional interfaces.

The documentation for these first interviews was collected in the form of notes (App B)

# 6.4. WORKSHOP WITH PWAS, SOCIAL OTHERS AND SPEECH THERAPISTS

The whole project group gathered one Saturday at AAU for a workshop with two goals: 1) the participant should come up with ideas for scenarios and activities in a virtual environment, and, based on the proposed activities, the speech therapists should define what kinds of training, the activities could support, and 2) the PWAs should put forward activities they miss being able to do and engage in a group discussion about whether known technologies could compensate for the problems.

Before the workshop, I sent out invitations with information about the workshop programme (App C) and a leaflet about the project (App D)

To be sure that everybody had insight into what an immersive virtual environment was, I began the workshop with a short video from the project *Coming Home* from ICT at USC, which shows interactions in SL. This first workshop gave rise to a vivid discussion. The participants worked in groups and presented in plenum.



Figure 27 Group discussion

Overall, a lot of good ideas were advanced and were placed as Note-Its on a poster.



Figure 28 Workshop on scenarios, activities and training

Many good and creative ideas were developed, and no one mentioned any kind of traditional learning setting known from the physical schooling and/or their rehabilitation lives. What they wanted was authentic environments, such as harbours, a city square, shopping possibilities, and a workshop for enjoying nature and being with others. Some of the ideas are listed below:

Scenario	Activities	Training
Construction site	Build a pavilion (so you can meet and have a beer ©)	Body language, tacit knowledge, collaboration, math, and calculating
Workshop	Make a nest house (for gifts for friends and family)	Body language, tacit knowledge, collaboration, math, and calculating
Garden	Plant, seed, pick, and harvest	Categorization, selection and naming
Genealogy	Tell the family a story and make a genealogical tree	Structure, naming, recognition of faces, matching, renegotiation af identity memory
Discussion group	Negotiation of meaning, discuss	Make oneself communicative and applicable, show who you are, renegotiate identity
Chat	Conversation, small talk	Turn taking
Harbour	Relax and watch the ship and the seagull (maybe eat a hotdog ©)	Enjoy life
Travel Agency	Visit new and known places in the world and take others to favourite places	Naming, overview, prices, time
Market place	Buy things	Categorization, selection and naming, calculating and recognizing money

#### CHAPTER 6. EMPIRICAL WORK

City square with a meeting point	Meet people, get information about what is going on	Seek information, time and place, read	
Hot dog stand	Buy things	Categorization, selection and naming, calculating and recognition of money	
Globe	Travel and get and overview of the world	Recognition of the world, naming, space and place	
Shopping center	Buy stuff	Categorization, selection and naming	
Lake or small river	Go fishing or take a boat ride	Relaxing in a beautiful place, naming, counting	
Restaurant	Ordering food, eating and being social  Selection and name calculating and recognition money		
Sport Center	Doing different kinds of sports	Place and space, body and body language, embodiment	
Ranch	Horseback riding	Embodiment, memory, naming	

Figure 29 Ideas for scenarios in an IVE

The second task, concerning the lacking and missing abilities, became very emotional. It was a tough theme. Being able to talk, count and name names were obviously high on the list, but things like missing the male jargon at work or with friends, going for a drive alone, being able to act independently and the like were also mentioned.

Things like random meetings while on the harbour, at the hot dog stand, playing sports or participating in other communities were considered huge losses. One of the men mentioned that women surround him all day long and really missed his

male friends. All the other men nodded and shouted: "YES", which was not easy to accept for some of the wives. This event gave rise, however, to some debate about how altered and dependent the lifes of the PWAs are. Several of the men had histories as craftsmen and even want to help to build the environment in SL. Their desires included an activity to jointly build a pavilion, where they could subsequently meet over beer.



Figure 30 Dysfunctions and technology

The workshop and the cooperation with the PWAs and their social others contributed to an understanding of the main problems related to being a person or a family member of a person suffering from aphasia. Furthermore, some ideas for learning environments to motivate and engage PWAs were pointed out.

Choosing a concrete learning environment was a significant issue in the beginning of project. Originally, we had, as mentioned, ambitions to create an environment with help from, for example, students from medialogy, designed specifically to the users and making it possible to simplify and adjust the interface and the features. However, this goal did not succeed. We realised that many research projects use SL because it is 1) web based (and, consequently, suitable for both PCs and Macs), 2) free to sign up for, 3) easy to remodel, and 4) driven by a typical keyboard and mouse. Thus, we decided to use SL.

# CHAPTER 6.

Based on the workshop, The Institute of Speech, Language and Brain Disorders invested in some land in SL called Wonderful Denmark (WD) and its associated rights. The land was designed as a small Danish town, with a city square, tourist offices, shops, banks, museums, prisons and other services, transport, ports and parks. The place was, luckily, for sale, with content that could meet the PWAs´ demands by offering activities on land, at sea and on horseback.

At that point, we had the land for the pilot courses, as well as a great part of the desired scenarios and the right to set up privacy throughout the land. We knew from the beginning that the situation was not perfect in relation to certain complex functionalities; on the other hand, the environment was rich and equipped with beautiful landscapes and milieus.

#### 6.5. PILOT 1 – COURSE FOR SPEECH THERAPISTS

Even though the involved therapists had experiences with ICT in rehabilitation and distance training, only one of them, Pia, had experiences with SL or other 3D virtual environments. Pia was, at the same time, in charge of ICT in rehabilitation at The Institute for Speech, Language, and Brain Disorders. Thus, her role in this case was to design the courses and teach her colleagues. A course for six therapists was set up one-hour twice per week for 6 six weeks (App E). The objective for the course was that the speech therapists, through activities and exercises in SL, would 1) gain experience with SL and 2) gain pedagogical ideas and be equipped to organize a course for one or two of their own PWAs. The course was concluded with a roundtable discussion in SL, in which new pedagogical possibilities and methods for PWAs in IVEs were discussed. The forum also explored how the IVEs support the re-development of language skills, communicative competences, accessibility to, and participation in discussion forays and society. Emphasis was placed on the avatar-mediated actions and on an assumption that the embodiment will positively affect the brain re-establishing process and promote cognitive and communicative functions, and finally renegotiate identity.

As mentioned, the speech therapists needed much more time to remediate their practices regarding IVEs. The features and technical obstacles took focus, and they did not have much surplus time to think didactically or realise benefits in rehabilitation in IVEs. They needed upgrading and more help with the technical aspects.



Figure 31 Roundtable discussion in SL

To realise their inadequate skills, a face-to-face, six-hour workshop was arranged.

#### 6.6. INTERVIEWS WITH SPEECH THERAPISTS

The pilot course revealed that the speech therapists did not feel ready to teach PWAs in SL. Even though we had had pedagogical discussions, I felt that I needed to know more about their technological competencies and their beliefs and motivations for participating in a virtual learning project. I had the feeling that some of the speech therapists saw more barriers than possibilities. I, therefore, set up five qualitative interviews, with the aim of clarifying: 1) the speech therapists' own experiences with using and understanding digital media and other technologies. Did they use technology in their work and/or spare time? Did they find it useful in aphasia interventions? If barriers occurred with the use of technology, who would solve the problem: the speech therapists or someone else? and 2) the speech therapists' professional dedication, how they considered their role, and what the most important goal in the aphasia intervention was in general.

#### 6.7. WORKSHOP FOR SPEECH THERAPISTS

Another initiative to further qualify the speech therapists was a six-hour face-to-face workshop at The Institute of Speech, Language, and Brain Disorders. Based on Pilot Course 1, Pia and I discussed the best route. We agreed that we had overestimated the speech therapists' technological competencies in relation to SL. We had to recognize that, to them, SL had a truly steep learning curve. We decided to conduct a basic course with all SL's elementary features and settings (App F).

# CHAPTER 6.

Furthermore, we made a suggestion of running a basic course for the PWAs with introduction exercises in SL. Finally, we set up a meeting in SL with Peter, who had been suffering from aphasia for many years and had been interacting in SL for five years. We also met with Inge, who had been teaching different courses in SL and had built some interesting places (e.g., for Peter). Both gave us guided tours, told us about their experiences, and invited everybody to visit and use their facilities in SL.

#### 6.8. PILOT 2 - COURSE FOR PWAS

A six-weeks course, held twice per week for one hour each, was conducted for 7 PWAs. Two of the participants—Brian and William—were considered to have too severe aphasia to participate. This time, four speech therapists—Patricia, Stephanie, Pia, and Laura—conducted the sessions. Vivianne had to withdraw due to illness. The rehabilitation course was not only a teacher-to-student course; it was also based on social interaction and communication activities drawn from the community-centred perspective, which meant that some group sessions were arranged, and the PWAs were motivated to go online in SL beyond the scheduled sessions. Furthermore, meetings with an experienced avatar (a man called Peter) were arranged. At the workshop, the speech therapists agreed on a course plan:

Scenario	Ideas for activities	How
Getting started	Creating an avatar Computer settings  Basic exercises:  • Movements (walk, run, fly, and sit) • How to go home (Wonderful.dk the square)	Face2face 2 hours Home or at The Institute of Speech, Language, and Brain Disorders
Wonderful DK	Movements:  Sit on the pink elephant Going by the tram Walk, run, fly, sit Perspective, zoom, sitting down	Guided tour by the speech therapist (one to one)  Putting words on the movements
Playground	Make a date with another and play	Action exercises Verbs
Inventory	Go to Tøjmagasinet in Korsbæk and buy clothes and other outfits Dress and undress	Naming subject e.g. body parts and clothes  Orientation and spatial exercises
Destination Nature	Teleport Flying	Finding your way
Destination City	Chose on of interest	Let the PWA be the guide, put words on your experiences, memory
Cultural site	Guided tour	Meet in a group, discuss what you see
Go dancing	Explore Korsbæk, dance with Misse Møghe	Meet in a group, learn how to dance

Figure 32 Course plan for PWAs

The plan was instructive, with the potential for individual adjustment. The approach that was ultimately carried out varied from person to person.

#### 6.9. GUIDED TOUR AND INTERVIEW WITH PETER

Peter is a man in his sixties, who has been suffering from aphasia for seven years and has been interacting in SL for the last five years. He met Inge Knudsen accidentally in SL. They developed a friendship and a collaboration, through which Inge helped Peter build a house and a learning space for training in language. Inge used her competence as a second language teacher to design various activities that have helped Peter. Peter took me on a guided tour while he was telling me about his time in SL. He noted, "in the beginning, I had no words; today, I have approximately 500 words that I use". Peter's ability to navigate, design, and act was amazing. Hearing his story about slowly relearning to communicate verbally was very motivating. Peter wanted to get in touch with people on an equal footing and he became a good model for the PWAs in the pilot course. The house he had built was designed personally for him, and he actually had a place he called *home* in SL.

