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SITUATED CO-PRODUCED FAMILY CAREGIVING WITHIN DEMENTIA

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BY
BARBARA EGILSTRØÐ

PhD Thesis 2025

AALBORG UNIVERSITY
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"In those interactions where the individual presents a product to others, he will tend to show them only the end product, and they will be led into judging him on the basis of something that has been finished, polished, and packaged…It will be long, tedious hours of lonely labor that will be hidden…we tend to conceal from the audience all evidence of 'dirty work'."

(Goffman, 1959, p. 44)

CV

Barbara Egilstrøð holds a Bachelor of Sport Science from Aalborg University (2015) and a Master’s in Public Health from Aalborg University (2018). Her journey into the research on family caregiving began when she had a one-year leave from her master’s studies and was appointed as a research year student at the Public Health and Epidemiology Group (PHE) at the Department of Health Science and Technology at Aalborg University. Her interest in research on family caregiving was sparked, and after finishing her studies in Public Health, she joined the PHE as an assistant lecturer in 2018, lecturing and supervising students enrolled at the BSc program in Medicine and MSc program in Public Health. Simultaneously, she worked on funding for a PhD project with her supervisors.

In 2021, she enrolled as a PhD fellow in PHE, and the Aalborg Municipality co-founded the study. In close collaboration with the Knowledge Centre for Dementia in Aalborg Municipality, the project was formed as an applied research project. In close dialogue with representatives from the Knowledge Center for Dementia in Aalborg Municipality, the research objective was formed and sought to investigate how to better support family caregivers in their encounters with the Dementia Service System.

During her PhD period, from March 2023 to April 2023, Barbara was affiliated as a Visiting PhD Fellow at the Roskilde School of Governance, Roskilde University, led by Professor Jacob Torfing who supervised her during her stay. Torfing is among the leading figures in the co-creation and co-production of public services in Scandinavia and Europe.

As part of her three-year employment as a PhD fellow, Barbara has dedicated six months to full-time teaching and supervising students in the BSc program in Medicine and the MSc program in Public Health at Aalborg University. Her teaching covers various topics, including problem-based projects in public health and academic writing, scientific methods, including qualitative methods, basic epidemiology, and the conduct of systematic reviews.

ENGLISH SUMMARY

In Scandinavian countries, the welfare state offers extensive welfare and public caring arrangements for people with dementia. Still, family caregivers are pivotal in providing home-based dementia care. Around 65-75% of people with dementia are cared for at home by family members. Caregiving has been thoroughly investigated during the last decades, investigating professional caregiving and family caregiving as separate units, which, in the literature, are defined as formal and informal caregiving. Formally separating the boundary has influenced knowledge creation and practice organisation based on a dichotomic relationship. However, in practice, most care and support is provided as home-based care, involving professionals and family caregivers entangled in a complex system of social relationships and interactions. To better support family caregivers in providing home-based dementia care, there is a need to gain knowledge on family caregiving through encounters with healthcare professionals and other family members and friends. In this PhD study co-production is applied as the overarching analytical concept to gain knowledge on complex social interaction in home-based caregiving to home-dwelling people with dementia. This concept challenges the distinction (or dichotomy), where the public sector provides services, forming citizens as passive receivers. This focus has dominated the public and healthcare sectors for the last decades. Co-production focuses on the active contribution of service producers and service users in service provision.

This PhD study aims to gain in-depth knowledge of family caregiving through encounters with healthcare professionals, family members, and friends. It is investigated through the situated co-produced family caregiving, acknowledging family caregivers as active contributors to home-based care for home-dwelling people with dementia. This knowledge can provide insights into family needs for support.

The overall aim is divided into three sub-objectives addressed in three papers:

- To identify and chart the application of co-production within research in community health services among older adult citizens, including people with dementia and their relatives (Paper I).
- To explore how co-produced care and support for persons living with dementia is negotiated over time in a triadic relationship between the family caregiver, healthcare professional, and the person living with dementia (Paper II).

- To explore situated co-produced family caregiving by analysing the problem perspective and problem-associated solutions approaching situated co-produced family caregiving (Paper III).

This study is designed as explorative ethnographic fieldwork, informed by a social-constructivist philosophy of science with a constructivist-interactionist theoretical perspective to capture the complex dynamic of social interaction in situated co-produced family caregiving. A scoping review and fieldwork, combining participant observation, semi-structured interviews and focus group interview were applied as data collection methods. The Fieldwork was conducted between February 2021 and April 2023. Seven dementia coordinators, 21 family caregivers, and 14 people with dementia participated. Data were thematically analysed using Ervin Goffman's theory about the presentation of self in everyday life. The scoping review followed Levac scoping review's guidelines, and six databases were searched (PubMed, Cinahl, PsycInfo, Sociological Abstracts, and Google Schoolar). Twenty-two studies met the inclusion criteria and were descriptively and thematically analysed (Egilstrøð, Wegner, et al., 2025).

Findings from the scoping review shows that co-production is applied as a collaborative approach where all stakeholders contribute substantially to the process within community health services among older adult citizens, including citizens with dementia and their relatives. Three different types of co-production were identified: 1) co-production applied in intervention and service development, 2) co-production applied in services provision, and 3) co-production applied in the design and process of research. Across the three types, co-production was applied fundamentally differently, which impacts how co-production emerges in practice (Egilstrøð, Wegner, et al., 2025). Findings from the ethnographic fieldwork provides a more dynamic understanding of co-production, as situated in practice, the dynamic is manifested through a preventive caring practice. The findings show how a preventive caring practice becomes the dominant strategy forming the situated co-produced family caregiving in encounters with healthcare professionals, other family members, and friends. Through face-saving strategies, proactive impression management is used to preserve the dignity of social identity for the person with dementia (personhood) and to maintain everyday life as normal as possible. Consequently, the dominant family story is intact, even as the dementia progresses, thereby downplaying the aberrant behaviour. The preventive caring practice is always practised in highly complex social interactions and encounters between healthcare professionals, other family members, and friends. It is also interconnected with normative expectations, social roles, social performances in social situations, and social identity. Therefore, family caregivers must navigate and adjust the situated co-produced family caregiving in encounters with healthcare professionals, family members, and friends.

In conclusion, this PhD contribute with knowledge on how family caregivers contribute to home-based dementia care through situated co-produced family caregiving, primarily using a preventive caring practice in interactions with others. It highlights the double bind of maintaining normality in a progressive illness, involving aberrant behaviour, which becomes increasingly complex to manage for families on their own. While a preventive care practice is meant to be helpful and supporting the whole family, it can oppress the severity of the dementia and related caring burden, hindering healthcare professionals from providing adequate support and potentially triggering psychosocial illness, like stress, anxiety, and depression. When family members become co-users of services not directly aimed at them, it is crucial to reflect on whether they are adequately supported through available services. The PhD study contribute with practical implication on how to better guide guiding family caregivers in navigating the complex normative landscape and associated caregiving practice. The PhD study contributes with practical implications by providing knowledge on how to guide family caregivers in navigating the complex compass of normative caregiving expectations and associated strategies for providing situated co-produced family caregiving to home-dwelling people with dementia. This is achieved by addressing and reflecting on dilemmas that arise early in the caregiving process when a preventive caring practice becomes the dominant caring strategy. Addressing and reflecting on these dilemmas can support both healthcare professionals and family caregiver. Both for healthcare professionals and for family caregiver addressing and reflection upon dilemmas that arise, when using a preventive caring practice, can give rise to acting differently. Future research should continue to gain a better understanding of the situated co-production processes focusing on the highly complex social interaction in providing home-based caregiving. It could be beneficial to explore these processes from different perspective, across healthcare professionals and family caregivers. Further studies are still needed on situated co-production processes in triadic encounters between family caregiver, the person with dementia and healthcare services aiming to organise service to better meet the needs of the families living with dementia.

DANSK RESUME

Den Skandinaviske Velfærdsmodel tilbyder omfattende velfærds- og omsorgsordninger for mennesker med demens; alligevel spiller pårørende en central rolle, når personer med demens skal støttes i eget hjem. Omkring 65-75% af mennesker med demens bor i eget hjem og får hjælp fra en pårørende. Der har været stort fokus på at bidrage med viden, og dermed til organiseringen af omsorg i praksis, både fra et professionelt og et pårørende perspektiv. Hidtil har disse dog været undersøgt som to selvstændige domæner, som i litteraturen defineres som formel- og uformel omsorg. Dette har ført til en dikotomisk forståelse af omsorg, hvor den enten udføres som formel omsorg eller som uformel omsorg. I praksis leveres størstedelen af omsorgen dog i et tæt samspil imellem det formelle og det uformelle, og involverer både professionelle og forskellige pårørende, dvs. i et komplekst system af sociale relationer. For bedre at kunne støtte pårørende, som bærer hoveddelen af ansvaret, når personer med demens skal støttes i eget hjem, er der et behov for at få dybdegående viden om pårørendes rolle i mødet med både sundhedsprofessionelle, andre familiemedlemmer og venner. Samproduktion anvendes som overordnet analytisk begreb for at bidrage med viden om det komplekse samspil, når personer med demens skal støttes i eget hjem. Samproduktion som koncept udfordrer dikotomien imellem formel og uformel omsorg, hvor det offentlige yder omsorg til borgere, hvor borgere bliver reduceret til passive modtagere. Dette perspektiv har domineret offentlige velfærdsservices, og derved også demensomsorgen. Samproduktion fokuserer på samspillet imellem sundhedsprofessionelle og borgere, hvor begge er aktive deltagere i omsorgsarbejdet.

Det overordnede formål med dette PhD studie er at opnå dybdegående viden om pårørende i mødet med sundhedsprofessionelle, andre familiemedlemmer og venner. Det undersøges igennem situeret samproduceret familieomsorg, hvor pårørende anerkendes som aktive medproducenter i omsorgsarbejdet. Denne viden kan bidrage med at afdække familiens behov for støtte.

Det overordnede mål er opdelt i tre delmål, som er adresseret i tre artikler:

- At identificere og kortlægge, hvordan samproduktion er anvendt inden for forskning i sundhedsservices for ældre borgere, herunder mennesker med demens og deres pårørende (Artikel I).
- At udforske, hvordan samproduceret omsorg og støtte til personer med demens forhandles over tid i en triadisk relation mellem den

pårørende, den sundhedsprofessionelle og personen med demens (Artikel II).

- At undersøge situeret samproduceret familie omsorg, hvor problemforståelser og problemrelaterede løsninger analysere, i tilgangen til situeret samproduceret familie omsorg (Artikel III).