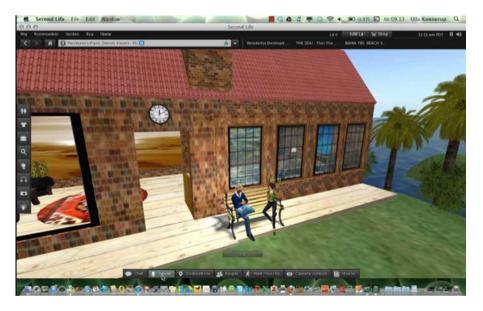


Figure 33 Interviewing Peter in front of his home in SL

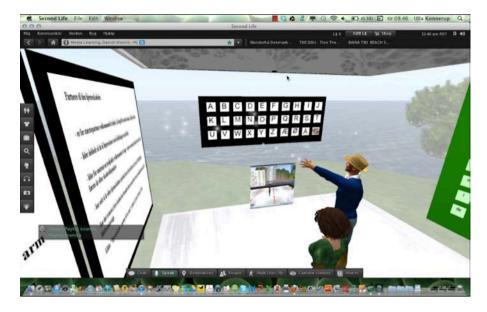


Figure 34 Peter in his language-training cabin

The tour was recorded with Camtasia and edited in Final Cut Pro. Unfortunately, the audio track became destroyed in the process; thus, a transcription was not possible. Before the track was destroyed, however, I did hear the audio several times, and I have also been with Peter on other occasions.

# 6.10. INTERVIEWS WITH PWAS—EVALUATION

To round off the pilot course 2, I interviewed the PWAs in their homes a second time. This time, I was alone with the PWAs. The interviews were qualitative and semi-structured, with the following themes: 1) the PWAs and their disabilities, 2) general experiences with technology, 3) experiences with SL, and, finally, 4) a direct question about their opinions of the SL method and whether they wanted to participate in another course (App G).

The interviews were audio recorded and processed in Transana.



Figure 35 Handwritten notes from Helen

I highlight Helen as a person who has been working with her language for 10 years. Today, she consciously uses strategies so effectively that people do not notice her aphasia. However, it is hard work. She has a kind of aphasia that makes it difficult for her to understand complex verbal language if a speaker speaks too fast about something unknown or if the speaker changes the subject frequently. Helen needs, so to speak, to *have a headline* for the theme of any discussion. She also needs to be prepared. When all these parameters are met, Helen speaks fluently with a high level of content and numerous meaningful words. For our discussion, I emailed her the points we planned to talk about before the meeting, and she prepared thoroughly by writing her reflections on paper.

In general, the interviews resulted in good outcomes. They were very reflective about both rehabilitation issues and technical ones. None of the participants were 100% satisfied with SL as a learning site. There were too many features, and a recurring problem was that the site was not totally translated to English. Some features were, but a mix of languages made the participants confused. Still, four of the six PWAs wanted to continue, since they had experieced a good and fun time and believed that their issues with the technicalities would improve. They liked the social media aspect, and they liked Wonderful.dk (their private land I SL). The other two participants could not see the point of SL and found there were too many technical obstacles.

#### 6.11. GUIDED TOUR AND INTERVIEW WITH INGE

Inge Knudsen, who is a teacher at Horsens Business School, also teaches in SL in English and art appreciation. In addition, she has built several buildings, artefacts, spaces, and holodecks for various educational purposes.

Inge has been using SL for six years, and she has given talks on the subject at several educational occasions in Denmark. She is, thus, an experienced user and designer, and I consider the data from my conversations with Inge to comprise an expert interview. During the tour, she showed me some of her very characteristic learning cabins and told me about her collaboration with Peter.

Inge took me to a cabin with inventory that was designed for language teaching, but that was also suitable for speech therapy. Most of her artefacts were interactive.



Figure 36 Inge's learning cabin

The next stop on the tour was Inge's holodeck. A holodeck is a feature in SL that can be used to store large amounts of object or scenarios. From a menu, the scenarios can be reloaded whenever a user wants. Users can also close down scenarios and load new ones. Inge demonstrated different scenarios suitable for language training: an airport, a hotel, a hairdresser's salon, and a hospital. Thus, using SL and holodecks, users can change scenes in no time and without going beyond a limited space.



Figure 37 Holodeck; at the interactive security check

Finally, we conducted an interview, sitting in armchairs, discussing learning (App H).

#### 6.12. ADDITIONAL DATA 2014

In the spring of 2014, Pia had conducted courses in SL for over a year. She was the only speech therapist who had continued to conduct courses in SL. She had made some changes based on the pilots, which I interviewed her about. The interview was semi-structured and qualitative, with a focus on the outcome of the pilot courses. I wanted to gain insight into The Institute of Speech, Language, and Brain Disorders plans for IVE courses in aphasia intervention, as well as Pia's experiences teaching for a longer period of time (App I). She was still very engaged with the project, and she had a strong belief that the courses had a good effect on her PWAs' identity formation and their ability to make themselves communicatively assertive.

I observed a one-hour SL session taught by Pia in April 2014. The users were all experienced users by then. Two (Helen and Allan) were participants from the pilot project. The other two PWAs (I call them K and L) were a high school teacher and an engineer respectively. Both were experienced IT users, both at work and privately. One of the major changes was that the group, to avoid problems with sound, had chosen to use Skype for speech, with some of them working from iPads to avoid using computing resources. The sound was remarkably good, and Pia could constantly get in touch with all the participants—even if they got lost in SL. Another striking feature was that the participants did not talk about SL or its functionalities; they simply *interacted in SL* using the different features.

#### 6.13. UNITS OF INTEREST

From the data, the following units of interest relevant for later analysis emerged.

Unit of interest	Sub-points
Identity	<ul><li>Gender</li><li>Age</li><li>Family</li><li>Occupation</li></ul>
Mood	<ul><li>Laughing</li><li>Confused</li></ul>
Rehabilitation	<ul> <li>Speech</li> <li>Understanding</li> <li>Reading</li> <li>Writing</li> <li>Orientation and space difficulties</li> </ul>
The speech therapist	<ul> <li>Teacher</li> <li>Teaching/role</li> <li>Avatar-mediated teaching</li> <li>Competencies</li> </ul>
Technics	<ul><li>Settings</li><li>Sound</li><li>Noises (background)</li></ul>

Figure 38 Unit of interest

#### 6.14. ANALYSIS

The next step was to transform the core concepts of interest (Chapter 5) and the units of interest from the empirical data into themes of scientific meaning relevant for a full analysis, which may provide answers to the research question. I call these themes *units of analysis*. I will use these units of analysis as tools in an indirect way. It can be difficult to illustrate the revealed phenomenon from an empirical work in a written descriptive language, since the data have an audio-visual format and some of the observations and interpretations build on participants' non-verbal actions and moods. Thus, the point of departure will be scenes and themes from the data. By telling the stories of those scenes, I will incorporate the units of analysis.

#### 6.14.1. LOCALE

Special interest will be given to the environment—or, rather, the mediated actions of the environment. The IVE is a new setting in which participants can act, and the data have revealed that this digital virtuality has a great influence on several of the other units of interest. The setting, whether it is a physical world or a computer-mediated world, mediates our cultural practices, social actions, and cognition. In my analysis, I am inspired by the work on *locale frameworks* by Fitzpatrick. Although the framework is developed for system design, it is based on activity theory as formulated by Leontjev (Leontjev, 1978), Engeström et al (Engeström, Miettinen, & Punamäki-Gitai, 1999), and especially Strauss´ (1993) sociological research on social worlds, action and interaction. "In short, Strauss´ theory of action provides an understanding of the working of social worlds to meet their shared goals, and a conceptual language to build further understandings" (Fitzpatrick, 2003, p. 19). What makes this piece interesting to my research and analysis is the unit of the *locale*. Fitzpatrick explains the concept as follows:

Locale does't exist a priori as does space or a room. A locale is the place constituted in the ongoing relationship between people in a particular social world and the "site and means" they use to meet their interactional needs, i.e., the space together with the resources available there, resources including whatever constitute the "thing" involved in the accomplishment of work, be they objects, artefacts, tools features mechanisms and so on. As such, the framework is based on a metaphor of the place as the lived interaction with space and resources.

(Fitzpatrick, 2003, p. 90)

Thus, locale embraces, so to speak, the whole concept of environments, actions, and artefacts as a whole. Artefacts, meaning, and cognition mediate actions and learning becomes a part or a result of these actions. This approach is in line with the previous description of cognition and learning.

#### 6.14.2. UNITS OF ANALYSIS

Since my analysis is based on both theory and data, it is relevant to merge the core concepts from the theoretical chapter with the units of interest to determine those units useful for the analysis.

Unit of Analysis	Sub-points
User perspective	• 1 or 3 people
Identity	<ul> <li>Gender</li> <li>Age</li> <li>Family</li> <li>Occupation</li> <li>Renegotiation</li> <li>Narrativity</li> <li>Renegotiation</li> <li>Multiple</li> </ul>
Immersiveness	
Presence	
Embodied cognition	<ul><li>Conceptualization</li><li>Mirror neurons</li><li>Motor</li></ul>
Mood	<ul><li>Laughing</li><li>Confused</li></ul>
Learning	<ul> <li>Situated</li> <li>Social</li> <li>Mediated</li> <li>Meaningful</li> <li>Knowledge</li> </ul>
Rehabilitation	<ul> <li>Speech</li> <li>Understanding</li> <li>Reading</li> <li>Writing</li> <li>Orientation and space difficulties</li> </ul>
Speech therapist	<ul><li>Teacher/role</li><li>Avatar-mediated teaching</li><li>Competencies</li></ul>
Technics	<ul><li>Settings</li><li>Sound</li><li>Noises (background)</li></ul>

Figure 39 Units of Analysis

# CHAPTER 6.

In recognition of how vital the speech therapists' ICT skills are for the outcomes of IVE-based rehabilitation, the data concerning the speech therapists are included more prominently in my analysis than originally planned.

In order to answer the research question regarding avatar-mediated rehabilitation, it is interesting to examine how people in general (and not only PWAs) react when they are acting in an IVE as novices. Thus, I have included both groups (i.e., speech therapists and PWAs) whenever the unit of analysis generally concerns the behaviour of human beings. When the reflections concern people in general, I name the speakers or relevant parties "participants"; if reflections concern only one of the groups, I use either "PWA" or "speech therapist".

All quotes and dialogues are translated from Danish. Some of the PWAs' verbal language is so compromised that I have modified it into understandable English.

Various scenarios from the courses will follow. All exerpts and scenarios descriptions are written in present tense for clarity and to best represent the situations as they were for the participants.

#### 6.14.3. HELL NO, I AIN'T LOOKING LIKE THAT

The first impression we get of other people is related to other people's physical appearance. Most of us are aware of this process of making first impressions in the physical world, but it was surprising how much visual appearance meant in SL for the participants in the pilot project. This is reflected throughout the process, but it is most clear in the beginning. All of the speech therapists were brand new to SL and, thus, were creating avatars for the first time. Most had picked the first avatar they had been offered, without being aware of the ability to design their own based on one of the basic human avatars. At the first meeting in the pilot course for speech therapists, there was, therefore, a motley crowd, with a rabbit, a dog, a robot, a dragon, and some beautiful young women. Not everybody was satisfied with their appearance.