Studiet er designet som et eksplorativt etnografisk feltarbejde med en socialkonstruktivistisk videnksabsteoretisk ramme kombineret med et konstruktivistisk-interaktionistisk perspektiv. Dette for at give mulighed for at undersøge den komplekse dynamiske sociale interaktion i situeret samproduceret familieomsorg. Et Scoping review, deltagerne observation, semi-strukturerede interview og et fokusgruppe interview blev brugt som dataindsamlingsmetode. Feltarbejdet blev udført fra februar 2021 til april 2023. Syv demenskoordinatorer, 21 pårørende og 14 personer med demens deltog i undersøgelsen. Data blev tematisk analyseret ved hjælp af Erving Goffmans teori om selviscenesættelse i hverdagslivet. Scoping reviewet fulgte Levacs retningslinjer for udførelsen af scoping reviews, og der blev søgt i seks databaser (PubMed, Cinahl, PsycInfo, Sociological Abstracts og Google Scholar). Toogtyve studier opfyldte inklusionskriterierne og blev analyseret, både deskriptivt og tematisk (Egilstrøð, Wegner, et al., 2025)

Fundene fra scoping reviewet viser, at samproduktion anvendes som en strategi for at fremme samarbejde, hvor alle involverede parter bidrager ind i processen, når lokalsamfunds- og kommunale initiativer skal sættes i gang, eller til at drive lokalsamfunds- og kommunale sundheds- og omsorgs indsatser, blandt ældre borgere, herunder borgere med demens og deres pårørende. Tre forskellige typer af samproduktion blev identificeret: 1) samproduktion anvendt i interventions- og serviceudvikling, 2) samproduktion anvendt i servicelevering og 3) samproduktion anvendt i design og forskningsprocesser. På tværs af de tre typer blev samproduktion anvendt fundamentalt forskelligt, hvilket påvirker, udfoldelsen af samproduktion i praksis (Egilstrøð, Wegner, et al., 2025). Fundene fra feltarbejdet viser en mere dynamisk forståelse af samproduktion, situeret i praksis. Indenfor demensområdet, vises det igennem en igennem en 'værnende omsorgspraksis'. Fundene viser, hvordan maskering bliver den foretrukne omsorgsstrategi for at opretholdende en 'værnende omsorgspraksis' i mødet med sundhedsprofessionelle, andre familiemedlemmer og venner, med det formål at bevare værdigheden af den sociale identitet hos personen med demens og familielivet. Proaktiv indtryksstyring bliver en selvbeskyttende facade for at nedtone demenssymptomerne og for at opretholde hverdagslivet så normalt som muligt. Herved kan den dominerende familiehistorie holdes intakt, selv når demenssygdommen forværres, og dermed nedtones afvigende adfærd. Maskering udføres altid i et højt komplekst samspil, og dermed også i mødet med sundhedsprofessionelle, andre familiemedlemmer og venner. Pårørende bliver nødt til at tilpasse deres maskeringstrategier, således at de tilpasses til den sociale situation, de indgår i. Den vil derfor se forskellig ud, alt efter hvem de møder. Det er nemlig forbundet med normative forventninger, sociale roller, sociale præstationer i sociale situationer og social identitet.

PhD studiets fund giver en dybere forståelse for, hvordan pårørende bidrager ind i omsorgsarbejdet, når personer med demens skal støttes i eget hjem ved at introducere situeret samproduceret familie omsorg, som belyser det komplekse samspil, når personer med demens skal støttes i eget hjem. Maskeringsstrategi bliver den mest dominerende omsorgsstrategi, og den er samproduceret i mødet med andre, især sammen med sundhedsprofessionelle.

Fundene er særlig relevante som en refleksion til praksis, hvor maskering bliver brugt som overskyggende strategiomsorgsarbejdet, når personer med demens skal støttes. Selvom maskeringstrategien har til formål at skabe et bedre liv og at leve godt med demens, så er det vigtigt at reflektere over, at denne strategi samtidig er med til at undertrykke demensens faktiske alvor og sværhedsgraden. Dette kan medføre, at sundhedsprofessionelle har svært ved at vurdere familiers reelle behov for støtte. hvilket kan hindre sundhedspersonale i at yde tilstrækkelig støtte og potentielt udløse psykosociale sygdomme som stress, angst og depression. Når familiemedlemmer bliver medbrugere af services, som i tilfældet for pårørende, hvor servicen ikke er direkte rettet mod dem, er det afgørende at reflektere over, om de er tilstrækkeligt understøttet gennem de tilgængelige støtteforanstaltninger. PhD studiet bidrager med praktiske implikationer, i det at der bidrages med viden om, hvordan man kan guide pårørende i at navigere i det komplekse kompas ift. normative omsorgsforventninger og associerede praksisser, ved at adressere og reflektere over dilemmaer, der opstår, når der anvendes maskeringsstrategier tidligt i forløbet. At adressere og reflektere over opståede dilemmaer kan give anledning til at håndtere omsorgspraksissen på en anden måde både for sundhedsprofessionelle og for pårørende.

Fremadrettet kan forskning med fordel fokusere på at opnå en bedre forståelse af de situerede samproduktionsprocesser med fokus på den relationelle kompleksitet, i forbindelse med hjemmebaseret omsorg. Det kunne være gavnligt at undersøge disse processer fra forskellige perspektiver, herunder fra forskellige sundhedsprofessionelle og forskellige pårørende. Flere studier er stadig nødvendige for at belyse de situerede samproduktionsprocesser i triadiske møder mellem pårørende, personen med demens og sundhedsprofessionelle, med henblik på at organisere støttede indsatser, der bedre imødekommer familiernes behov, der lever med demens.

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A PhD thesis is not a one-person achievement; it involves a whole range of people who, willingly or unwillingly, become part of the process. In my case, there are many people to whom I owe a great thanks.

First and foremost, I would like to thank the families who allowed me to gain insight into one of the most vulnerable moments of their lives. It has been insightful and, at times, a harsh reality to witness. Thank you to the Dementia Knowledge Center in Aalborg Municipality for granting me access and providing valuable input for the project. Thank you to the dementia service coordinators and the staff at "Active with Dementia". It has been a pleasure to witness how compassionately and wholeheartedly you engage with families affected by dementia.

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To my fellow PhD students and colleagues at FSV, thank you for being there when I hit emotional rock bottoms and for your constant support. The care and encouragement you provided are deeply cherished.

Lastly, but certainly not least, to my family - thank you! Thank you for still being here! You have seen the unpolished reality and experienced the behind-the-scenes struggles. It has been intense, a mix of frustration, tears, helplessness, anger, joy, passion, and fighting spirit. When you are truly passionate about something, the experiences can be overwhelming.

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Rúni, thank you — from the bottom of my heart! Balancing life with young children, a full-time job, and writing a dissertation has sometimes been a tough daily grind. Still, you helped me manage and balance all parts, ultimately taking over as the head of the family. Not only did you run the family, but you have also been the best partner in academic crime; discussing my project with you has been a pleasure. You always believed in me, comforted me, and cheered me when I most needed it. Thank you for your tireless support — none of this would have been possible without you!

Helena and Jóhannes, it has been challenging to be absent and set you aside to prioritize finishing this PhD. I have missed you so much and look forward to enjoying the time with you again. You remind me of what truly matters—time spent with you and your dad! I am so grateful to have you in my life, and you never make me doubt being alive. I love you both so much!

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Funders had no role in the research process and in the publication process.

Representatives from the Knowledge Center for Dementia, Aalborg Municipality were involved throughout the project discussing the rationale and aim of the project to adhere to Research in Applied Practice.

Representatives from the Knowledge Center for Dementia, Aalborg Municipality also recruited participants to the project.

This is addressed in the methodology's chapter and their influence is discussed in the discussion's chapter.

LIST OF PAPERS

This PhD thesis is based on following papers hereafter referred to by their Roman numeral in text.

Paper I: Exploring co-production within research on community health services among older adult citizens, including citizens with dementia and their relatives: a scoping review

Egilstrøð, B, Wegener, W, Henriksen, L.S., Petersen, K.S, Exploring co-production within research on community health services among older adult citizens, including citizens with dementia and their relatives: a scoping review. Ageing International. 2025 (Under revision before re-submission)

Paper II: The Social Process and Changed Dynamics in the Co-produced Care and Support to People Living with Dementia within Healthcare Services: An Ethnographic Study

Egilstrøð, B. Vardinghus-Nielsen, H. Henriksen, L.S., Frederiksen M.S., Petersen, K.S. The Social Process and Changed Dynamics in the Co-produced Care and Support to People Living with Dementia within Healthcare Services: An Ethnographic Study. Qualitative Health Research. 2025 (Revised and re-submittet)

Paper III: Problem Perspective and Problem-associated Solutions in Situated Co-Produced Family Caregiving: An Ethnographic Field Study

Egilstrøð, B, Petersen, K.S., Henriksen, L.S., Vardinghus-Nielsen, H. Problem Perspective and Problem-associated Solutions in Situated Co-Produced Family Caregiving: An Ethnographic Field Study. Medicine and Social Science. 2025 (Final draft before submission).

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CHAPTER 1. INTRODUCTION

To set the scene, I introduce the background for this PhD thesis. Hereafter, I elaborate on the main topics influencing home-based caregiving for home-dwelling people with dementia, introducing how the Scandinavian welfare reform and the Scandinavian caring research influences, the family caregivers' roles, and derived needs in home-based caregiving for home-dwelling people with dementia. This concerns the Scandinavian welfare reform and its implications for dementia care practice, involving family caregivers as the backbone of home-based dementia care and their derived needs for support. It also concerns the Scandinavian caring research, knowledge creation and influence on the caring practice within dementia, and family caregivers' perceived role. Ultimately, this leads to the PhD study's rationale and aim.

1.1. THE STUDY'S BACKGROUND

Dementia is recognised as a pressing global public health concern, with around 55 million people living with dementia worldwide, with nearly 10 million new cases every year – a number projected to increase to 75 million by 2030 (Dua et al., 2017; World Health Organisation, 2025). This progressive neurological condition places multifaceted demands on the caring system, often requiring a combination of professional and familial support to manage its complexities (J. Li & Song, 2019; McCabe et al., 2018). Around 65-75% of people with dementia are cared for at home by family members, involving family caregivers as a primary resource (Alzheimer Europe, 2018; Bell et al., 2019; Hoffman & Zucker, 2016; J. Li & Song, 2019; Tremont, 2011).

Family caregivers are the cornerstone of home-based dementia care, on average providing 13,8 hours of care per day (Venkatesh et al., 2024). Before institutional care, the family caregiving responsibility is massive, and supporting and caring for the people with dementia requires several logistics tasks (Egilstrod et al., 2018). Family caregivers experience taking over practical responsibilities at home, providing support, coordinating medical treatment, and coordinating and participating in community services (Brodaty & Donkin, 2009). Alongside these responsibilities, family caregivers undergo emotional changes, such as loss and loneliness (Egilstrod et al., 2018), and experience changes in family social relationships (La Fontaine & Oyebode, 2014).

When the Scandinavian welfare reform moves towards more community and home-based healthcare systems provided in the homes by family members, it often increases the involvement of family caregivers (Cottam, 2012; J. Li & Song, 2019). In Denmark, home-based services are provided as the primary service, performed by the family caregiver, where the municipality supports the family through home visits (National Knowledge Center for Dementia, 2023). In Scandinavian countries, with extensive welfare and public caring arrangements, the care and support is shared approximately between family care (45%), social care (40%), and medical care (15%) (Rostgaard et al., 2015).

Family caregiving is, therefore, provided in the encounter between healthcare professionals, family members, and friends, and becomes nested in a complex ecosystem of social relationships entangled in everyday life practices (Egilstrod et al., 2018; Egilstrød & Petersen, 2021; Johansen et al., 2024). Healthcare professionals mostly support to equip and guide family caregivers to manage everyday life with dementia to be able to continue the care and support at home as dementia progresses (Lethin et al., 2016).

Home-based caregiving for home-dwelling people with dementia is therefore provided by combining professional and family caregiving, which are most often referred to and defined as formal and informal caregiving, respectively. Separating this boundary has influenced knowledge creation and organisation based on a dichotomic relationship.

To better support family caregivers in providing home-based dementia care, there is a need to gain knowledge on family caregiving through encounters with healthcare professionals, family members, and friends. Co-production is applied as the overarching analytical concept to gain knowledge on complex social interaction in home-based caregiving to home-dwelling people with dementia. This concept challenges the distinction (or dichotomy), where the public sector provides services, forming citizens as passive receivers. This focus has dominated the public and healthcare sectors for the last decades. Co-production focuses on the active contribution of service producers and service users in service provision.

In the following, primary topics implicating home-based care within dementia are elaborated. The following elaborates on primary topics, encapsulating the organisation of dementia care services in Denmark, and its influences on caring practices.

1.2. THE SCANDINAVIAN WELFARE REFORM'S INFLUENCE ON THE CARING PRACTICE WITHIN DEMENTIA

The movement towards a more community- and home-based care system is argued to be cost-effective to prevent institutionalisation. However, another primary reason is the increased incidence of chronic illnesses, such as dementia, which medical interventions cannot cure (Cottam, 2012). This calls for care and support provided in the homes, where people with chronic illnesses, including dementia, can maintain life as normal as possible, including maintaining everyday routines and social life (Cottam, 2012; The Danish Ministry of Health, 2017). Organising healthcare to address this locally, in the homes, the workplace, and the community allows people with dementia to maintain their social life as citizens despite their chronic illness (Cottam, 2012; O'Connor et al., 2007). Dementia is a progressive neurological condition that changes physical, psychological, and social living conditions and influences the ability to maintain everyday life routines and participate and engage in social life, and the intensity, changes, and progression of dementia symptoms differ depending on the type of dementia (Alzheimer's Association, 2025). The symptoms of dementia are everyday related and include memory loss disturbing daily life, challenges in planning and solving problems, difficulties in completing familiar tasks, confusion with time and place, decreased or poor judgment, withdrawal from social activities, difficulties in following and joining conversations, and changes in the mood and personality (Alzheimer's Association, 2025). The first symptoms of dementia may be detected up to 18 years before the onset of dementia (Jia et al., 2024), and on average, people live with dementia for 4.5 years, varying between 2.3 and 8.3 years, after being diagnosed with dementia (Xie et al., 2008). Therefore, caring for a person with dementia often requires a long-term commitment from both dementia services and family caregivers.

Organising healthcare as close-to-home as in Denmark and other Scandinavian countries (Cottam, 2012; National Knowledge Center for Dementia, 2023) can potentially delay the symptoms, as it becomes possible to provide everyday related rehabilitation in the home of people in combination with medical treatment (Maki et al., 2018). Providing home-based care, therefore, underpins an approach that broadens the lens toward social citizenship within dementia, acknowledging that people with dementia live and interact in society in a complex ecosystem of social relations (Bartlett & O'Connor, 2007). This may help destigmatize living with disabilities such as dementia, empowering people with dementia as citizens with rights and a voice. It encourages society to allow them to define their own identities and ways of engaging with the world, ultimately influencing decisions about their lives, including care and support (Bartlett & O'Connor, 2007). However, it also involves a paradox, as it also involves massive challenges, especially towards the family caregiver, who is primarily involved in providing care and support (Caregiving & AARP Public Policy Institute, 2020; Dua et al., 2017). This will be elaborated in the following.

1.2.1. FAMILY CAREGIVERS: THE BACKBONE IN PROVIDING CARE AND SUPPORT – AND THE CHALLENGES INVOLVED

As dementia progresses, people with dementia struggle with self-care and managing everyday life, involving family caregivers as cornerstones to support managing and supporting everyday life (Alzheimer's Association, 2025; Clemmensen et al., 2019; Egilstrod et al., 2018; La Fontaine & Oyebode, 2014). This responsibility often becomes substantial, involving several logistics tasks and requiring family caregivers to compensate (Egilstrod et al., 2018; Vikström et al., 2008). They adopt the practical responsibilities at home, providing support, coordinating medical treatment, and participate and support in community services (Brodaty & Donkin, 2009), altogether, while undergoing emotional changes, such as loss and loneliness (Egilstrod et al., 2018), and experiencing changes in family social relationships (La Fontaine & Oyebode, 2014).

Family caregivers and the person with dementia often find alternative strategies to live as normal as possible. For couples, it involves maintaining and reconstructing marital relationships, developing practical and emotional management strategies, and seeking support (Egilstrod et al., 2018). Family caregivers focus on continuing to maintain their social life and continue to uphold everyday routines (Boylstein & Hayes, 2012; Egilstrod et al., 2018; Vikström et al., 2008), and in this way focusing on their couplehood and thereby distancing the illness as a strategy to live positively with dementia (Egilstrod et al., 2018; Hellström et al., 2007).

As dementia progresses, it becomes difficult for the family caregiver to continue the care and support (Clemmensen et al., 2020b). The caring responsibility and demands end up being a burden, which may lead to anxiety, stress and depression (Chiao et al., 2015). Therefore, they are often named 'the invisible second patient' (Brodaty & Donkin, 2009). Alongside, family caregivers also experience a need to involve others, including other family caregivers, friends etc., and professional and formal services to continue the care at home as the disease progresses (Issari & Tsaliki, 2017; Lethin et al., 2016; McCabe et al., 2018).

When family caregivers are highly involved in providing the home-based care and support, this derived need for support from others, however, is often unmet or mismatched. This will be elaborated on in the following section.

1.2.2. MISMATCH IN FAMILY CAREGIVERS' NEEDS AND SERVICE PROVIDED

In general, family caregivers experience a need for support to maintain their role as family caregivers. The family caregivers' need for support derives from an interactional relation between needs originating from the person with dementia and from being a family caregiver (Clemmensen et al., 2020b).

Overall, Clemmensen et al., (2020) identified four key themes of family caregivers' needs: 1) Support for providing care, 2) support in gaining knowledge of dementia, 3) support to the family caregiver as a person, and 4) support being a family caregiver.

To meet the families' needs, supportive initiatives are offered to accommodate the family caregivers' challenges in managing everyday life with dementia. In the research literature, supportive initiatives are referred to as interventions aimed at the caregivers' physical and mental health. There has been a predominant focus on educational programs, including developing coping and supporting strategies and providing self-management support (Dam et al., 2016; Gilhooly et al., 2016; Jensen et al., 2015; Laver et al., 2016; Selwood et al., 2007). However, family caregivers' respond differently to these supportive initiatives. The educational programs significantly reduce caregiver burden and depression (Jensen et al., 2015; Parker et al., 2008). Interventions focusing on developing coping strategies decrease depression, eventually followed by an increase in dysfunctional coping immediately after termination of the intervention (R. Li et al., 2013), While interventions focusing on social support show inconsistent effects (Dam et al., 2016).

The psychosocial interventions listed above are collections of systematic reviews using randomised controlled trials (RCT) as the most common method to investigate the caregivers' needs for support. A cause-effect relationship characterises RCT studies and is the most robust way to determine whether an association exists, aiming to generalise the relationship to other conditions and situations outside the experiment (Berg & Latin, 2008). However, the cause-effect relationships have been difficult to determine in interventions aimed at caregivers' psychosocial health. Others have ascribed the variation in the results to the heterogeneity in the caregivers' characteristics, living conditions, and personal health (Cox, 2013), as interventions with homogeneous caregiver experiences seem more effective (Thoits, 2019). However, from an everyday life perspective, focus on the family caregivers' support needs are explored as being more complex in their origin (Clemmensen et al., 2019, 2020b, 2020a; Egilstrod et al., 2018; Egilstrød & Petersen, 2021), because dementia is situated in everyday living, influencing the conditions of social life for family caregivers. I argue that only targeting supportive initiatives through education and coping strategies reduces the complexity of being family caregiver and meeting the needs derived. When dementia differs in intensity and progression, dementia becomes unpredictable. This leads to continuous changes in needs and uncertainty in managing dementia, and families are different as individuals, and therefore, have different needs (Clemmensen et al., 2019, 2020b; Roberts, 2018).

Previous analysis of how spouses experienced everyday life changes, which is based on a theoretical standpoint of how people manage disruption in everyday life, outlined by Professor Birthe Bech-Jørgensen (Bech-Jørgensen, 1995), showed how family caregivers' life was unpredictable and constantly changing (Egilstrød & Petersen, 2021). The changes often initiated well before receiving the dementia diagnose, and the changes were often unnoticed, where spouses adapted without being fully aware of the changes (Egilstrød & Petersen, 2021). Thus, family caregivers often experienced the changes retrospectively when changes were accumulated (Egilstrød & Petersen, 2021). Family caregivers became aware of the changes and needed to find new strategies to restore the everyday life routines, e.g. to adjust working duties or participating in social life (Bech-Jørgensen, 1995; Egilstrød & Petersen, 2021). As dementia continues to progress, it became difficult to adjust everyday life routines, and the everyday life needed to be restructured, where the family caregivers need to find alternatives, such as seeking support from the outside (Egilstrød & Petersen, 2021). As outlined by Bech-Jørgensen, new ways of managing everyday life often arise in the boundary between familiar routines and chaos. In a dementia progression, this boundary is constantly shifting, with an ongoing interplay between these three states throughout the progression of dementia (Bech-Jørgensen, 1995; Egilstrød & Petersen, 2021). These findings indicate the difficulty for family caregivers to seek timely support and to respond to their own needs, as there is a delayed awareness of their needs. Moreover, family caregivers often oppress their own needs, because their primary focus is on the person with dementia

(Clemmensen et al., 2020a). Clemmensen et al., (2020) also highlight how the need for supportive encounters with healthcare professionals, family, and friends become pivotal. This involves feeling understood by family and friends, and taking an interest in caregiving, which includes involving family and friends in shared decision-making (Afram et al., 2015; Barca et al., 2014; Clemmensen et al., 2020b; Lord et al., 2016). However, family caregivers describe a fear of burden and involving others (Dam et al., 2016).

These aspects indicate how it becomes difficult for family caregivers to seek support, both in regard to being reflective about own needs, but also in their fear of reaching out despite their wish being supported. This could explain why it becomes difficult to initiate and seek support. Another need for support in the encounter with healthcare services is flexible respite services. Family caregivers experience how these services are not appropriate to their situation (Clemmensen et al., 2020b; Millenaar et al., 2016). Additionally, supportive encounters towards enhancing the collaboration involving family caregivers was important, described as frequent communication and involvement in care and treatment plans (Afram et al., 2015; Clemmensen et al., 2020b; De Jong & Boersma, 2009; Jennings et al., 2015; Moyle et al., 2016; Muders et al., 2013). Furthermore, healthcare professionals often underestimate the severity of caring for the person with dementia, and therefore, family caregivers often lack emotional support, which impacts the provision of timely support (Moermans et al., 2022).

In general, supportive encounters with healthcare professionals and family caregivers are often unmet and manifested by a lack of self-care and referrals to appropriate community resources (Black et al., 2013; Pinto et al., 2016; Queluz et al., 2020). This can be reflected in the complex origins of the family caregivers' needs and how it can be challenging to fully respond to them.

Family caregivers often experience being left alone, and as dementia progresses, they need to rearrange their social life and everyday life routines, seeking ways to uphold their everyday life and marital relationship (Egilstrød & Petersen, 2021). Initially, family caregivers try to maintain the social life and everyday routines. However, as dementia progresses, family caregivers become increasingly isolated in their homes, finding ways to organise life, mainly at home, isolated from the outside (Egilstrød & Petersen, 2021).

Even if the movement towards home-based care within dementia practice is meant to support people with dementia and their families to live as normal as possible, despite the dementia, it can lead to unintended consequences.

Unintended consequences are, by Robert K. Merton, described as negative outcomes arising from an action or decision with initial good intentions (Merton, 1936). The involvement of family caregivers as the backbone of healthcare, and the derived and unmet needs of family caregivers may be seen as an unintended consequence led by organising healthcare as home-based care. If home-based care should fulfil the potential to create better lives for people living with dementia and their families, there is a need to match the family caregivers' needs for support and provide services.