Patricia is a rabbit. She is essentially pleased with the avatar, but she hates the red eyes. They affect her in several situations. When one of the others suggests that everyone should go to a dance bar, Patricia refuses promptly, saying: "Not with the red eyes". Over several sessions, she asks the others if they can help her get other eyes. She even asks a stranger for help (otherwise, she is very sceptical of strangers). She does not succeed, and on several occasions, you can hear her swearing to herself: "Hell, no, I won't look like this." Despite the eyes, at the evaluation meeting, Patricia affectionally exclaims: "Now, I love my little avatar!"

Stephanie is a dog from the beginning. She likes dogs, so she is okay with the situation, but she really wants the dog to stand up like a human and act like a human. She claims repeatedly that she is sure that this is possible, but that she can no longer remember how. She is frustrated, and she says: "Oh, no. I become that kind where something is missing, and I don't want to be like that." The pattern here is the same: She asks everybody on her way for help and is given the same instructions by everyone, but the Stephanie does not succeed to have her dog to stand like a human.

Common to Stephanie and Patricia is that they find it difficult to concentrate on the course as long as they are unhappy with how their avatars look or move. It seems as if their dissatisfaction with themselves (i.e., their avatars) blocks their ability to learn. They pay no attention to the agenda, and they do not hear what the others are saying. Thus, they miss some shared messages and instructions.

In the interview with the PWA, Helen, she stresses that the appearance of her avatar means a lot to her:

Helen:

I would like to change my looks in a way, so I will look more like me...I think it is very exciting. If other people could see me and think, oh... there is Helen... or in any case something close to my looks

Helen is one of the PWAs, who continued in SL after the pilot course. When I meet her again in April 2014, her looks have changed from those of a young, basic avatar to those a more mature avatar with grey hair and a ponytail—very much the way Helen looks in real life. In fact, in seeing her avatar, I did think: "Oh, there is Helen."



Figure 40 Helen 2012



Figure 41 Helen 2014

# CHAPTER 6.

In general, most of the participants care about their appearance, and it is fundamental to them to know how to change clothes and so forth.

The participants are not only concerned about their looks. They also want to move and behave properly. In one session, Stephanie takes Michael to a place that communicates information about Danish folk high schools. They are to sit around a table and watch a presentation on the wall.



Figure 42 Michael accidentally sitting on the floor

By accident, Michael sits on the floor. When Stephanie makes him aware of it, he laughs and continues to try to sit correctly until he succeeds.

(0:15:49.3)

Stephanie: I just realised that you are sitting on the floor,

but perhaps it was intentionally?

Michael: No, it was not! Hahahahaha. No, I will get up.

Stephanie: Try to click. Put the cursor on the chair, and

right click.

Michael: Okay.

Stephanie: Okay, sit down.

Michael: I try, but I sit on the floor again? I do, yes.

Stephanie: Michael, you need to have the cursor on the chair,

and then, when the chair has become like it is lit

up, and then you click on the chair.

Michael: What did I do ... hm. It is like it has been

moved. It won't ... I need to find out how I did

it before.

Stephanie: If you put the cursor on the chair, Michael.

Michael: What do you say I need to...

Stephanie: If you put the pointer on the chair and right-

click.

Michael: Yes, I do.

Stephanie: And then, you can say sit.

Michael: NO, I need up here. Where is it that I have to put

my hand? I did it yesterday. I just cannot figure

out how to do it.

Stephanie: You put the arrow, or the cursor, on the chair,

right-click, and then the chair will light up.

Michael: Sit... That is .... many ... it is... so... I sit

on the floor, I think. Yes, I do, hahahaha. It's because my hand... it is because I, my hand, it

has to transfer the...

Stephanie: Just try to click on the chair itself until it

gets lit up.

Michael: Only the chair, it is...

# CHAPTER 6.

Stephanie: Yeah!!! Beautiful.

Michael: Now I am sitting here (smiling and proud).

(0:19:05.5)

It takes more than three minutes for Michael to sit properly. One could say that he might as well watch the presentation sitting on the floor, but the feeling that they are sitting there together, with him on the floor, seems so silly to him that he just MUST sit properly. Michael and Stephanie are both very patient and calm people. In addition, this interaction is what it takes to be teacher (as well as a student) in a setting in which teacher and students are physically apart and only digitally connected. The two continue investigating the courses at Ry Højskole via a link to the Internet on the wall.

A similar situation occurs with Helen in South Africa. Instead of sitting at the table, she stands on the table.



Figure 43 Helen standing on the table

Patricia: Helen, where are you?

Helen: Look at me, I am standing on the table, hahaha.

Patricia: Haha

Helen: (to herself) Well, how does she get down, this

Helen, well, well, well...

Helen: Phew, now I got down, hahaha hahaha

A frequent difficulty arising from aphasia is distinguishing prepositions. All of the direct and indirect exercises to place oneself and artefacts in a room are very instructive, and the users get an idea of their own positions in relation to their surroundings.

#### 6.14.4. ME, MY, MINE, I OR IT

Helen's remarks above about her looks represent one example of a PWA who quickly feels so familiar with her avatar that she talks about it as "me" and "I". The way in which the participants name themselves is an indicator of their degrees of immersiveness and presence. It is significant that most of the participants in the very beginning call the avatar "it" or "mine", but they soon switch to "I" and "me". It is also significant that it is in action situations that "I" and "me" are most commonly used. When it comes to discussing the interface or technical obstacles, the users continue to say "it" and "the avatar".

In the first session for speech therapists, Patricia and Stephanie are occupied with their appearance and how the avatars move. They exchange experiences and learn from each other:

```
Patricia: Well, when I make a right-click on mine... mine is sitting now. Do you see?
```

Later, at the first session, when they are learning how to dress and undress, they are all given similar t-shirts. Patricia is now more familiar with her avatar, and she asks Pia:

```
Patricia: I'm not sure, do you see that I'm wearing it Do you see me, Pia?
```

Stephanie is still not satisfied with her avatar dog:

Stephanie: I have difficulties making **mine** turn its head. I don't know how to do... last Thursday, **it** was standing on its hind legs, but then...

On several occasions, the participants move around on their own, speaking aloud to themselves. Vivianne has just learned to fly, and she is happy about it:

Vivianne: Excuse me, I will fly a little.

Karen: Oops, where are you? Who is flying there?

Vivianne: It's me.

Much later, during the pilot course for PWAs, we see the same tendencies. Several of the PWAs have good imaginations, and they immerse themselves in the activities in SL. Most of them act positively and playfully:

Patricia: Today, we are going to South Africa.

Helen: To South Africa?!! Oh... with animals and

everything?

Patricia: Yep, haha, I hope so, haha.

Helen: Then I have to be vaccinated before we go.

Patricia: Yes, do pop by the pharmacy and buy some malarial

pills.

Helen: Yes, I have to, haha haha.

Patricia and Helen have a shared agreement to pretend that they actually are going to South Africa. They are immersed in the experience, and the shared understanding and good laughs give both of them the feeling of a high degree of presence.

Breakdowns in understanding or technical obstacles can impede the feeling of presence. In one scene, Chris and Ian are taught to get a bike and ride on it. Chris has many difficulties of a technical nature, and he is not exactly positive about SL. Pia does not succeed in guiding Chris and Ian to get bikes themselves, so she decides to give them the bikes by transferring bikes directly to both of them. They still have difficulties. A sense of abandonment and irritation arises, but, suddenly, they succeed:

Pia: Yah↑ exactly, try to do as if **you** walk straight

ahead

Chris: I have to get over this [biking over at table],

hahahaha

Ian: Hahahaha.

Pia: Finally, you bike

Chris: Yep...

Ian: Yah...

Pia: ... and we remember to put out our hands when we

bike, it's awesome!!



Figure 44 Chris and Ian biking

In SL, it is possible to change the view to different perspectives. In the screen settings, users can choose between seeing themselves from behind, from the front or from the side. Users can furthermore choose to see the scene in the first person perspective.



Figure 45 Different perspectives possible in SL

For some people, it is difficult to imagine an avatar *being* them when they actually see the avatar in third person. Thus, most of the participants choose a perspective in which they see themselves from behind. A third-person perspective gives users an object view for navigating, so to speak, and for moving with the avatar. Thus, it feels like a first-person perspective.



Figure 46 Object view

It is possible to choose a first-person perspective. This perspective, however, gives a feeling of being an outside observer, allowing users to forget that they are actually able to act as part of the scene. This perspective feels like watching a movie or a TV show. It is important for participants to have pictures of how their avatars look, since seeing and moving the avatars facilitate immersion.

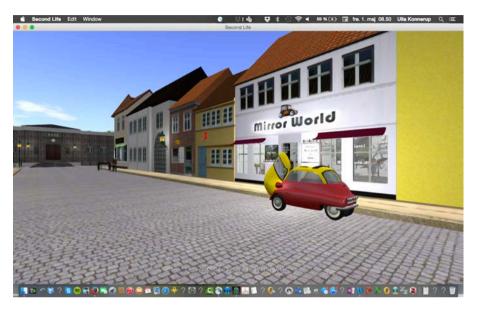


Figure 47 First-person mouse view

In one session, Michael is moving around, seeing himself from behind. At the playground, he turns the perspective so that he sees himself from the front, including the face. Happy and surprised, he exclaims, enthusiastically, "Wow, this is me! It really is!"



Figure 48 Michael

### 6.14.5. WATCH OUT FOR THE TRAM

Michael is one of the PWAs who, during the pilot course spends a lot of time in SL. Every session with Stephanie starts with Michael eagerly (and very persistently) telling about his experiences. He is working his way through Wonderfuldenmark visiting the different areas and houses. He often uses the phrases "this is awesome" and "it is fantastic that it is possible". Michael suffers from the kind of aphasia in which speech is spontaneous and fluid. It involves longer sentences, but also a tendency to use paraphrases, neologisms and agrammatisms. This type of aphasia is called Wernicke aphasia. Michael's ability to hear and criticize his own speech is a little compromised. PWAs with this kind of Aphasia get easily distracted and they will easily associate. It is difficult to say whether this is what leads Michael to quickly identify himself with the environment and to immerse himself in what is happening around him. In talking about a church visit, he suddenly switches to an incident with a tram:



Figure 49 Michael close to the tram

Michael: It was like before, in the evening, suddenly,

traces ... sport sprint ... strain, train, it

is...

Stephanie: The tram?

Michael: Yes, a trolley ... tram on the rails. Yes, the

tram, on the rails. Then, I say to my wife: Watch out... I better hurry across the road before I get hit, before the tram gets here. Suddenly it is close... I think it is awesome... hahahaha, that

it suddenly...

This is a characteristic picture of Michael. He immerses himself in the situations and the scenarios he is in within SL. When I conduct an interview with him, asking if he had had any difficulties, he tells me vividly about an incident in which he was taking a walk on the harbour, fell in the water, and could get up again. He must have spoken loudly to himself, because his wife shouted from the other room to ask what had happened, and he shouted back that he had fallen into the harbour. "We laughed and laughed, hahahahaha", he said. The fact that Michael becomes so immersed that he spontaneously finds the correct words and speaks aloud is good training for him.

Pia supports indications that the persons suffering from the kind of aphasia that Michael is suffering from, Wernicke, benefit specifically from avatar-mediated rehabilitation. In an email message (June 2012), she sent me reflections after a session I did not observe:

Hello Ulla

Want to share a great experience with you.