Two Canadian studies have shown that the unintended consequences of home-based care arise when the allocation of resources are inadequate (St-Amant et al., 2012; Ward-Griffin et al., 2012). There is a perception that formal care resources are limited, while family caregiving is seen as abundant. This dynamic often leads to families heavily being relied upon for care, with formal services used only as a last resort (Ward-Griffin et al., 2012). As the demand for dementia care increases, the available resources are shrinking, creating a mismatch between the needs for care and the received support (Ward-Griffin et al., 2012). Scarcity of formal care resources, therefore, often places an overwhelming burden on families, who are expected to provide the majority of care (Ward-Griffin et al., 2012). This adds complexity in supporting encounters, as it involves both the family's needs and the limitations of the services, due to scarcity in resources.

Cottam argues that there is a general mismatch between the needs and the services provided when moving healthcare closer to people's homes (Cottam, 2012), which leads to unintended consequences in healthcare services (Merton, 1936). Another argument could pertain to the ways in which caregiving has been studied for the past decades, forming the knowledge creation, and influencing the caring practice within dementia, neglecting basic needs for the family caregiver. In the following, I will elaborate on how Scandinavian caring practice has been studied and how this has informed the knowledge creation and organisation of healthcare.

1.3. THE SCANDINAVIAN CARING RESEARCH, KNOWLEGDE CREATION AND INFLUENCE ON THE CARING PRACTICE WITHIN DEMENTIA

Scandinavian caring research has predominantly focused on professionalised and institutionalised caring practices in the welfare state (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Timm et al., 2020), dominating the knowledge creation of caring practice and the organisation of healthcare services. Additionally, professional caregiving and family caregiving have been studied as separate units (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; J. Li & Song, 2019). While caring theories have been developed to guide professional caring practices as a moral and practical endeavour – primary focusing on the patient-professional relationship – (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Førland et al., 2018; Timm et al., 2020), there remains a lack of clear guidance for family caregivers in navigating the complex normative landscape and associated caring practices Instead, research on family caregiving has focused on the invisible care performed silently, focusing on caring demands, caring responsibility, and the healthcare consequences of contributing to provide care and support to people with illnesses in general (Bell et al., 2019; Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Procter et al., 2018).

The formation of professional caregiving has resulted in the implementation of patient-centred care as an ethical standard in Danish Dementia Services, and thereby at the municipalities (Terkelsen et al., 2020) as well as globally (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Tuijt et al., 2021). This model advocates for a Person-Centred Care (PCC) philosophy that acknowledges and values individuals with dementia as unique human beings with the right to self-determination, irrespective of their condition. It emphasises to focus on personhood rather than the illness, organising care and support around the individual's perspective, life history, habits, and psychosocial needs (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Kitwood, 2019). In an interventional setting, PCC have had positive impact in clinical care practice when provided by healthcare professionals. During the intervention period, dementia-related and depression symptoms reduced and, generally, the quality of life for the person with dementia improved (Kim & Park, 2017). The intervention was effective for people with mild and moderate dementia symptoms, while being less effective among severe dementia cases (Kim & Park, 2017). Short-term interventions are also shown to be more effective than long-term interventions, and the short-term interventions to a larger degree maintain the effects of PCC education to promote learning and skills towards providing PCC (Kim & Park, 2017). In home-based settings, healthcare professionals struggle to balance the citizens' needs and organisational policies, which challenges the ability to provide PCC and support the citizens' autonomy (Olsen et al., 2019). Therefore, supportive structural conditions are become crucial to enhance PCC in home settings (Olsen et al., 2019), and enhancement of the professional's qualification to provide PCC becomes crucial (Aasgaard et al., 2014).

Altogether, this indicates that PCC becomes important for promoting personhood for people with dementia. However, challenges arise when practising PCC in real-world settings where other logics are at play, such as organisational policies, resource constraints, and different educational support, as illustrated by Kim & Park, (2017; Kitwood, (2019); Olsen et al., (2019). Additionally, the PCC focuses on the patient; in this case, the person with dementia is limited to involve a dyadic relationship between professionals and the patient (Kitwood, 2019). Therefore, PCC does not fully account for the complexity of the care provided in practice in the encounters between healthcare professionals and family caregivers, where home-based care is mostly provided by family caregivers, and in reality, often multiple family caregivers. Home-based dementia care must, therefore, be expected to operate within practice, shaped by diverse origins regarding the caregiving task. In the following section, I will elaborate on how family caregivers perceive and relate to their role to deepen the understanding of the origin of family caregiving practice.

To understand the family caregiver role, I will also elaborate on the family caregiver identity to explore family caregiver role engagement. Family caregiving identity has been studied as a proxy for exploring family caregivers' perceived roles.

1.3.1. FAMILY CAREGIVERS’ PERCEIVED ROLES

From a general caregiving perspective, being a family caregiver emerges from different kinds of relational connectedness to the person living with an illness, and being a family caregiver, therefore, covers more than taking on caring labour (Johansen et al., 2024). When family caregivers describe their family caregiver role, it reflect their previous relation to the person being ill (e.g. a spouse, child, friend, neighbour) (Andersen et al., 2023; Johansen et al., 2024; Madsen & Birkelund, 2013), and the term family caregiver becomes particularly relevant in the encounter with the healthcare system and the patient’s organisations (Johansen et al., 2024). The motivation for providing family caregiving constitutes a wide range of combined feelings: a sense of love and/or reciprocity, duty, guilt, and social pressure (Brodaty & Donkin, 2009). Thus, being a family caregiver captures complexities, and the previous relation to the person with illness seems to impact how they are cared for. Before the onset of dementia, families share a ‘dominant family story’ (Roach et al., 2014), and the family caregiver prolongs the ‘dominant family story’ by combining the family role and the caregiving role into a family caregiver (Zhu et al., 2024). This implies how families cope and adjust to transitioning their experiences to dementia (Roach et al., 2014). Therefore, family structure, roles, and how families function may influence how family caregivers engage in family caregiving (Roach et al., 2014).

From a spousal viewpoint, the family caregivers try to sustain couplehood and reconstruct marital closeness as a way to hold on to their ‘dominant family story’ (Bergman et al., 2016; Boylstein & Hayes, 2012; Egilstrod et al., 2018; Hellström et al., 2007; Lin et al., 2012). This becomes a strategy to distance the illness and their role as family caregivers, and to practice their previous role as spouses to live positively with dementia (Egilstrod et al., 2018; Hellström et al., 2007). (Boylstein & Hayes, 2012) found how re-constructing and maintaining the dominant storyline through marital closeness had an impact on the perceived role of family caregivers and helped frame their role. When family caregivers grew apart in their marital closeness, it became more difficult to be a family caregiver (Boylstein & Hayes, 2012).

Moreover, family caregivers describe an experience of a changed role when a family member is affected by dementia. Spouses experience their roles and identity to change from being a spouse to become a family caregiver (Boylstein & Hayes, 2012; Madsen & Birkelund, 2013). While spouses experience loss of marital relation, children experience losing the parental-child relation and describe a swopping role, where they are parenting for their ill parent (Madsen & Birkelund, 2013). Adult children experience the loss of their parent in person, but also a loss in parental role figure (Barca et al., 2014). Children may also feel neglected and overseen in their role as family caregivers to their families and the healthcare professionals providing healthcare services (Barca et al., 2014). Children, as well as their parents, experience a significant burden and stress, and experience that dementia affects most aspects of their lives. However, children’s experiences have a broader variation due to the family connection (Barca et al., 2014). Children also experience that their parent's dementia affects not only their family roles and relationships but also their roles and relations with others outside the family (Barca et al., 2014). Some children experienced taking over the family caregiving role, as their healthy parents were reduced from their role of family caregiver, initiating a feeling that their parents acted irresponsibly when they were supposed to act responsibly (Barca et al., 2014).

Family caregivers often wish to continue the family caregiving (Egilstrod et al., 2018; McCabe et al., 2018), describing their role as voluntary and bound at the same time, because family caregivers find it meaningful to support and care for their near relation. Opposite, there are also part of the caring that family caregivers do foresee or innermost joyfully do. Nevertheless, they experience a moral commitment to the person with the illness (Johansen et al., 2024). However, family caregivers seldom experience being involved and acknowledged in their collaboration with healthcare services (Mouchaers et al., 2023). Particularly, children feel overseen by their family and healthcare professionals in spite of their crucial role in providing family caregiving, which makes the care provision more difficult, as they miss valuable healthcare information (Barca et al., 2014).

Providing home-based family caregiving to home-dwelling people with dementia is complex because its complexity both relates to the progression of dementia and its intensity, which, therefore, affects everyday life differently. Being the primary family caregiver leads to different needs at different times due to the progression of dementia. Family caregivers manage and perceive their role quite differently, and the urge to provide family caregiving emerges from a combined feeling, including a sense of love and/or reciprocity, duty, guilt, and social pressure. When family caregivers are primary contributors in providing home-based dementia care, and most often in the encounter with others, there is a need to gain knowledge on family caregiving in the encounter with both healthcare professionals and the encounter with other family members and friends to better support family caregivers in providing home-based dementia care.

1.4. ENCOUNTERS BETWEEN FAMILY CAREGIVERS AND HEALTHCARE PROFESSIONALS

Former studies have explored direct encounters between family caregivers, healthcare professionals, and people with dementia, highlighting how professionals develop strategies for supportive encounters (Bosco et al., 2020; Reinhoudt-den Boer et al., 2022).

Bosco et al. (2020) previously focused on enablers and barriers for co-producing care and support in decision-making throughout dementia, focusing on a professional perspective, revealing how healthcare professionals develop strategies for fruitful co-production in the encounter between healthcare professionals, family caregivers, and people with dementia (Egilstrøð, Vardinghus-Nielsen, et al., 2025). Healthcare professionals facilitate supportive encounters by building trusting relationships with both the person with dementia and the family caregiver, and see this as a key factor focusing on the involvement, especially of the person with dementia (Bosco et al., 2020). Creating trusting relationships, however, can take time, depending on the families' openness, and the person with dementia and family caregivers' awareness of the dementia condition. However, Bosco et al., (2020) underscores how acknowledging the family caregiver in their role was important, and attend to their needs, as this also could benefit the person with dementia. In situations where it was difficult to involve the person with dementia, the healthcare professionals facilitated a one-to-one dialogue with the person with dementia (Bosco et al., 2020).

Reinhoudt-den Boer et al. (2022) explored which strategies were used, when conflicts arise in the encounter between the healthcare professional, person with dementia, and family caregiver, especially in later co-production processes in decision-making related to homecare. This conflict often occurs, because family caregivers experience to navigate in a range of complex family, ethical, and legal dilemmas when making decisions about care. Reinhoudt-den Boer et al. (2022) identify two main overarching strategies: collaborative end-empowering strategies, where the healthcare professionals act as mediators and provide information to support informed decision-making for the person with dementia and the family caregivers. When these strategies are challenging to use, healthcare professionals use detective and protective strategies, where healthcare professionals put pressure on the family (e.g. for choosing home-care solutions), chooses side in disagreements between the family caregiver or the person with dementia, or overrule by making decisions (Reinhoudt-den Boer et al., 2022).

Healthcare professionals seem to struggle to find this balance, and to balance the needs of family caregivers and the person with dementia (Quinn et al., 2013). Furthermore, Tuijt et al., (2021) systematically reviewed the function of the 'dementia triad', covering the encounters between family caregiver, the person with dementia, and a healthcare professional, and highlighted how healthcare professionals excluded the person with dementia from consultation when the progression of dementia got too advanced.

Strategies used by family caregivers in the encounter with healthcare professionals, and with other family caregivers and friends, seem to be unexplored, and a potential exists in focusing on family caregivers' strategies to better support family caregivers' needs.

1.5. RATIONALE AND AIM OF THE STUDY

Professionals and family caregivers, who are entangled in a complex system of social relationships and interactions, most often provide home-based dementia care. However, professional caregiving and family caregiving have been investigated as separate units and is referred to and defined as formal and informal caregiving, respectively. Formally separating the boundary has influenced knowledge creation and practice organisation based on a dichotomic relationship. To better support family caregivers in providing home-based dementia care, there is a need to gain knowledge on family caregiving through encounters with healthcare professionals and other family members and friends. Co-production is applied as the overarching analytical concept to gain knowledge on complex social interactions in home-based caregiving to home-dwelling people with dementia. This concept challenges the distinction (or dichotomy) where the public sector provides services, forming citizens as passive receivers. This focus has dominated the public and healthcare sectors for the past decades. Co-production focuses on the active contribution of service producers and service users in service provision.

This PhD study aims to gain in-depth knowledge of family caregiving through encounters with healthcare professionals, family members, and friends. It is investigated through the situated co-produced family caregiving, acknowledging family caregivers as active contributors to home-based care for home-dwelling people with dementia. This knowledge can provide insights into family needs for support.

The overall aim is divided into three sub-objectives addressed in the three papers:

- To identify and chart the application of co-production within research in community health services among older adult citizens, including people with dementia and their relatives (Paper I).
- To explore how co-produced care and support for persons living with dementia is negotiated over time in a triadic relationship between the family caregiver, healthcare professional, and the person living with dementia (Paper II).
- To explore situated co-produced family caregiving by analysing the problem perspective and problem-associated solutions approaching situated co-produced family caregiving (Paper III).

CHAPTER 2. CO-PRODUCTION

This chapter presents and delves into the concept of co-production, its development, and its implications for practice. To capture the essence of the circuitous development, a historical wrap-up of the concept's development is provided. This aims to sharpen the gaze on the concept's ambiguity, as the ambiguity has directly implicated research and applied practice. The chapter is completed by the definition of co-production used in the present PhD study.

Co-production was introduced and conceptualized in the late 1970's by Elinor Ostrom, recognising that the production of public services was difficult without the active participation of those supposedly receiving the service (Ostrom, 1996). Thus, Ostrom and colleagues highlighted the lacked focus on *citizens' participation, which for a long time had been considered undesirable or unimportant, where citizens were only seen as passive users of public health* (Brandsen et al., 2020). Co-production was, therefore, introduced as an analytical concept *to analyse the relationship between service provider and service user contributing to a service provision* and was conceptualized as following:

> *"We developed the term co-production to describe the potential relationships that could exist between a "regular" producer (street-level police officers, schoolteachers, or health workers) and the "client" who wants to be transformed to the service into safer, better education, or healthier persons"* (Ostrom, 1996).

During the 1990's, the academic interest of co-production declined, primarily conquered by the ascendancy of the New Public Management, which became the dominant approach in public administrations before it was replaced by New Public Governance (Brudney, 2021; Pestoff, 2018a). New frames for studying co-production were developed, and co-creation was introduced (Brudney, 2021; Pestoff, 2018a; Voorberg et al., 2015). Co-creation and co-production were inscribed in the public administration regimes as a means to improve governmental performance, moving toward a more inclusive democratic approach to govern the welfare (Brudney, 2021; Pestoff, 2018a), consequently embraced as a new reform strategy for the public sector to manage the complex economic, political, and social challenges within social and welfare services (Pestoff, 2018b).

The Scandinavian welfare reform moved healthcare services closer to the patients' homes, as home-based care is an example of providing a more inclusive approach to government, where people with chronic illness can continue to participate as citizens in the society (Cottam, 2012). Co-creation and co-production refer to the active involvement of end-users in various stages of the production process, and within public services, the citizens represent the end-users (Brandsen & Honingh, 2018). Co-creation and co-production represent approaches to provide citizens with a voice by involving them in the design of services and contribute to service production (Brandsen & Honingh, 2018).

In its overarching sense, co-creation and co-production share the same definition:

> *"An active involvement of citizens… in a joint effort of citizens and public sectors professionals in the initiation, planning, design and implementation of public services… A collaboration between professionalised service providers in public agencies and citizens"*
> *(Brandsen & Honingh, 2018, pp. 3–11).*

Within academia, the concepts have been claimed to be poorly formulated, ill-defined, and muddled (Brandsen & Honingh, 2018; Lopes & Alves, 2020; Masterson et al., 2022; Needham, 2007; Pestoff, 2019; Voorberg et al., 2015), because the conversion of co-production and the introduction of co-creation into a commercial government strategy has created overlapping and conflicting definitions, interests, and logic, causing ambiguities in the field due to different scholars (Brandsen & Honingh, 2018; Lopes & Alves, 2020; Masterson et al., 2022; Needham, 2007; Pestoff, 2019; Voorberg et al., 2015). To create a better understanding of the concept and its applicability in empirical research, definitions, models, and conceptualisations of the concept have been developed to standardise an overarching definition as a means to manage this ambiguity (Brandsen & Honingh, 2018; Lopes & Alves, 2020; Masterson et al., 2022; Needham, 2007; Pestoff, 2019; Voorberg et al., 2015). There is a general academic consensus to break down co-creation and co-production into two interacting concepts: co-creation underpins active involvement in the planning and design phase of services, and co-production underpins active involvement in the service provision (Brandsen & Honingh, 2018). Hofstad and colleagues distinguish between co-creation and co-production in a fundamental understanding (Hofstad et al., 2023). Co-creation has a broader focus on solving complex problems and challenges through a joint effort, where it has a network-based relationship involving relevant actors from the state, market, and civil society, and a continuous focus on the development of innovative service public solutions (Hofstad et al., 2023). Co-production, on the other hand, has a narrow focus on service production, working in dyadic relations between the service producers and individual service users. The service solutions are pre-determined based on active contributions from producers and users (Hofstad et al., 2023). Acknowledging the many ramifications of co-production within different scholars, also in contrast with Hofstad and colleagues' interpretation, this analytical standpoint is chosen as the present PhD study is situated in home-based dementia care settings, and the service solutions are pre-determined. Within the co-production literature, no consensus exists in studying co-produced care situated in practice rather than a standardised concept applied in practice (Loeffler & Bovaird, 2020). Loeffler & Bovaird, (2020) argue that co-production is situated and dynamic, because it involves continuous interactions and may involve different social relationships. As the aim of the present PhD study is to gain knowledge about family caregiving through encounters with healthcare professionals and other family members and friends when providing home-based dementia care, the definition of co-production used in the present PhD study is based on *user and community co-production,* and is defined as:

> *"The provision of services through regular, long-term relationships between professionalised service providers (in any sector) and service user or members of community, where all parties make substantial resource contribution"* (Bovaird, 2007, p. 84).

In this PhD study I extend the professional-user perspective by highlighting the key role of the family caregiver in the triadic relationship between the healthcare professionals and the person living with dementia.

CHAPTER 3. METHODOLOGY

In this chapter, I present the study's methodology to demonstrate how knowledge has been produced, which is reflected in the philosophy of science and the chosen methods, and how these implicate the data collection, the analysis and interpretation of data (Carter & Little, 2007; Maxwell, 2005).

> Producing scientific knowledge is a normative matter, as different scientific directions assert the nature of reality quite differently insight into the philosophy of science, theoretical orientation and methodology is therefore valuable, as it demonstrates how knowledge is produced and what kind of knowledge is produced (K. B. Pedersen, 2012)

The research process is structured around Stacy M. Carter (Carter) and Miles Little's (Little) relationships model for qualitative research processes illustrated in figure 1 (Carter & Little, 2007). The model support to reach coherence and transparency in the research process and, thereby, the validity of the results which are important quality criteria (Carter & Little, 2007; Justesen & Mik-Meyer, 2012).

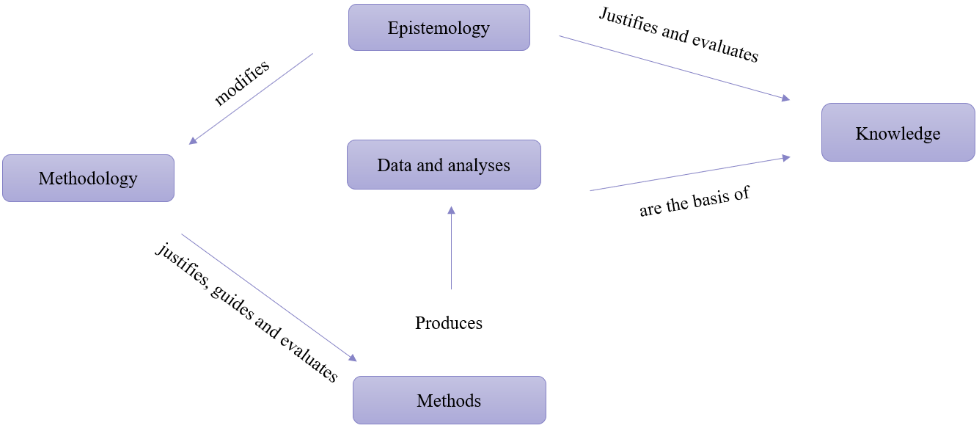

Figure 1: Carter and Little's relationships model for qualitative research processes

3.1. THE PHILOSOPHY OF SCIENCE

Given the overall objective, to gain in-depth knowledge on situated co-produced family caregiving, I draw on a social constructivist approach. This approach is suitable as the scientific contribution of the social constructivist perspective enriches the understanding of co-production as a social phenomenon. Social constructivism offers significant contributions to understanding co-production as a dynamic social phenomenon shaped by interactions and contextual practices. Through a social constructivist lens, co-production is deeply embedded in social encounters and evolving relationships between healthcare professionals and family caregivers (Burr, 2015).

One of the core assumptions within social constructivism is that knowledge and meaning are not fixed entities but are continuously created and reshaped through social interaction (K. B. Pedersen, 2012). Knowledge becomes culturally and contextually situated, and rejects the idea of one objective truth, in preference for multiple constructed perspectives, shaped in social interactions (K. B. Pedersen, 2012). The ontology in social constructivism is fluid; therefore, the knowledge created within this PhD project about situated co-produced family caregiving can appear different in another home-based dementia care context. The truth can thus be said to be perspectival, which means that the knowledge contributed by the thesis cannot be regarded as truth but rather knowledge that can contribute to new strategies for addressing issues in practice. The social constructivist perspective holds the potential to explore situated co-produced family caregiving and encounters with others and contribute to policy with reflections when family caregiver contributes into home-based dementia care. According to the epistemological assumption, knowledge is constructed and created together with the participants throughout the research process; knowledge is therefore not discovered through research (K. B. Pedersen, 2012).

3.2. EXPLORATIVE ETHNOGRAPHIC RESEARCH DESIGN

This PhD study applies an explorative ethnographic study design which allows an in-depth knowledge of situated co-produced family caregiving by engaging personally and intellectually with practice and thereby capturing the 'doing' of situated co-produced family caregiving. (Atkinson, 2015). The ethnographic explorative fieldwork also allows a flexible, interactive, engaged process of conducting research closely with stakeholders, contributing with knowledge deeply rooted in practice (Atkinson, 2015). Therefore, the explorative ethnographic fieldwork is in line with the overarching intention to contribute with practice-oriented knowledge rooted in challenges faced within practice and research.

The present explorative ethnographic fieldwork is inspired by James P. Spradley’s (Spradley, 1980) methodological field thinking to adhere to the study’s aim, and the study is designed in two iterative processual phases:

Phase 1) The grand tour, consisting of an explorative phase entering the field in openness and aimed to discuss challenges faced in practice with situated co-produced family caregiving, and to locate *social situation*, where situated co-produced family caregiving takes place in the encounter between family caregiver and other service providers, both professional and voluntary, and families and friends. The grand tour, therefore, contributed to focus the PhD study's rationale and aim and to design Phase 2.