Joined Jack in SL for the first time today - and what a success.

He experimented for dear life. Named spontaneously objects and movements and commented on how it felt in his own body.

He was very crazy about it. Especially sitting on a Puch Maxi at the harbor looking out over the ocean with a beer in the box  $\ensuremath{\odot}$ 

Came to think about whether Wernicke aphasia have a particular advantage of this method of teaching. They're often much more spontaneously speaking and

#### CHAPTER 6. EMPIRICAL WORK

acting than others. There is certainly a big difference between those, who just are doing the things that they have been told, and for example, Michael and Jack and their spontaneously desire to explore.

This was just some reflection from me.

Pia

Janice is a woman who, in real life, is very occupied with her looks. In real life, she loves to buy new clothes, and she surfs a lot on the Internet for clothes. It has not been easy for her to remember the functionalities of the different computer programs she has been using in the rehabilitation. Nevertheless, she has tenacity and an interest in technology, and she has participated in several computer-based courses at The Institute of Speech, Language, and Brain Disorders. Over the years, she has learned to email and use the Internet, and she loves it. Even though her written language is severely compromised, she manages to communicate by mailing and texting with people who know her. The speech therapist knew from the start that using SL would be a struggle for Janice, but also that she would love to give it real try. Unfortunately, SL is not successful for Janice. She becomes frustrated that she cannot remember all the different functionalities, that there is too much to do, too many places to go, and sometimes too many people. Janice, though, quickly manages to get new clothes and dress herself in SL: "but I have also ... eh ehe, what's it called, such what is it called ... the clothes ehhh such a suitcase, I have also learned that..." From time to time, she forgets how to undress her avatar, and, on more occasions, she meets up at sessions with several layers of clothes. She cannot concentrate on anything else if she is not satisfied with her appearance. This is an indicator that, despite the difficulties, she gets immersed, she feels a kind of presence. In one scene, she realises that the other persons (avatars) have long sleeves, and she might be cold in her summer dress.

Patricia: What do you want, Janice? Do you need something

with sleeves?

Janice: Yes, yes, I think so, as the weather is now...



Figure 50 Janice is feeling cold

The behaviour of Janice's avatar very much reflects the person Janice is in real life—and, thus, tells a story about Janice. A fun little scene unfolds as Patricia wants to train Janice in navigation and movement through biking.

Patricia: Please, get your bike now, Janice.

Janice: I was thinking of that car, but I know not where

it was ... but it was just the one I should have.

Patricia: (Burst out laughing) Hahahaha

Janice: But it was ... there was a car, and then I

thought, it was damn smart that you could have

your own car.

Unfortunately, it is not possible to drive the particular car Janice wanted in WD. However, it would have been smart to offer Janice a course with content on dressing, undressing, shopping and driving cars, so that the rehabilitation could have been built around things that motivate her. It is obvious that Janice is able to

forget her difficulties and use her stubbornness to learn if a topic is motivating and interesting. Another twist in this story is that I, as an observer, actually met Janice several times near the car mentioned. Janice really wanted that car.



Figure 51 Janice really wanted that car

Lauren also says in the interview that she once got cold in real life because it was snowing in SL: I hadn't been there for a while. Then I go straight in, and it was winter and snow ... there I was in a tiny top, I became freezing cold..."

In general, most of the participants show a good ability to immerse themselves in the environment and the scenarios. They express having a sense of presence, which, from time to time, breaks down if they experience any kind of difficulty. There are several means in SL that might optimize this feeling (e.g., through the form of sound effects and movements).

A favourite activity for both speech therapists and PWAs is horseback riding. At a beautiful ranch at the ocean, it is possible to rent or buy a horse. Several participants mention that they like to go to this ranch, look at the horses, and hear the birds singing. When you ride, you can hear the hooves beating rythmically, feel

the speed, and see the wind in your hair. You often hear "hush" and "ihhh" from the riding participants, and many mention the place as a place where they feel as if they are really there riding.



Figure 52 Horseback riding

It is obvious that it is mainly activities that contain some degree of action that provide the greatest degree of immersion. Helen describes this directly in her interview:

Helen:

Well, it's obvious to do things with a horse and a bike. They are action. It is quite super uh. I like the horse especially because it's new for me to get on a horse. Uh, bike I am more used to, but it is a great feeling, because you ARE on the bike ... like when you bike down to the supermarket, and you also feel that you go somewhere ... and you turn and all.

Another popular place is a beach with watersports activities (e.g., surfing and jet skis).

#### CHAPTER 6. EMPIRICAL WORK



Figure 53 Water sports resort



Figure 54 Helen surfing

The participants are engaged, laughing, and exclaiming spontaneously: "Cool", "awesome", "oh", and "wow". Surfing in SL requires good balance and concentration, just as in real life.

It is not only activities with speed and action that provide a sense of presence. Michael describes a visit to a church, where the music catches his attention and immerses him:

Michael: I have been to the church several times. I have found out that when you come to the church, the church there ... it's so amazing walking to the door. You can look inside and then suddenly through the door. ... looking up, it's great ... I was in the church, then there was suddenly music. It was the organ, quietly, quietly music in there, I went out of the church again, the music further and further away, so I think that's fantastic that you can make it like that.

Random and unexpected happenings make Michael curious, and it seems that these motivate him from step to step and encourage him keep staying in SL. In this way, the open social environment, with other known and unknown persons, makes the space interesting to him.

The data reveal many examples of the participants sensing a presence and having concrete bodily experiences. Here are some quotes from the speech therapists:

...when I'm practicing to jump, my whole body tightens, and I find myself quite physically stretched upwards and onwards the moment I jump, and a relaxation when I'm well down to earth on the other side.

 $\dots$  and I felt both thirst and taste when I looked at Lauren drinking her coca cola

When I am walking, I cannot feel anything, but when I fly - then I get butterflies in my stomach. It's fantastic. Normally, I am afraid of heights...

I was out dancing one day, and suddenly I was dancing myself ... I really like to dance in here, but only when I am with some of you! Otherwise, I do not really know what to do with myself!

A little annoying thing - I get carsick / seasick when I move around in SL

From these quotes and scenes, I conclude that SL affords a high degree of a sense of presence—and, with Schroeder's words, a sense of "Being there".

## 6.14.6. FINDING MY WAY HOME

Another indicator of the sense of presence is that several of the PWAs are afraid of getting lost in SL. All of the participants' SL profiles are set to automatically log in at the square in WD. Objectively speaking; you could just turn off the computer if you got lost, and then log on again. It is also clarified that you can teleport yourselves and others wherever you like. Yet, this provides a sense of insecurity. SL is made up of land, islands, and holodecks in many layers, and it may seem overwhelming to navigate. Having brain damage and (possibly) spatial orientation difficulties can make this even more confusing. Among others, Michael is very nervous about getting lost. At the end of each session, Stephanie asks whether she should follow him to the square, but Michael hesitates and says, "No, I will try slowly to go back to the square by myself." After a few sessions, he says, relieved that he has figured out a way to move around in WD without losing his way:

Michael: So I was just ... in the town ... so I try to go around and around and around all the time to the right - no, it was all the time to the left - so I knew I could come back home.

Stephanie: That was smart.

Michael: I will also try some place when we're flying.

Somewhere that I would like to ... I will just go home...just home, damn it! I need to know a lot to go home. On the other hand ... I also think ... maybe every day ... so we say: We are back. We

must have somewhere that is HOME, right?

In the interview, later on, he tells about his strategy:

Michael: I either went to one side or the other, and then there was always the sun, the light, helping me to find my way home, my brain still manages to do

that.

### 6.14.7. PROUD TO SOLVE PROBLEMS ON MY OWN

Even though Michael is concerned, he tries to solve the problems he faces by himself, and it is a victory for him to succeed. He willingly shares his solutions with others. Some of the PWAs are eager to investigate SL by themselves. They use the nights to try things out on their own. It is not, though, without obstacles. One of the recurring problems is that the avatars suddenly freeze on the screen, or the movement occurs in a kind of self-oscillation, so that the avatars are just standing and doing the same movement repeatedly. Accidently, Michael discovered that if he clicked h-i on the keyboard, his avatar would jump and get out of the repetitive movement.



Figure 55 Michael demonstrates how to jump

It is never discovered why SL teases some days, making the avatars difficult to control. One assumption could be that the participants' bandwidth or computing capacities are not sufficient. Solving computer-related problems requires some prior experience with IT, and certainly not all PWAs have the courage or competence to attempt it. Some do, and for some, the technical issues are motivating. Michael has been an electrician and has been using computers for work since 1989 (as he says, "from the DOS days"). ICT is a natural culture tool to him, and, in general, he is used to solving the problems he faces on his way. Breakdowns do not scare him, either in the real world or in the virtual.

#### 6.14.8. RENEGOTIATION OF IDENTITY

One of the focuses of this thesis is whether it is possible to give space for the renegotiation of identity in an IVE. Thus far, I have given some examples of people trying to make their avatar look like them in real life, of how some avatar behaviours reflect the owners in real life and, finally, how most of the participants quickly name their avatars "I".

When I interview Helen, it has been exactly 10 years since she had her brain injury and retired from her job as a nurse. Helen had been very active as a nurse: she was a safety supervisor and had professional pride. Being a nurse was a significant part of Helen's identity, besides being a woman, a mother, and a wife. Having a brain injury and even having retired does not mean that she stopped being a nurse. Helen has tried to keep professionally updated:

Helen: I miss a lot, of course, to read SYGEPLEJERSKEN

(magazine for professionels). I still feel like a little in between. Last week I managed to read the new SYGEPLEJERSKEN, and I thought, YES! Then I go for research - and the new stuff, I really like!

Ulla: So even though you don't work anymore, it means

something to you to keep up with it.

Helen: Absolutely!

In the ATA project, Helen has been working a lot with nursing themes. She has been working very hard to regain her language, and the speech therapist is aware that the training content has to be meaningful, since Helen is continuously seeking more knowledge. After the pilot course, Helen, as mentioned, continues with a course in SL. Pia takes a group to a virtual hospital ward, designed to educate nurse students. Helen is very excited. Among other things, the participants have to try different uniforms and then choose the one that suits the hygienic codex at the hospital. It means a lot to Helen to be able to share her knowledge with her fellow participants, and that they take up a theme in which she is the expert. The group shows great respect for Helen's knowledge and asks her many questions.



Figure 56 A hospital ward in SL

Another important thing in Helen's life is her family and the travels they have taken together. Earlier in her real life, Helen had made Powerpoint Presentations at The Institute of Speech, Language, and Brain Disorders about her tours. Helen and other PWA speakers were very nervous. It is very frightening to speak to an audience when you are not eloquent. Helen has suggested making presentations in SL in order to manage the nervousness.

I have often been asked about whether computer-mediated teaching/learning is alienating, especially for people with communication difficulties. For some people, it might be; for others, they speak the same way as if we are in the room together; and for still others, it becomes even easier to communicate when they are hidden behind their avatars. One of the participants asked one day whether I would stay just a little longer in SL. I did, and the person in question confided very private things about illness in the family.

Michael always tells Stephanie about his weekends at the SL sessions. Sometimes, these are long stories. One day, he tells her about a christening at his next-door neighbour's house. He and his wife were in charge of cooking for 50 people. He tells, in incomplete but thorough pictorial language, about meat and barbecue.

Michael: ...so much meat to 50 people, so things were really jumping...on the barbecues, two large grills, we should put on...and also in the kitchen ...also had meat in it that we should manage, we should eat at...and it was the...food. Things were really jumping those hours, so it was. So you can still feel this aphasia, talk to many people, it will not work for me; it's easy to make something, but talk so many people...hear, on the other hand, I cannot. That's how it is. So, now you have tried that.

In his storytelling, Michael manages to show who he is. He tells about his family and what they are doing. In this specific episode, he shows that, in his neighbourhood, they help each other, and that he enjoys taking part and taking lead in practical things. However, now that he suffers from aphasia, it is not easy to understand what is said when there are several people.

The fact that an avatar mediates your actions might allow some people to dare to do things they would not dare to do in real life. Karen reflects on this in an interview:

Karen: I think...I think, I felt like when I was young,
when I could take the liberty to do what I wanted.
It was a freedom. There was no one who wrinkled

their noses at me - a bit like I felt, when I was young. Now I think, damn, I always have to behave so nicely and I...I have been very shy. I still am, though, but now I can handle it, and I certainly have worked on it, so it was great for me, when I discovered that I could do everything possible, and it was this experience I had. I did not feel that I should be concerned with how the other ... the stranger, I did simply not.

Karen expresses that she feels a freedom in SL and an opportunity to show who she really is, as well as that she enjoys the world and the opportunities offered. Patricia, on the other hand, has concerns about the unknown, stating that SL might feel overwhelming to some people. This is reflected several times. If Patricia is not sure who is behind the other avatars, she feels insecure. She advocates strongly for a space with no entry permission for strangers, and she expresses a general concern regarding unknown places on the Internet. As a speech therapist, she is afraid that she leads PWAs to something unpleasant:

Patricia: I have to be confident that I can manage things. If they get to a page or something where they feel unsafe or do not feel comfortable, I need to know that I can guide them to get AWAY - and perhaps also try to guide them not to go there in the first place, because I cannot see that there is any reason that you should...at least, well, I know that everybody might get to any pages, or somewhere not nice, but I must be able to help

The statements from the two speech therapists show two very different understandings of the digital environment. The approach is very subjective and depends on the experiences of the individuals. It is obvious that qualifications for speech therapists are necessary. However, it is not a good starting point for a teacher to feel insecure in the educational environment.

am...

them quickly away again - and I'm not sure that I

#### **6.14.9. BETWEEN MEN**

Here, we return to identity. As mentioned, the workshop with PWAs and relatives reveals a recurrent problem among male participants. In general, they feel surrounded by women, both rehabilitation-wise and privately. What they miss from going to work is male jargon and male activities. Meeting Peter, the experienced SL inhabitant, opened up the possibility to build a community of men in SL. The

PWAs were introduced to Peter, and his story seemed to motivate the newcomers. Peter took the pilot project participants on some guided tours (e.g., to his own house, to the church, and for a ride in his own helicopter). Furthermore, he shared how he has been a co-designer of his own house.



Figure 57 Guided tour to the church



Figure 58 Peter in his home

Peter is, of course, very proud of his home, and it is obvious that he loves to present it and to have listeners to his story. When Peter and Michael meet for the first time, it is in WD, and they do not know anything about each other. All they know is that they both suffer from aphasia. They may have trouble finding the words, but they manage to introduce themselves to each other and to share information about themselves.

Peter: Yes, okay, okay. I reckon that I

have fif...No...two...no...500 words that I use

Michael: Okay, yes.

Peter: Today, eh...I use...eh, 500, which I can use

fairly good, and then 1000 words that are not

really good at...it comes once in a while

Michael: It's nice to hear...

Peter: What do you say? ... Try again

Michael: All right, you are through.

Peter: Yes, yes.

Michael: But I cannot see you.

Peter moves in front of Michael

Michael: There you were.

Peter: Yes. I'm called Peter.

Michael: Yes.

Peter: Well, I am seven...eh one...seven...I suppose

eh...eh I have ill.

Michael: Seven years ago?

Peter: Yes....No....six eh...five years ago.

Michael: Years ago...yes

Peter: And to begin with, I had no language at all, for

almost three years, and then...

Michael: Wow

Peter: And then gradually, I could...re...find out

Michael: It's great, that's for sure

Peter: But it is fairly speak for others eh...it's all

wrong once in a while, but this is...

Michael: It's all wrong, we know that, for me, it's also

hard for me once in a while...

Peter: Yes, yes...How old are you?

Michael: Im 66.

Peter: Okay. I'm 68.

Michael: Yes, yes. It is right in the end. It is the 18th

of May, when I was 66, yes.

#### CHAPTER 6. EMPIRICAL WORK

Peter: Yes, but on May 12, then I was 68

Michael: Where do you live?

Peter: I live ... what's it called ..... bb bb bbb

. . . . . . . . .

Michael: I live in Vre...

Peter: In what do you say?

Michael: In Vr...

Peter: I live in eh, whole ... in V (you can hear his

wife say the name of the city)

Michael: W E R E L S E, yes, on the island haha.

Michael: I live five kilometres from Aalborg.

Peter: Oh, haha. There is a long time, then, but it's

fine...

Michael: It is certainly.

Michael: You are so good at writing, you write - for me

it's hard to write, for me, writing...

Peter: Yes, that's it. I cannot write. I always use

things that I need some time to make. Very difficult, eh eh, language...no, what's it called ...word document, which I use for the things I see

Michael: It's hard to understand everything, it really is.

Peter: Oh, yes...yes yes.

Michael: When I started, I could NOTHING.

Peter: If I get a newspaper, then I really have problems.

Michael: I think it is nice. I say it's great to meet

another man.

Peter: Sure...hahaha.

Michael: It's something we need to do again, that's for

sure

Peter: Yes, yes, note, when one has communication

disabilities, I think in SL, there are fif...no,

50...no, 200 people.

Michael: That's a lot.

Peter: Yes, yes.

Michael: Are you saying 200 people?

Peter: Yes.

Michael: Wow.

Peter: Yes, it's awesome. It helps, your language

eh...much better.

Michael: Well, that's for sure, I am from Northern Jutland,

you can probably hear that.

Peter: Yes, yes, but it's fine. My mother was born in eh

...Fuhr

Michael: Fuhr...yes

Peter: She came to Copenhagen when she got married.

Michael: Yes.

Peter: But, she's dead now...yes.

Michael: Yes, my mother is dead, too.

Peter: Well, do you have any plans?

Michael: Today? My son, he is the man now, two

grandchildren, I will clean the house.

Peter: We have five-six-seven-...eight, yes, I have eight

grandkids.

Michael: We have four grandkids.

Peter: Okay.

Michael: A son and a daughter and two grandchildren from

each.

And so it continues. The long dialog expresses what is important to tell people you meet for the first time. In the beginning, the men are acting in a seeking and hesitating manner, but as they realise that they are peers and actually have much in common, the atmosphere eases, and they laugh and get a little humorous. Despite their communication difficulties, they manage to give a picture of who they are. They end the session by friending each other in SL and arranging to meet again. Afterwards, Michael says to himself: "Oh it felt good to meet another man". Meeting other people on equal footings, both in age and in gender, is not very easy in real life for PWAs. The IVE is a good facilitator for meeting across the country.

#### 6.14.10. PETER'S REHABILITATION CABIN

Peter's story is amazing. From having two words—"yes" and "no"—he can now make himself understandable. Meeting Inge in SL became a turning point for him. Together, they have built a cabin with tools for training. Interactive boards with letters, words, and sentences read aloud give Peter an opportunity to train for hours. The fact that Peter has been involved in the design of his house has probably contributed to his progress. As the expert in suffering from aphasia, he has had to reflect and express his needs for tools.

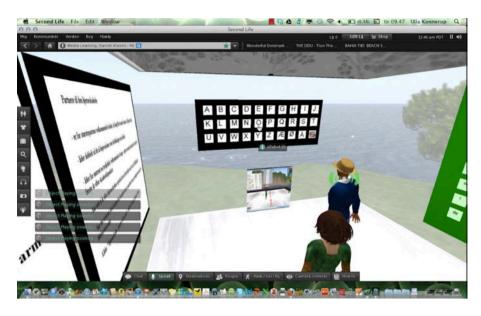


Figure 59 Peter in his cabin

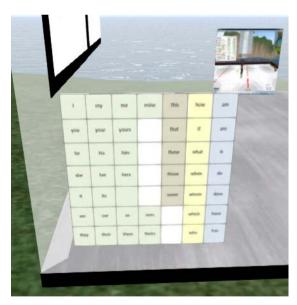


Figure 60 The mobile display

Furthermore, he has a network in SL, to which he has repeatedly explained how he is working with the boards. His latest board is one that can be put up to a display on the computer screen—and, thus, does not link the user to the cabin, instead giving

the user the freedom to move around and still use the board. There is also the possibility to have words and sentences read aloud. Inge explains Peter's reaction to the rehabilitation cabin:

Inge:

He was very, very happy with this, and not so much because it was the best way to learn the language-clearly, it is not. There are much more advanced programmes for people out there for people who have to relearn their language-but because of the social network he got in here...he was mobile, he could walk around, he could talk to me and to other people. It was a project for him, and was very welcome for a person who is not very mobile and stuck at home.

In real life, Peter is physically disabled, and he does not have the ability to move around easily. In SL, he builds, designs, travels by his own airplane, and so forth. He has a sense of presence that makes him feel like a whole person. He interacts as if he were embodied, though his real body is disabled. With reference to the discussion about whether interactions in virtual worlds make people leave inert bodies behind the screen—and whether avatars are disembodied subjectivities—you can say that Peter leaves his disabled body behind and gets an extended one in SL.

It is very inspiring to visit Inge's land: Media Learning, Danish Vision in SL. The cabins for treating different kinds of phobia and for deaf people provide ideas for methods for language training, as well.

### 6.14.11. NARRATIVES AND AUTOBIOGRAPHICAL MEMORY

In her interview, Pia tells about one of her visions: She wants to design individual memory spaces to support the autobiographical memory of the PWAs. She also wants to do this in collaboration with relatives, using things and pictures from real life. Karen talks about an idea, in which each participant would have his or her own office as a private space, with private things. Karen thinks that the PWAs, from time to time, need to withdraw and feel at home. Such projects demand that these spaces be set as private, so that each person can invite whomever they want. The holodeck would be a suitable pedagogical tool for this purpose. The artefact would be changeable and easy to set up, with no demand for land cost in SL.

As mentioned in Chapter 5.6.1, research has demonstrated that identity is shaped and constructed partly of autobiographical memories and partly of social interactions and narratives told about memories (Hirst et al., 1997, p. 164; Rubin, 1988). This indicates that surroundings and artefacts that support autobiographical

memory and invitations to action will facilitate the renegotiation of identity and the re-shaping of oneself.