Phase 2) The mini tour, consisted of more focus and narrowed fieldwork, where social situation, were selected, were family caregivers encountered with, family caregiver and other service providers, both professional and voluntary, and families and friends based on knowledge from the fieldwork in Phase 1.

The PhD study's design is illustrated in Figure 2. The methods applied, and processes related to Phase 1 and 2 will be elaborated in the following.

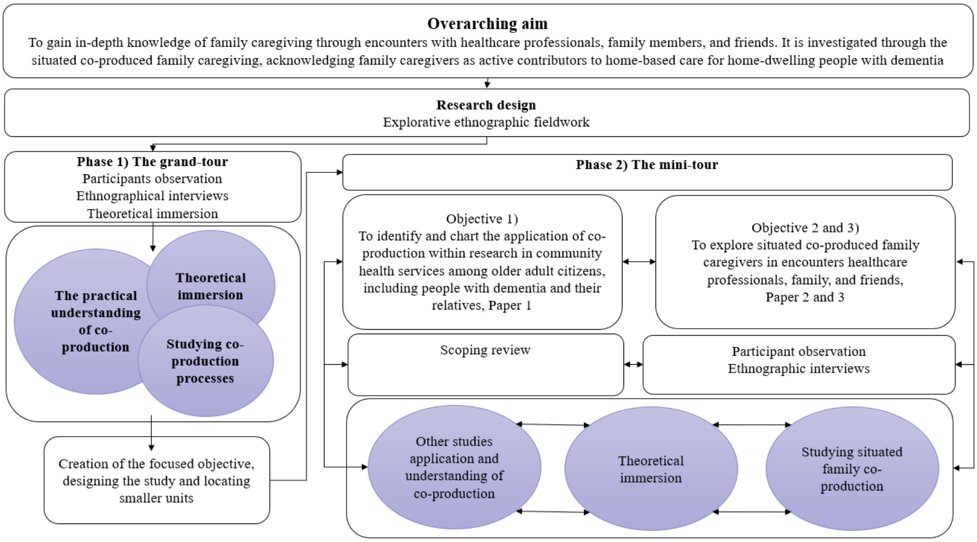

Figure 2: The PhD study's design

3.3. PARTICIPANT OBSERVATION AND ETHNOGRAPHIC INTERVIEWS

To gain in-depth knowledge on situated co-produced family caregiving, and service-provision context, I conducted participant observation. Participant observation allows to entering the world of others, engaging with them in their everyday life and interacting, listening, learning and imitating, and thereby participating in 'social situations' (Atkinson, 2015; Spradley, 1980).

‘Social situations’ are defined by three elements: Place, actor, and activity, as outlined by Spradley.

"In doing participant observation you will locate yourself in some place; you will watch actors of one sort or another and become involved with them; you will observe and participate in activities" (Spradley s. 39-40).

Participant observation is also a unique method as the empirical data emerges in the interaction between the researcher and the participants (Spradley, 1980).

When doing participant observation, I was inspired by Spradley’s ethnographical interviews. Spradley define informal ethnographic interviews as the conversation takin place during the fieldwork. (Spradley, 1980), which is an integrated part of doing participant observation, as we engage with others by talking to them (Tjørnhøj-Thomsen & Whyte, 2012).

3.4. CONDUCTING PARTICIPANT OBSERVATION AND ETHNOGRAPHIC INTERVIEWS IN THE DESIGN OF THE STUDY

Inspired by Spradley’s methodological field thinking the fieldwork was initiated by doing participant observation and conducting ethnographic interviews.

I started out doing fieldwork in accordance with the aim of Phase 1) to discuss challenges faced in practice with situated co-produced family caregiving, and to locate *social situation*, where situated co-produced family caregiving takes place in the encounter between family caregiver and other service providers, both professional and voluntary, and families and friends.

Through sperate dialouge meetings with representatives from the Knowledge Center for Dementia, Dane Age, Alzheimer Association and previous family caregivers, I discussed my project ideas and theoretical insights on the challenges faced by family caregivers as presented in the literature. Additionally, I introduced the idea of studying family caregivers' encounters with professionals, volunteers, family, and friends. In this way, I gained insight into practice perceptions of situated co-produced family caregiving and identified social situations for situated co-produced family caregiving. The insights from ethnographic interviews and participant observation were written down as fieldnotes and social situation were mapped.

Cumulatively, after meeting with representatives from the municipality and the voluntary organization and gaining an overview of the challenges faced by healthcare professionals, the voluntary organization, and family caregivers, two main challenges were highlighted: The complexity to support family caregivers sufficiently, and the challenges related to co-production. The challenge about supporting the family caregivers adequately was multi-pronged involving complex organisational challenges, complexities in family-service encounters, and differences in family's capabilities to provide home-based care to home-dwelling people with dementia. The other main challenge was previous experienced challenges working with co-creation and co-production processes in practice across municipal dementia services and voluntary organisations. I, therefore, immersed in these two challenges.

To map the situated co-produced family caregiving*,* social situations were located. Potential *actors* were identified, and all *actors*, who contributed into the home-based dementia care supporting people with dementia were identified.

I attended for a week in an activity centre for people with dementia and their family caregivers. In the municipalities services I participated in a mutual training session for couples, where one of them had dementia and in a café, where round table talk and cultural experiences where combined. In the voluntary services offers I participated in 'singing along', which is a dementia friendly come together for all interested, and in a self-standing service 'the optimists', affiliated at the Alzheimer association central organisation 'social dining and sing along'. The dementia services, both voluntary and municipal, were affected by the lockdown of COVID-19, and the care and support services were sparse.

The encounters between ‘regular’ public service users, voluntary organisation and family caregivers were mapped, to locate those who were involved in providing care and support to people with dementia and their family caregivers, illustrated in Figure 3.

In the Figure the potential existing encounters between the municipality, the voluntary organisations and the family are mapped. The Figure is divided into two main levels: the wite-coloured administrative level in the outer circle, and the purple-coloured in the inner circle. The administration level illustrates administrative employees having a peripheral role in service provision of care and support to people with dementia. While the floor level illustrates employees and voluntaries having the direct contact with the people with dementia and their family caregivers. The families are placed close to the centre of the floor level. The arrows illustrate the relationships between the municipality, voluntary organisations, and the family with dementia.

During the fieldwork, it became clear, that the administrative level and the floor level worked differently, when it came to co-creation and co-production processes.

The administrative level sought to engage and establish as many partnerships as possible to jointly address and solve societal challenges and continuously aimed to participate in co-creation processes. Conversely, the employees at the floor level, tried to delimit their partnerships to manage the relational complexities. Based on these insights a distinction was made between the administrative level and the floor level, identifying the administrative level working with co-creation, and the floor level working with co-production.

According to Hofstad and colleagues, co-creation has a broader focus on addressing and solving societal challenges. Therefore, involving as many relevant and affected actors as possible contributes to a better brainstorm and identification on the challenges, and more solutions can potentially come into play (Hofstad et al., 2023). On the other hand, co-production has a narrower focus on service delivery, where services are pre-defined, working in dyadic relations between the service producers and individual service user (Hofstad et al., 2023). In co-production, there is a need to delimit the relational complexity in being able to manage the relational complexity in practice.

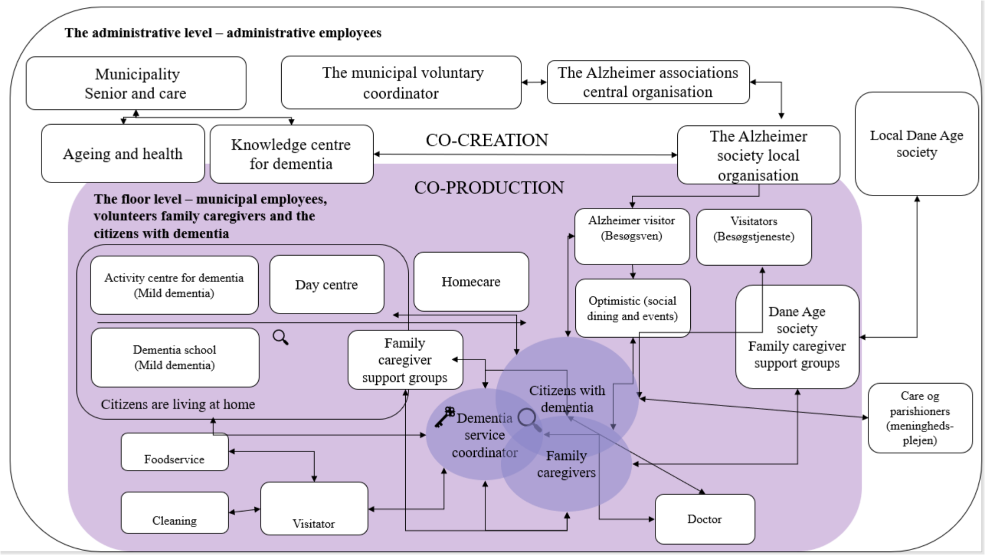

Figure 3: The fieldwork's delimitation and the mapping of social situations.

Based on the insight discussing the two main challenges and mapping social situation, and identifying co-creation and co-production processes, phase two was designed, and the PhD study's rational and aim was narrowed. The project was delimited to focus on the floor level, investigating co-production on the floor, in direct contact with people with dementia and their primary caregivers.

In phase 2) the fieldwork was intensified and narrowed in an iterative process continuously engaging in the field through participant observation. As illustrated in figure 3 with the four purple circles, the aim of the study was refined as follows:

To gain in-depth knowledge of family caregiving through encounters with healthcare professionals, family members, and friends in home-based dementia care. It is investigated through the situated co-produced family caregiving, acknowledging family caregivers as active contributors to home-based care for home-dwelling people with dementia. This knowledge can provide insights into family needs for support.

The overall aim is divided into three sub-objectives addressed in the three papers:

- To identify and chart the application of co-production within research in community health services among older adult citizens, including people with dementia and their relatives (Paper I)
- To explore how co-produced care and support for persons living with dementia is negotiated over time in a triadic relationship between the family caregiver, healthcare professional, and the person living with dementia (Paper II)
- To explore situated co-produced family caregiving by analysing the problem perspective and problem-associated solutions approaching situated co-produced family caregiving (Paper III).

As outlined by Atkinson, when working ethnographically the research insights are continuously developed in an interplay between collecting data and analysing data (Atkinson, 2015).

> "(…) In practice, we make preliminary assessment of a given field and spend an initial period of time there. On the basis of those initial observations, we derive some preliminary working ideas. From those preliminary ideas we start to identify more cases and possibilities in the developing data, and out data collection is guided by those developing ideas. And so on. The process is rarely, if ever, perfect complete, but we go on developing, extending and refining our ideas (…)" (Atkinson. P. 35).

To intensify the ethnographic-analytical-theoretical dialogue, I was inspired by Short-Term Theoretically Informed Ethnography (Pink & Morgan, 2013). This allows to an interactive process between immerse theoretically and data collected through participant observation.

3.5. INVOLVEMENT WORKSHOP

Midway during the fieldwork, a panel group was involved. The panel group consisted of five formal caregivers, one representative from the public dementia sector, and one representative from the voluntary. They were involved as consultants to discuss the importance of public involvement in developing and producing services, and to discuss challenges faced in situated co-produced family caregiving. This aimed to integrate insights from the literature with lay perspectives and practical experiences, enhancing academic rigor and narrow the location of social situations (Grotz et al., 2020; Levac et al., 2010).