### 6.14.12. LOCALE

As mentioned, locale refers to the place constituted in the on-going relationship between people in a particular social world and the world's space and artefacts. It has been demonstrated that some of the scenarios in SL motivate and even persuade participants to act. The primary learning space in SL - Wonderful Denmark (WD) was chosen carefully based on the workshop with the PWAs, their relatives, and the speech therapists. It not only fulfilled the desired scenarios, but it also is built based on a very well-known (in a Danish context) fictive provincial town called Korsbæk. Korsbæk is known from a television series called Matador, which first aired on Danish television in 24 episodes from 1978 to 1981. At that time, there only was one TV channel in Denmark, so nearly all Danes watched Matador. Since then, the series has been rebroadcasted many times. The series is about life in a small town, and viewers follow the town's inhabitants from 1928 to 1947. The series has become a shared heritage for most Danes. I know of several PWAs that, in the time after the onset of their injury, actually used the series on DVD as a listening exercise for the Danish language.

Thus, the participants have a relationship with the space. It is familiar, and several express reunion joy in meeting the known buildings and persons. At Postgården, Patricia exclaims, with warmth in her voice, "Oh, there is Misse Møghe", when she spots the piano player. In the last session, Helen and Patricia are evaluating. Helen is sorry that the course has ended:

Now we have finally reached the point, where we Helen:

eh ... can use it; here in Korsbæk, I think this

is the most cosy place.

Patricia: I agree.

And you learn more. You really get in-depth with Helen:

it... eh, and it definitely has something to do

with that we are from DK.

Patricia: What are you thinking, Helen?

Helen: Suppose, for instance, we go to Africa. Then, we

> just walk around and see some animals, but it's just something you SEE - it's not something you DO. In Korsbæk, you can go dancing with Misse

> Møghe, it makes you happy, and you think of all

the publications [broadcasts] back then. It was over a long, long time - for how long? We did watch many episodes on the television, didn't we?

Helen's statements demonstrate that the locale means a lot for learning. There is a difference between being an observer and being an actor. Korsbæk is not any town; it is a particular town with lots of joint memories—a town in which participants unconsciously know when they are hearing Misse Møghe playing the piano at Postgården, they do not send mail or borrow books—no, they dance! Acting in known locales triggers memories, invitations to act, and mood influences.

### 6.14.13. DANCING WITH MISSE MØGHE



Figure 61 Dancing with Misse Møghe

In one scenario, Helen is really triggered. She has discovered Korsbæk's dancing school at Postgården on her own the night before. She has also taught herself how to dance in SL and is eager to show it to Patricia. Patricia is hooked immediately, and both are laughing and dancing together:

Patricia: You are so fine!...it's kind of fun. Have you seen

yourself from the front, Helen?

Helen: It is nice from the front. I did [last night]. I

enjoyed myself for a very long time.

Helen: One can really learn to dance here, don't you

think so? Because there are so many options, so ... eh... you can see... you can see the different dances... ehhh, and can learn from them, actually, those steps, you can use them. Wow, it's

wild! Hahahahahaha.

Patricia: Do you feel it in your own body, Helen?

Helen: Ya, I feel a kind of jerk. It's like when we were riding the horses. It's awesome! It's like my bike. I'm so pleased with my bike. I think it's cozy here in Korsbæk. I like it.

It is obvious that these culture-dependent actions—certain dances, biking, etc.—motivate learning. Patricia and Helen have a joint heritage in Korsbæk, but also in the different dances. The dances and their names are the ones used in real life (e.g., they practice Saturday Night Fever and laugh a lot, remembering their youth and John Travolta). Helen is very observant about the steps and considers whether it is possible to learn from the movements and practise them with her real body.

In this study, it was neither possible nor intended to subject the participants to brain scans. Therefore, there is no evidence of affected mirror neurons. It has, however, been demonstrated that the participants are affected. The avatar-mediated actions make them want to dance, bike, or feel thirsty for coffee. Their moods are affected: some laugh a lot, some get angry, they say "oops" when they bike into each other, they become frightened when they fall into the water, and so on. This indicates that they are putting themselves in the avatars' place and acting from that perspective. From a speech therapy perspective, one can also assume that these actions stimulate language. According to previously described research on embodied cognition, acting in an IVE that reflects a user's socio-cultural and historical situation allows the user to use multimodal systems (i.e., hearing, vision, speaking and writing), provide conceptual representation and, in time, contribute to rehabilitation.

#### 6.14.14. AND WE DID ALSO HAVE A GOOD LAUGH

There is nothing like a good laugh. Laughing brings people together and makes them feel that they share something. The participants laugh a lot, in the beginning at themselves, when they cannot succeed in doing what they want. Later, however, they laugh more and more in funny situations and in situations in which the avatars act unexpectedly or are more human than expected. Hanne stresses in the interview: "and we did also have many good laughs. Well, it's really fun. Wow, it really was, exactly, to feel that joy, and the community, and to have those laughs. Wow, it's good". According to mentioned brain research, the nervous system is stimulated by emotion and moods—and, thereby, plays a role in brain plasticity and the brain's ability to learn (Fredens, 2004; Goldberg, 2005). Laughter releases dopamine to the blood and can relieve feelings of embarrassment. It briefly increases the degrees of arousal and attention, which might also have an impact on learning (Banas, Dunbar, Rodriguez, & Liu, 2010, p. 131).

### 6.14.15. AND WHEN IT IS NOT WORKING

The data reveals several examples of situations with joy, laughter, good discussions and real learning outcomes. There have, however, been some obstacles and breakdowns, which can be divided into the following categories:

- 1. System/interface issues
- 2. Competencies (speech therapist/PWA)
- 3. Technical issues

SL is a complex IVE, with many functions, places, and spaces in different layers. It may seem overwhelming and difficult to become orientated. Even though the system contains maps, it is still complex to get an overview of the world. Orientation difficulties are a common consequence of brain injuries, which may make SL unsuitable for some persons. The interface has a great deal of information. Although it can be simplified, one needs to look for messages from co-participants and to use a minimum number of controls. For the experienced user, though, it is possible to adjust the setting to individual needs.

SL was brand-new to the speech therapists. Several were experienced teaching web-based courses; however, nobody was experienced in setting up SL profiles either generally or optimally. Most of the technical problems were related to audio/sound issues. Besides knowing how to adjust the sound in an individual SL profile, a user must know how to match the preferences for audio settings for his/her computer. Additionally, good-quality headsets are needed. Finally, it is optimal for a user to only press the "speak" button on the screen, when you are speaking, yourself. In general, there are an overwhelming number of adjustments that can be made to SL's preferences, which seems too complex for the speech therapists.

In the interviews with the speech therapists, a recurring issue is that they do not feel qualified to teach in SL. The technical obstacles make them insecure. As experienced speech therapists and teachers, they are used to being in control and setting the agenda. They find it very unsatisfying to have problems with fundamental functions and to be unable to conduct a course due to technical, interface, or skill issues. Moreover, in the pilot course for the speech therapists, they did not manage to learn the fundamental skills. It was very hard to bring the speech therapists together in these sessions to give shared instructions, since each of them was too occupied with their appearance, movements, and possibilities regarding exploring the world. However, their concentration improved after a few sessions, once they were given specific tasks to present to one another and for explaining didactically. In the following interview, one speech therapist mentioned that there was too much non-productive time during which they were waiting on each other "when you do not enhance your ability to act, it is

difficult to think pedagogically and we spent really much time, just waiting". The speech therapists also requested individual coaching. Due to the statements in the interviews, a face-to-face workshop was arranged.

As mentioned, some disabilities related to aphasia might complicate interactions in IVEs. In this present project, orientation problems and audio processing are the most dominant obstacles preventing full benefits. Anterograde amnesia affects one's ability to learn new skills, and SL might be too difficult and complex. It is possible to set the language as Danish in SL, but the translation is not yet thorough: some words are still in English, and this is very confusing for the PWAs. Even if they had mastered the English language before onset, many PWAs had forgotten it.

It was never clarified why breakdowns sometimes occurred. One possibility concerns the bandwidth or the computing capacity. However, these breakdowns certainly hampered teaching, leading a few of the participants, including Chris and Ian, to become very demotivated.

## 6.14.16. COULDN'T WE JUST AS EASILY GOOGLE IT?

In 2014, 18 months after the pilot course, several obstacles were eliminated based on the experiences from the pilot. To optimize the sessions with the speech therapist, Pia now sends agendas to the PWAs a couple of days before their online sessions. For those of the PWAs that suffer from poor auditory processing, it might be challenging to understand verbal instructions. As mentioned before, it can be helpful for them to know the theme beforehand or for the interlocutor to stick to one topic at a time. Helen describes the strategy as follows:

Helen: It is good for me to go in [to SL] beforehand. That's super.

Pia: Yes, you benefit from that?

Helen: Well if I only...by hearing, then I do not benefit
 much, but if I know a little about what it's
 about, then I can say, oh, this is what it's all

about.

Realising that the sound settings were causing several problems, Pia has opted to use Skype to speak with participants while they are logged onto SL. The quality of the sound is much better, and a side effect is that the speech therapist never loses track of the PWA, even if they accidently log off SL or get lost. This gives both parties calmness, allowing them to concentrate on the content. To save computer resources, one of the PWA even uses an iPad for Skype and his computer for SL.

Earlier, we saw examples of cultural and social activities, and we have now seen how the IVE's leading the PWAs to a sense of presence provides the possibility for the renegotiation of identity. The PWAs in this 2014 course are more experienced in using SL. When I meet them, they are in a stage in their rehabilitation at which they are avid to gain new tools that can help their level of knowledge and keep them updated with news and what is happening in the world. Their goal is to assert themselves communicatively in their interactions with others.

For example, Helen tells about a place she visited the night before:

Helen: I went for a walk in the eco-country. It is great

to go to various places. I went along the railway.

Pia: Yes, it's a great place, too.

Helen: There are actually many things about the

environment.

Pia: It is called Utopia Island.

Helen has a strategy for not getting lost: She follows the railway. Then, she is sure to find her way back. She takes great interest in organic and environmental issues, so the described visit is not just about being in SL, but also about gaining knowledge about a topic of interest.

In the same session, the participants are visiting Genome Island. A dialogue about bacteria takes place:

 $K^{2l}$ : I'm by the bacteria.

Helen: I'm about to see something about DNA.

L: I would actually like to read something about

bacteria also.

L: Teleport us over to the bacteria.

K: Okay.

Helen: What is it, it's called, the bacterium that we

should talk about now ... Ebola?

\_

<sup>&</sup>lt;sup>21</sup> K and L are the new PWAs in this course

L: Yes, it is in bursts down in Africa - West Africa.

K Has it also come to Canada?

L: It spreads much faster than it did in the past.

They reckon it's because people go much more by

plane than they did in the past.

Helen: Oh, this is only the bacterium. It is not virus.

Pia: No, it is only bacteria.

Helen: Well, we will not find it here.

L: No, we must find a virus museum. Hahaha.

In a multimodal way, the PWAs share knowledge about bacteria and viruses. They learn from each other and from the information at the Bacteria Museum, and they associate what they see to a topical theme. They also find an interactive board and laboratory animals.



Figure 62 Gnom Island

At the end of the session, Pia asks her PWAs what they think about visiting a virtual museum in SL:

Pia: Do you think it is a good way to learn, for

example, about genetics?

K: I think you have to spend much time.

Pia: Yes, you need a lot of time to read all the things.

L: Yes, one might as well Google it and find some material, but I think especially for people who like video games, then it is probably a good way. But for my part, I'd rather go on the web and look exactly at the things I need

Yes, you might as well Google it. But sitting alone behind the screen will not give the same experience of being together, sharing your knowledge, saying the words out loud, and maybe arguing for your opinion. You will read the information in a two-dimensional way without being there.

#### 6.14.17. THE SPEECH THERAPIST AS AVATAR

To sum up what is expressed in the data about the speech therapist being an avatar, the key issues are:

- 1. That the speech therapist and the PWA are physically separated
- 2. That the speech therapists lack ICT competencies

Not being in the same physical room reveals to be a major issue. Speech therapists are used to being very observant of the PWA, using body language, gestures, and facial expressions in communication. To be an SL speech therapist, one must get used to communicating differently and must know the PWAs thoroughly beforehand.

The possibility of getting remote access to PWAs has been requested. In the beginning, the speech therapists are frustrated in the verbal guiding situations, but they learn to slow down and let the instructions take turns, one step at a time. In one scene, Pia wants to teach Chris and Ian to receive an object. In the beginning, she gives too much information at the same time:

Pia: We didn't succeed getting a bike that way, so uh, you get it right here by me. You shall go… see here now; then you go in there, to the left side, ...there is a suitcase, then press on...there is a box...beneath...It is named "new things". There, you choose objects...then, there's what's called

Wonderfuldenmark.dk...then, bike, and then you simply double-click, and you get the bike.

Chris: ...I... [confused and defeated]

Pia: Yes yes, come on. Try to go over to the left.

Don't you have a picture of a suitcase over there?

Chris: Uh, yes...yes

Pia: On your left hand, there is a bar with some people

and a globe, and number three is a suitcase. Try

to press on the suitcase.

Chris: Yes, yes.

Pia: A box is coming up, called "inventory".

Chris: Yes, yes.

Pia: Yes?

Chris: Yes [uh?].

Ian: New things?

Pia: It says my inventory and objects, right?

Ian: Inventory and objects? Yeah, YEAH

Pia: YEAH.

As Pia realises that she has been too impatient, she slows down and makes sure that the PWAs follow her before she continues. At last, they succeed and go for a ride.

Dealing with technical issues was too time consuming. The speech therapists would have preferred to focus on the pedagogical and didactical matters. Some had to get new computers to run SL, and one was working on no fewer than three computers in three different physical destinations and was confused about setting the preferences.

In the first sessions of the pilot course for speech therapists, they were very occupied with simply adjusting to the environment. Over time, and after the extra workshop, they felt safer and could take the lead in the teaching situation using creative teaching ideas. Unfortunately, it took longer to get the full benefit than was available in the pilot project. If The Institute of Speech, Language, and Brain Disorders will provide working hours, everybody was interested in continuing to do avatar-mediated rehabilitation.

### 6.15. SUMMING UP THE FINDINGS

The goal of the analysis chapter has been to tell a story about avatar-mediated rehabilitation. The use of relevant examples from empirical material has accomplished this. Relevant in this context refers to themes that are deemed to contribute to answering the thesis research question. Using excerpts of dialogues, the persons involved are given a voice. The statements are put into context and, thus, construed. The aim was to indirectly circumvent the units of interest listed in the beginning of the chapter. These will be summarized briefly and then contextualised in a proposal to achieve a didactic framework for avatar-mediated rehabilitation for people suffering from aphasia, which will be presented in the next chapter.

The pilot project involved a generally good and positive atmosphere. The participants have been committed and have contributed many comments and ideas. Particularly, the PWAs have demonstrated significant enthusiasm in contributing to the development of aphasia interventions and rehabilitation methods. They have immersed themselves in the interactions and scenarios of SL. They have used significant time and engaged in training before and during the sessions. On several occasions, it has been clear that they have sensed a high degree of presence. Of the specific training practices, naming, categorization, selection, orientation, and spatial disabilities have been mentioned. It has also been mentioned that SL is well suited to PWAs with a type of aphasia called anomic (involving problems with prepositions). Furthermore, persons suffering from Wernicke's aphasia have immersed themselves, been associating, and been using a lot of (correct) words to describe their actions and experiences. By contrast, SL might be difficult for PWAs with audial processing problems, at least when the quality of the sound is poor.

Interaction in SL has also been marked by frustration. With regard to PWAs, the most significant issues are those concerning running SL or other technical matters. In contrast, the speech therapists were primarily concerned with competencies related to ICT: mostly technical issues.

Despite the difficulties, the participants appeared to be the persons we knew from their physical lives—or the people as whom they deliberately chose to appear. They were eager to communicate about their lives, families, and skills. Thus, they were

able to renegotiate their identities. They also enjoyed being in the company of others.

Some of the PWAs had more peripheral participation roles. This could be due to their personalities, the aphasia, or their lack of written and verbal skills. Nevertheless, in such an IVE as SL, participants are visible through the presence of avatars. Through shared experiences and a shared repertoire with other participants, the creation of a common culture, narratives, chats, and any other kinds of interactions that contribute to strengthen their perceptions of their own identities give visibility to the other participants.

Most of them would like to continue to interact in SL. The PWAs, however, want an optimized interface that is more simple and does not break down. The speech therapists want more education and more working hours.

The pilot course for the PWAs ran for six weeks. This is a too short a period to provide any evidence regarding whether communication improved. When the locale meets the requirement; when the environment, actions and artefacts are merged into one whole to unconsciously motivate the participant to be active; when memory is triggered and facilitates storytelling; when you get the opportunity to enjoy social interactions and language supported by multimodal features; and when you forget that you are behind a screen—and, thus, forget yourself and become immersed to the degree that you can feel presence—there is a good indication that mirror neurons and other brain cells have been activated and that a conceptualization will happen over time. SL provides easy access to different places from real life in order to facilitate a meaningful, situated, and motivating rehabilitation.

Inge, Peter, and the group from 2014 demonstrate that long-term interactions in SL make participants *inhabitants*, rather than just *users*. The group members have stopped talking about the interface and the functionalities; instead, they simply interact and live.

## 6.16. DOING VIRTUAL ETHNOGRAPHY IN SL

As mentioned in the methodology chapter, I was a present ethnographic observer. Specifically, I was present in the sense that I followed the participants online in SL as an avatar during some of the sessions. Without being logged in SL as an avatar, it is not possible to *be* there or to observe or video-capture the sessions. Furthermore, I wanted to be visible to the participants—saying hello and goodbye as in real life—mostly for the purposes of acting as naturally as possible and demystifying the role of the researcher.

#### CHAPTER 6.

In analysing the data, it was impossible not to notice my own behaviors. I was aware of the double role I had in the project. Not only was I in the research group, but I had also been a co-designer of the course. Moreover, the speech therapists were former colleagues, and I had even taught two of the PWAs several years prior. I stressed that, during the course, I would be observer—and, thus, would not participate. However, the participants occasionally forgot my role, posed questions, and involved me in the activities. They knew me from past interactions as an ICT-competent person. Karen obviously had forgotten all about me being there. During one session, she suddenly spotted me:

Karen: Ulla Konnerup, oh, why are you sitting there...Ulla, I am glad you are here; can you help me not just being a cloud?

Karen had difficulty in that her avatar had not loaded completely; unfortunately, I could not help her. However, if someone had major difficulties, I could not help but interfere. I even unconsciously interfered in activities on my own initiative a few times. As these behaviours grew clear to me during the data processing, I was, at first, a bit embarrassed to think that I did not handle my role as researcher professionally. Now that I have seen the videos repeatedly and reflected on the situations, I choose to consider myself as a researcher that had immersed herself so much in the environment that she sensed presence.

# CHAPTER 7. A FRAMEWORK FOR AVATARMEDIATED REHABILITATION

Based on the theoretical considerations and the findings of the data analysis, I will outline some recommendations and a framework for an avatar-mediated rehabilitation in an IVE.

New methodological and pedagogical tools for rehabilitation call for reflections on didactics. It is important that professionals not just transfer methods and activities from former practice, but are also critical towards the media and the kinds of didactics facilitated in the new media.

At The Institute of Speech, Language, and Brain Disorders, web-based rehabilitation has been offered for more than 10 years. According to Pia, the Institute has a vision to develop its computer-based aphasia interventions further. This thesis has indicated that avatar-mediated rehabilitation might facilitate persons' renegotiation of identity, support conceptualization, and rebuilding of lost skills. The result is a recommendation to develop current methodology further. However, the data analysis revealed that moving the learning space from a 2-dimensional website (ATA) to an avatar-mediated platform (SL) has proved to be a challenge, especially to speech therapists. The study has also demonstrated the concrete problem areas, which must be considered in relation to establishing avatar-mediated rehabilitation in any platform. In the following, I will list recommendations for professionals and others who are working with aphasia and people suffering from aphasia.

Before getting started, it is essential to consider the environment and its features.

#### The environment must:

- Be web-based or a web-based client to make it accessible from home or any other place, from any computer. This will give participants flexibility and independence of time and place.
- Have an interface with required screen formats/organizations, layouts, menu structures, and function keys.
- Be avatar-mediated and invite immersiveness.

- Be in the user's native language.
- Contain replications of real-place destinations relevant for the user group, which will motivate them to act, communicate, and promote memory.
- Have content that is possible to make dynamic, user-generated, customized, and topical.

#### Available features:

- Public and private places and settings.
- Good-quality voice and text chat to support multimodal communication in public and private groups.
- Human-like avatars that can be designed and dressed individually.
- Messages that can be sent to and from the environment, allowing users to get in touch easily, without logging into the environment.

With regard to technical issues, it is essential to develop detailed requirement specifications concerning the computers related to the chosen environment. To ensure that participants' IT equipment meets requirements, the fundamentals include:

- Resources
- Performance capacity
- Graphics card
- Audio functions

Furthermore, earphones with microphones are essential; otherwise, an echo will occur. Technical staff should be involved to check on firewalls, etc. Viewer software should be installed so that speech therapists can take over the screens of the PWAs, while ensure that they still give the PWAs the time needed with respect to potential latency. If the PWAs are challenged, they might solve the problems themselves and learn from them. Learning to manage technical issues, logging in and out, and other general manoeuvres provide their own kind of cognitive training (Dirckinck-Holmfeld et al., 2004).