3.6. CONSTRUCTIVIST-INTERACTIONIST PERSPECTIVE ON SITUATED CO-PRODUCED FAMILY CAREGIVING

A constructivist-interactionist perspective is applied to guide the data collection and analysis processes (Järvinen & Mik-Meyer, 2005). The constructivist-interactionist perspective serves a lens through which the empirical material is examined and determines which aspects of the empirical data are highlighted, and swaying how the empirical material is generated, processed, and analysed (Järvinen & Mik-Meyer, 2005). By adopting a constructivist-interactionist perspective, attention shifts away from individuals and instead focuses on human interactions and how the context influences these interactions (Järvinen & Mik-Meyer, 2005). The constructivist-interactionist perspective is added to focus more directly on the immediate face-to-face interactions and study the micro-level personal interactions and their influences on everyday aspect of situated co-produced family caregiving (Järvinen & Mik-Meyer, 2005). By combining the social constructivism and constructivist-interactionist perspective, it is able to focus both on how behaviour is created through a broader social structures and through direct interactions with others (Järvinen & Mik-Meyer, 2005; K. B. Pedersen, 2012).

3.7. CONDUCTING PARTICIPANT OBSERVATION IN DIALOUGE MEETINGS BETWEEN THE PERSON WITH DEMENTIA, FAMILY CAREGIVER AND THE DEMENTIA SERVICE COORDINATOR

To explore situated co-produced family caregiving, and to explore how co-produced care and support for persons living with dementia is negotiated over time in a triadic relationship between the family caregiver, healthcare professionals, and the person with dementia, participant observation was used during dialogue meetings between the family caregiver, the person with dementia and the DSC (Egilstrøð, Vardinghus-Nielsen, et al., 2025). Furthermore, ethnographic interviews involving informal conversations were employed during participant observation (Egilstrøð, Vardinghus-Nielsen, et al., 2025). I engaged with the DSC, the people with dementia, and their family caregivers during the dialogue meeting, and before and after the dialogue meeting, I engaged with the DSC (Egilstrøð, Vardinghus-Nielsen, et al., 2025). A typical participant observation began with a meeting at the DSCs' office, providing insights into their working routine before a visit. I engaged with the DSC, discussing the person with dementia and the family caregiver (Egilstrøð, Vardinghus-Nielsen, et al., 2025). Hereafter, I drove with the DSCs, and the dialogue continued until we entered the families' homes

(Egilstrøð, Vardinghus-Nielsen, et al., 2025). The family visits generally had a warm and cosy atmosphere, where the dialogue aimed to sense the need for day-to-day care and support (Egilstrøð, Vardinghus-Nielsen, et al., 2025). We always sat at the dining table, with everyone having their regular seat (Egilstrøð, Vardinghus-Nielsen, et al., 2025). I observed, engaged, and asked probing questions during the conversation, when it felt natural to enter the conversation (Egilstrøð, Vardinghus-Nielsen, et al., 2025). The observations especially focused on the content of the dialogue between the families and DSCs, how they talked and engaged in the dialogue, and how they negotiated everyday life needs (Egilstrøð, Vardinghus-Nielsen, et al., 2025). When the dialogue meetings finished, me and the DSCs returned to the office, allowing to ask into some observations. Field notes were written immediately after the observation (Egilstrøð, Vardinghus-Nielsen, et al., 2025). The participant observation was conducted from August 2022 to March 2023 and lasted for approximately 2 hours(Egilstrøð, Vardinghus-Nielsen, et al., 2025). Concurrently, semi-structured interviews, inspired by Spradley’s formal ethnographic interviews, were employed with family caregivers to explore situated co-produced family caregiving from November 2022 to April 2023 (Egilstrøð, Vardinghus-Nielsen, et al., 2025).

3.8. FIELDNOTES

The observations and informal ethnographic interviews were converted into fieldnotes. Fieldnotes were typically written down after the visits. When visits lasted for an entire day, there were always gaps between the activities, during which I was able to set aside to write fieldnotes. Beside fieldnotes, field journals were written. The field journals comprised information regarding the researcher's experiences, ideas, confusions, and breakthroughs regarding to the research process.

3.9. SEMI-STRUCTURED INTERVIEWS

The semi-structured interviews aimed to gain in-depth knowledge on family caregivers caregiving experiences and situated co-produced family caregiving experiences. Inspired by Spradley's ethnographic interviews and consisted of open-ended and focused questions (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Spradley, 1980). An interviewguide (cf. appendix 1) was developed based on the research question, theoretical conceptions and fieldnotes from the dialogue meeting, covering the thematic dimensions (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Kvale & Brinkmann, 2009). The thematic dimensions were operationalised into dynamic questions (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Kvale & Brinkmann, 2009), covering everyday questions to promote the family caregivers everyday life experiences in relation to the co-production of care and support. Two main themes were covered to gain in-depth knowledge of family caregivers' co-produced care and support: 1) the family caregiver's social practices about care and support in their everyday life, and 2) the family caregiver's social relationships (formal and informal) and the interaction with their social relationships in the co-production of care and support. We applied a participatory 'social network map' (S. Campbell et al., 2019; Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025) to visualise and reflect upon the social relationships and their involvement in the co-produced care and support (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025).

3.10. FOCUS GROUP INTERVIEW

The focus group interview is applied to gain in-depth knowledge of the DSC' perceptions and caring practices in their encounters with the families when supporting situated co-produced family caregiving, where the knowledge is produced through discussion (Halkier, 2016). This gives a unique insight into how DSCs collectively perceive and form their caring practice through collective interactions, discussing certain topics addressed during the focus group interviews in regarding to their encounter with families when supporting situated co-produced family caregiving (Halkier, 2016). A semi-structured interview guide was developed to facilitate mutual discussion based on three overarching topics: 1) the DSC's role when supporting situated co-produced family caregiving; 2) matching of expectations when supporting the situated co-produced family caregiving, and 3) supporting family caregivers in providing situated co-produced family caregiving. To support group interaction, group exercises focusing on negotiations were included (cf. Appendix B). The focus group interview was developed based on field notes from participant observation and knowledge from existing literature investigating the encounter between family caregivers and healthcare professionals.

3.11. RECRUITMENT STRATEGY AND ACCESS TO THE FIELD

A combination of a purposeful and maximum variation was applied as a sampling strategy (Palinkas et al., 2015; Patton, 2002). This strategy aimed to achieve information-rich cases of co-produced care and support provided by family caregivers, and to exhibit diversity across potential common patterns concerning gender, age, degree of dementia, and living area.

To get in touch with families, I used different recruitment strategies: Distributing flyers, where families were able to make the first contact, as this strategy has shown to be effective, as the participant can take the first contact. However, participant resource constraints are a well-known phenomenon in research, where people faced with the stresses of daily life often deprioritise participating in research (Ellard-Gray et al., 2015). Dementia is one of the three major illnesses for needing time-intensive support (Alzheimer Europe, 2018), and family caregiving involves significant responsibilities and complexities in providing care and support, including logistical tasks entwined with emotional challenges (Egilstrod et al., 2018). With these insights and drawing on previous experiences with recruiting of family caregivers for people with dementia (Ellard-Gray et al., 2015), I combined different recruitment strategies: Gatekeeping, hanging around and snowball strategy.

Through the gatekeepers, the centre leaders for the knowledge centre for dementia, and the Alzheimer associations' chairperson, I got access to municipal services for both people with dementia and their family caregivers to locate social situations where there was an interaction between the family caregiver, the person with dementia and the municipal dementia health services. Thereby, I was able to get in touch with people with dementia, family caregivers, and health care professionals. The centre leader recruited five DSCs, whom I followed during dialogue meetings with people with dementia and their family caregivers. Seven DSCs were recruited to participate in the focus group interview. Four of these DSCs also participated in the dialogue meetings. The DSCs thereby acted as gatekeepers and gave access to a wide range of families in an ongoing dialogue between me and the DSCs to reach maximum variation among the families. The gatekeepers and the family caregivers were essential to access the relevant locations. Furthermore, I recruited participants by hanging around and being physically present, where I could present myself, talk to the participants and schedule an appointment. In this way, I would ease the family caregivers' coordination. The snowball strategy is convenient when the population may be hard to reach due to the subject's sensitivity (Shaghaghi et al., 2011). In snowball sampling, informants recruit people they know who are in the same situations as themselves.

3.12. INCLUSION CRITERIA, SAMPLE SIZE AND PARTICIPANT

All primary family caregivers, who provide daily or almost daily support to the people with dementia were considered eligible to participate and were considered knowable or experienced with the phenomenon of interest

(Palinkas et al., 2015). To determine the sample size, I was inspired by Malterud et al., (2016) concept on *saturation* and thereby 'information power' and therefore the sample size was an ongoing reflection. Malterud provides five aspects, which can reflect on ‘information power’, 1) the aim of the study – narrow or broad – , 2) sample specificity – dense or sparse - 3) use of established theory – applied or not - 4) quality of the dialouge – strong or weak - and 5) analysis strategy – case or cross-case (Malterud et al., 2016)

We aimed to achieve in-dept knowledge and had narrow scope on situated co-produced family caregiving. The sample specific was dense, as the participants gave comprehensive depictions, both in the dialouge meetings, in the semi-structured interviews and in the focus, group interviews, and therefore the quality of the dialouge was strong. As the aim was to achieve in dept- knowledge, the analysis also aimed for in-depth analysis (Malterud et al., 2016). I assessed that a rich-data material was reached after 15 field visits across five dementia coordinators, 15 individual interviews and one focus group interview with 7 DSCs to cover and in-depth analysis on situated co-produced family caregivers in the encounter with healthcare professionals and people with dementia.

3.13. PARTICIPANTS

In total 45 people participated: 23 family caregivers, 14 people with dementia, and seven DSCs.

Table 1: Participant characteristics for family caregivers and people with dementia

Participant characteristics [1]	**Family caregivers (n=23)**	**People with dementia (n=14)** **Attending the dialogue meeting**
Age	Mean 75 years (58-87 years)	Mean 73 years (60 - 94 years)
Sex	17 females 6 males	10 males 4 females
Educational level **EU classification system	Low: n=10 Medium: n=9 Higher: n=4	Low: 4 Medium: 4 Higher: 6
Residential area	Low SES: n=6 Medium SES: n=9 High SES: n=8	***
Degree of dementia	Reasonable suspicion n=3 Mild n=6 Moderate n=7 Moderate to severe and severe = 7	

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[1] Table 1: Illustrates the variation within cases across age, sex, education level, residential area, and degree of dementia. ** www.ec.europa.eu *Reasonable suspicion: The dementia coordinator had reasonable suspicion and sent the person to a dementia assessment and offered needed services *** The residential area is not shown to ensure anonymity, as the value from SES class is below 3. (Egilstrøð, Vardinghus-Nielsen, et al., 2025)

Table 2: Participant's characteristics for the dementia service coordinators

Participant characteristics	**Dementia Service Coordinators (n=7)**
Sex	Females
Educational level	Higher
Graduating	Between 1987 - 2011
General working experience	Mean: 17 year (5-25 year)
Employment as DSC	Mean: 10 year (6 months - 22 year)
Affiliation	All seven DSC were colleagues and from the same organisation

3.14. SETTINGS

In Denmark, healthcare services are mainly publicly funded (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Olejaz et al., 2012), and dementia care is provided by the municipality primarily as a 'close-to-home service' (Danish Ministry of Social Affairs and the Interior, 2019; Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; National Knowledge Center for Dementia, 2023). Most municipalities in Denmark provide counselling and support through DSCs, who act as gatekeepers to municipal service provision. Among others, DSC provides dialogue meetings one to two times a year. The dialogue meetings are home-based visits lasting for approximately an hour, encouraging informal conversations about the family's everyday needs. The DSC sets the agenda with input from the person with dementia and the family caregiver, while carefully observing and analysing during their conversation to make professional judgements to provide support. The DSCs follow the people with dementia and their families throughout the dementia trajectory. Thus, DSCs can intensify the services provided according to the progression of dementia (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; National Knowledge Center for Dementia, 2023). In the study's region, a specialised collaborative dementia assessment model is employed between the region and municipalities. Therefore, DSCs affiliated with the municipalities are pivotal in conducting initial assessments in patients' homes, initiating contact with families, and initiating long-term caring relationships.