It is difficult to say who can benefit from avatar-mediated rehabilitation. It has been mentioned that the method is suitable for naming, categorization, selection,

#### CHAPTER 7. A FRAMEWORK FOR AVATAR-MEDIATED REHABILITATION

orientation and spatial disabilities, as well as for PWAs that benefit from supplemental text and speech. However, I will not highlight one type of aphasia as being more suitable for this kind of rehabilitation than others. When the speech therapists were directly asked whether they could provide guiding principles regarding who or what type of PWA may profit from technology, specifically avatar-mediated rehabilitation, all responded that the answer was subjective and that evaluations were indivual. IT competencies—or, at least, an ability to solve problems and keep up spirits in the case of failure—are more essential than the type of aphasia. Motivation and an urge to interact socially are the driving forces of success. For the PWAs, the most important thing is that the speech therapy is able to be extended over the course of several hours and another, longer period and that it can deal with more than the optimization of language production and communicative competence by focusing on identity, participation and action. Furthermore, the cognitive rehabilitation must be positioned in a social context that allows the PWAs to interact with people on an equal footing.

It has been mentioned that the data revealed that the speech therapists did not feel competent enough to teach themselves in SL. From the ATA project, they were been used to playing a teaching role, alternating between classical speech therapist training (e.g., naming, grammar, syntax, sounds and building sentences) to roles as scaffolders, mentors, and facilitators in a virtual environment. To design and conduct virtual therapy, new competencies are demanded. The data demonstrate concrete problem areas in relation to the speech therapists' practices that need to be addressed in the qualification of the speech therapists:

- First and foremost, speech therapists have to be familiar with social media
  in general and IVEs especially. To avoid unnecessary uncertainty, they
  must learn more about the Internet and the online culture and how these
  work.
- In general, speech therapists must be more familiar with common computer features and applications, so their knowledge from one interface or software can spill over to another.
- Speech therapists must develop practical proficiencies with computerbased teaching and learning, concretely plan courses and construct objects and other features.
- Speech therapists must train practical skills through actions.
- Speech therapists must know about online socialisation, "netiquette", and not causing offence.

• The role of the speech therapist must be reconsidered, as well as how they can facilitate and guide PWAs over distances and as an avatar.

Finally, it is essential to acquire knowledge based on theories about aphasia, cognition and communication development, as well as on what avatar-mediated rehabilitation might add to the classic rehabilitation.

#### 7.1. PEDAGOGICAL CONSIDERATIONS

The re-development of language after a brain injury must involve the whole person and his/her relation to social others and the environment—not be limited to linguistic grammar. Avatar-mediated rehabilitation facilitates an approach involving the realisation of language through use. It facilitates an approach that combines knowledge of language, cognition, and sociocultural learning and didactics. With Fredens' and Thybo's terminology, this is a neuropedagogical approach.

Re-learning through a new media is a challenge for cognition in itself. To log into SL and to recall and remember its functionalities involves cognitive stimulation. The same applies to navigating, meeting others and using the environment. However, focused activities facilitated by a speech therapist who knows a person's difficulties and strengths will optimize the interactions.

Depending of the charecteristics of an individual's aphasia and communication disabilities, the communicative approach, use of perceptual means (e.g., written, visual or/and auditory approaches), and choice of activity must differ and be modified to the individual person and his or her strategies.

Most often, a combination of various approaches that support each other promotes the best outcome. For example, a PWA who has difficulties maintaining an auditory soundtrack in memory have be sent the same information in speech and writing (e.g., through online chat or a written paper sent beforhand); thus, reading competence supports auditory understanding. By repeating functions and related tasks, repetitive loops and, later, generic memories are formed. This will lead to new challenges being met—not as if it were the first time, but through the creation of learning strategies.

By designing land and holodecks for individual needs and integrated private photos, places, locales, and fields of interest it is possible to trigger autobiographical memories, engagement, and—thereby—cognition and language.

Avatar-mediated rehabilitation offers various opportunities to involve cognitive rehabilitation into a socio-cultural perspective, with the possibility for the PWAs and the speech therapists to be there together and have a sense of presense. This

#### CHAPTER 7. A FRAMEWORK FOR AVATAR-MEDIATED REHABILITATION

method facilitates a motivation and an impetus for linguistic rehabilitation to participate in a social virtual community in which the interactions among participants will play a central role in re-gaining competencies. The virtual framework is independent of time and place and allows for active participation by the PWA—and, thereby, promises success in terms of communicative strategy, time, and fields of interest.

It is important to clarify that avatar-mediated rehabilitation should not be considered a substitute for options already available; instead, it is a benefit with added value. It should be seen as a way to extend and prolong rehabilitation, such that PWAs have the opportunity to attend a social community in which they can tell their story, show who they are, stimulate their memory and, thus, regain their ability to communicate.

I am aware that there is still a long way from demonstrating rehabilitation potential, before this method finds its place in practice and becomes fully implemented. New projects with long-term programs and greater numbers of participants must identify the potential even further and help to implement the methodology.

When media changes, it is likely that cognitive strategies also change (Fredens 2006, 17:31). Generally, avatar-mediated rehabilitation challenges communication and cognition and, thus, has the potential to develop new and different kinds of communication.

# CHAPTER 8. CONCLUSIONS

This thesis has been driven by an urge to explore whether new technologies provide an opportunity to challenge the brain's strategies for re-learning language after brain injury. The specific focus has been how the rehabilitation of a PWA can be extended to involve the renegotiation of identity, quality of life, and competent participation in society. The research question was: How can avatar-mediated rehabilitation and social interaction in immersive virtual worlds equip persons suffering from aphasia to renegotiate their identities and enable them to maintain knowledgeable and cultured persons?

To answer this question, I have searched for knowledge from previous related projects and for theories on the brain, cognition, virtual interaction, and rehabilitation. In addition, I have followed a case exploring the development of rehabilitation methods in an IVE. The aim has been to reformulate aphasia speech therapy to address and include psychosocial problems. Psychosocial problems are often caused by the fact that a lack of communicative competency is followed by difficulties in renegotiating identity.

One answer is to put rehabilitation into a sociocultural framework that facilitates non-verbal and verbal communication using various multimodal tools. By facilitating social inclusion, a social community will offer the potential to focus on the WHO's recommandations to consider impairment as the limitation of opportunities for participation in society. Learning and re-learning language takes place through social interactions with others and is dependent of feedback people receive from others. Research has shown that re-gaining language takes many hours of rehabilitation.

Research on the brain has demonstrated that processing language is distributed throughout the neocortex and is not limited to specific areas. Cognition is developed in relation to a person's interactive life process, depending on culture and tools. By using the concept of embodied cognition, it is stressed that there are close ties between cognitive processes and the body's action. Research indicates that interacting in immersive environments provides an opportunity to use multiple sensory stimuli and to promote and develop the nervous lanes in the brain. Rizzolatti and Sinigaglia's research on mirror neurons shows that observing other people's goal-oriented actions fires (almost) the same neurons as completing those same actions in the real world, and Damasios' research demonstrates that the sensory-motor areas in the brain are used both for producing an action and for the conceptual representation of that action. This means that words and concepts are

formed through the same process; thus, we learn by doing. The data in this thesis have revealed that PWAs stressed action-related activities as the most profitable. Moreover, even when they became confused, they put words to their experiences. The pedagogical consequences of the knowledge of mirror neurons indicate that acting through an avatar will fire relevant action neurons in the person controlling the avatar. Dancing with Misse Møghe is one scene that indicates that the dancing avatar is mirrored by the persons involved.

An avatar-mediated environment seems to meet all of the above-mentioned requirements for aphasia rehabilitation. PWAs can be immersed to the degree that they sense presence and use their preferred communication strategies in collaboration with others. Interactions in familiar locales will trigger their autobiographical memory, and they might be able to tell their own stories, learn new things, have culturel experiences, and renegotiate their identities. The data show a tendency for people with Anomic's and Wernicke's aphasia to benefit the most.

The pilot course revealed that the speech therapists did not feel qualified to conduct rehabilitation in SL. They needed further training and qualification, especially concerning ICT didactics and tools. The pilot course did not sufficiently take into consideration that most of the participants had no previous experience in Second Life. Six weeks of rehabilitation is too little time for a person to become familiar enough with a virtual world to be comfortable integrating it into his/her teaching. The SL rehabilitation platform is too complex and it is not fully translated into Danish: both significant problems. Nevertheless, I conclude that avatar-mediated rehabilitations as general method have huge potential for success.

Furthermore, I have briefly mentioned that labelling might stigmatise people. Tests and diagnoses might be useful to professionels, PWAs, and social others, but only if they are conducted and used to provide strategies for regaining competencies—not only to achieve labelling. Neuroimaging can be considered in the same way: That is, brain scans cannot make final diagnoses; however, in combination with pedagogical and didactic knowledge, they can contribute to neuropedagogical rehabilitation.

My conclusions are not based on evidence in the form of brain scan; rather, they are based on the acknowledgement of storytelling as part of science. Thus, I build my conclusion on the data from the narratives of the participants, combined with theory within the field.

# CHAPTER 9. FURTHER RESEARCH

Ending a research project and formulating conclusions opens up new questions. Inevitably, there are threads and discourses that require further research. In this case, it would have been interesting to follow the PWAs for several years to investigate long-term results.

The speech therapists' (and teachers' in general) lack of ICT competencies is an area that has already been significantly addressed in the literature; however, further research and suggestions on what to do are still needed. This is a dominant issue in several projects. This was not meant to be the primary point of this thesis, but the issue became impossible to ignore, since a lack of ICT knowledge is important in learning situations.

One interesting research area is how our brain, our cognition, and our behaviour are affected by interactions in an avatar-mediated virtual world and in real life. What are the consequences (good or bad)? If we learn and develop from interactions in cosy social communities for learning, then what are the consequences for interacting in evil or violent scenarios?

Within brain research, further research on mirror neurons, imitations, perceptions, and the processing of language and conceptualizations could add value to the speech therapy realm.

In relation to persons with brain injuries, it would be interesting to conduct research on the newest technologies developed for virtual reality. Inspired by VHIL at Stanford, research on how VR affects people's cognition, interactions in rooms with spatialized sound, virtual touch (haptics), and three-dimensional imagery (as seen through headmounted displays) would constitute a relevant continuation of this thesis.

## **APPENDIX**

Appendix and data are confidently, therefore all relevant documents, video and audio recordings are distributed on an extern hard disk to the Ph.D committee only.

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### **SUMMARY**

This thesis is about using immersive virtual environments in the rehabilitation of persons suffering from aphasia. More specific, it is about how acting through a virtual representation, a so-called avatar, might contribute to renegotiation of identity and regaining lost communicative competencies after a brain injury.

With roots in a social-cultural understanding of learning and rehabilitation, Ulla Konnerup demonstrates how avatar-mediated rehabilitation offers new possibilities in the communicative rehabilitation. Learning and communication through shared experiences and narratives, joint repertoires, joint culture and heritage, have been shown to be fruitful triggers of memory and word-mobilising for persons with aphasia and renegotiation of self. Furthermore, avatar-mediated embodied cognition strengthens conceptualisation and relearning language. The results build on a case study with data collected in relation to two pilot courses in an immersive virtual environment, Second Life. The first course is a pedagogical course for speech therapists, the other a rehabilitation course for persons suffering from aphasia. The courses were conducted by speech therapists at The Institute for Speech, Language, and Brain Disorders in Aalborg, DK in 2011-2014.

The approach is qualitative and phenomenological with an intention to give persons with aphasia a voice.

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