The central policy in Denmark focuses on providing dignified care for people with dementia and their families in their everyday lives (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; The Danish Ministry of Health, 2017). The individual human being behind the illness and the lived life becomes a core value in dignified care, thereby meeting the families with dignity and respect towards the individual wishes, needs, and resources (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; The Danish Ministry of Health, 2017).

3.15. ANALYSIS STRATEGY

A flexible thematic analysis strategy was applied to systemise the analytical process, in all three studies. This analysis strategy allows the analysis of patterns of the shared meaning units by a core concept across the data (Braun & Clarke, 2006, 2019; Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). A six-stepped flexible thematic analysis was followed: 1) Familiarising with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining the themes and naming the themes, and 6) reporting the themes by (Braun & Clarke, 2006, 2019; Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). Analysing in ethnographic fieldwork is an ongoing process, beginning immediately with interacting with the social phenomenon under study (Atkinson, 2015), the flexible thematic analysis therefore, correspond well, as it allows an iterative analysis process. When approaching the research field ethnographically, the analysis underpins to form and guide the research process in studying the phenomenon under investigation. Hypotheses and theories are not pulled out of thinned air but derived from various sources that mirror our general experiences bound in the academic discipline in question and specific experiences based on the general comprehension of the research topics, the work of others and our engagement with the research field (Atkinson, 2015). This is a part of step 1) Familiarising with data, within the flexible thematic analysis.

For each single sub-study, the flexible thematic analysis was supplemented with other analysis strategies. The supplemented analysis strategies for the scoping review are presented in the section: *Methods for the scoping review*. In sub-study II: inductive, deductive, and diachronic analysis strategies to analyse co-produced family caregiving within dementia and changes over time were applied. The inductive strategy allows a strong link to the empirical data when analysing, and a deductive analysis allows to take a theoretical point of view when analysing data. Combining these two allowed to stay close to the data, but simultaneously analysing from a theoretical standpoint. The diachronic analysis strategies allowed to capture the temporality within the progression of dementia (Egilstrøð, Vardinghus-Nielsen, et al., 2025). In sub-study III: Inductive and deductive analysis strategies were applied as well and supplemented with a functional analysis strategy. The functional analysis allows to guide family caregiving practices and to enable reflections on caring practices. Through a functional analysis, differences, dynamics, and complexities in situated co-produced family caregiving are captured by demonstrating different problem perspectives and problem-associated solutions and, thereby, different ways to approach situated co-produced family caregiving (Egilstrøð, Petersen, et al., 2025; Nissen, 2014).

In both sub-studies 2 and 3, I followed an iterative analysis process. The first three steps of the analysis consisted of entering a dialogue between data, theory, and existing literature about co-produced family caregiving within dementia (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). Initially, I inductively got familiar with the data within this ethnographic fieldwork (data corpus), coded the data corpus and searched for themes. I identified the core concept of co-produced family caregiving within dementia, including the shadow of family caregiving, 'the concealed work of family caregiving' and 'the unarticulated dignity, when co-producing care and support'. Erving Goffman's sociological theory was applied to interpret how family caregivers and healthcare professionals co-produced care and support through social interactions (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959).

Reviewing the initial codes through the lens of Goffman's analysis of the exchanged self-presentation and everyday roles, themes were searched, reviewed, defined, and reported. Through Goffman's lens, I perceive the situated co-produced family caregiving as a social interaction, which can be illustrated as a role-play managing everyday life with dementia.

3.16. AN INTERACTIONIST PERSPECTIVE ON SITUATED CO-PRODUCED FAMILY CAREGIVING

The situated co-production of family caregiving within dementia care is perceived as a social interaction that, which from a Goffmanian perspective, seen as a role play in managing everyday life with dementia (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959).

Dramaturgical analysis provides insights into a functional social process, where individuality and social order converge in an ongoing staging and relational dynamic. This is framed through three interconnected concepts: performances, roles, and scenes, enabling an analysis of situated co-produced family caregiving. Social interactions are orchestrated performances where people navigate various roles on different stages (such as frontstage and backstage) based on the audience's presence, as described by Goffman. These contexts shape how people present themselves, with behaviour and appearances adjusted to fit the expectations of the audience (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959)..

In Goffman’s framework, daily life is viewed as a cyclical process of scene shifts, where most social interactions involve impression management aimed at presenting a “normal” performance in the eyes of others. Here, "normal" refers to what aligns with the norms and expectations relevant to a given context, as opposed to behaviour considered aberrant by societal standards (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Jacobsen & Kristiansen, 2002). Normative expectations play a significant role in shaping individuals' self-presentation, influencing their attempts to manage impressions. Successfully managing impressions is tightly linked to adherence to these social norms (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Jacobsen & Kristiansen, 2002).

Impression management, in this sense, becomes an art form that encompasses a range of issues, requiring it to be performed convincingly and credibly (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959). According to Goffman, normative expectations encompass rules, conventions, and behavioural standards that maintain social coherence (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959). These guidelines shape the roles people must perform and adhere to within social scripts. In contrast to behaviours deemed "normal," Goffman highlights the concept of "aberrant" behaviour, which deviates from normative expectations (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959)...

For people living with dementia, maintaining a credible and convincing performance becomes challenging due to the cognitive changes that manifest as changes in personality and social behaviour (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959). Impression management strategies are therefore employed to align behaviours with societal norms, particularly in everyday social settings(Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959). This PhD study focuses on analysing an overarching strategy 'preventive practices,' both aimed at protecting one's self-image and the dignity of others (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025).

These strategies include "passing" and "covering," which are face-saving mechanisms designed to downplay or conceal aberrant behaviours that may attract negative attention. By incorporating these concepts, it becomes possible to explore the range of strategies adopted by families to maintain a sense of normalcy when living with dementia, situated within a relational social context (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959).

The situated co-produced family caregiving within dementia is perceived as a social interaction, which, from a Goffman perspective, can be illustrated as a role play when managing everyday life with dementia (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Goffman, 1959).

Role commitment refers to the degree to which an individual identifies with and is invested in a particular role. High role commitment means the person puts significant effort and resources into fulfilling the role’s expectations. This commitment can be influenced by various factors, such as personal interests, social pressures, and the rewards associated with the role (Goffman, 1959).

Role attachment describes the emotional and psychological connection an individual has to a role. This attachment often grows over time as individuals become more involved in the role and its associated activities. Strong role attachment can lead to a deep sense of satisfaction and fulfilment when performing the role, as well as distress if the role is threatened or lost (Goffman, 1959).

Role embracement occurs when an individual fully accepts and internalises a role. This means the person identifies strongly with the role and integrates it into their self-concept. In this state, the boundaries between the individual's identity and the role they play become blurred. Role embracement is characterised by genuine enthusiasm and a willingness to go above and beyond in performing the role’s duties (Goffman, 1959).

Role distance is the concept that individuals may maintain a psychological separation between themselves and the roles they perform. This distance allows them to demonstrate that they are more than the role they occupy at any given time. Role distance can manifest in various ways, such as through humour, irony, or overt demonstrations that the role does not fully encompass their identity. It serves as a way for individuals to manage the potential constraints or limitations imposed by the role and to assert their multifaceted identity (Goffman, 1959).

3.17. ETHICS AND ETHICAL CONSIDERATIONS IN QUALITATIVE RESEARCH

Ethics and ethical considerations for this PhD study apply to the research's overarching study aim and objective. In its overarching ethics, this PhD study aims to produce knowledge about family caregivers’ social life when living with dementia through ethnographic fieldwork, gaining access to part of the social life which is not publicly open to everyone. This study is partly aimed at revealing knowledge of family caregivers' experiences when sharing the caring responsibility with the welfare state and hereby giving the family caregivers a collective voice in public. Therefore, this study is based on utilitarianism as a moral and ethical philosophy as it aims to contribute knowledge supporting better conditions for family caregivers to people with dementia when co-producing care and support to improve the health of families with dementia (Rendtorff, 2003).

This PhD project follows the Helsinki Declaration, Danish ethical principles for qualitative research, and Danish Code of Conduct for research integrity (Danish Ministry of Health, 2011; Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; The Danish Ministry of Higher Education and Science, 2014; The World Medical Association, 2013). Therefore, it follows both international and national conventions concerning informed consent on voluntary participation, withdrawal, confidentiality, anonymity, and management of data. Moreover, throughout the fieldwork I strived not to cause unnecessary trouble or inconvenience or unnecessarily violate the family caregivers’ privacy (Kristensen, 2019), while investigating the family caregivers’ lifeworld.

The PhD study is registered with the Danish Data Protection Agency (Reg. No. 2019-899/10-0136) and data is handled in accordance with the General Data Protection Regulation legislation (Otto, 2018).

All participants, with or without legal authority, were verbally informed about the project's aim, their contribution, and the processing and use of their information in the project (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; The Danish Ministry of Higher Education and Science, 2014). Participants, DSCs, and family caregivers who had the legal authority were informed verbally and in writing. The DSCs were informed at an information a few weeks before visiting the first family. Family caregivers and the person with dementia were informed at the first visit, and the visit was initiated by me telling them about the project and going through the written information consent before giving the informed consent for participation in the project.

To ensure confidentiality and anonymity, all participants were given pseudonyms, and personal information that could reveal the participant's identity was erased with pseudonyms in the fieldnotes and the interview transcription. All data were stored in a locked encrypted file drive, to which only I had access (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025).

Ethnographic fieldwork involves personal, intellectual, and emotional engagement with the lives of others. It requires a commitment to the field and dedicating time and attention to those involved (Atkinson, 2015). Therefore, situational ethics regarding potential implications for participants have been applied throughout the research project by being reflexive throughout the process, since ethical considerations cannot always be fully anticipated in advance (Birch & Miller, 2000; Maddens, 2010).

3.18. REFLEXIVITY DURING THE FIELDWORK

Reflexivity is an important quality criteria because, embodied in the epistemological assumption, knowledge is constructed, not discovered. Moreover, knowledge is constructed through mutual engagement, and the phenomenon under investigation is constructed (Atkinson, 2015; Burr, 2015; Carter & Little, 2007). The everyday social life is explored by engaging in the social life of others, by observing, listening and talking, and otherwise engaging. (Atkinson, 2015). In the overarching, it means that the researchers need to be conscious and self-aware of their doings as researchers and be methodologically explicit about the doings throughout the research process (Atkinson, 2015; Burr, 2015; Carter & Little, 2007). This PhD project is practice-oriented and is partly financed by the municipality. Therefore, there has been a written agreement that this project aims to contribute with practice-oriented knowledge to the municipality. From the beginning, the research has adhered to principles of integrity, including truthfulness, transparency, and responsibility, in accordance with the Danish Code of Conduct (The Danish Ministry of Higher Education and Science, 2014). For this project, it means that the researcher has had the total responsibility for the design, execution, and dissemination of the project. Knowledge has been collected through different approaches, and leaders and administration have been involved in dialogue meetings in discussing the study's rationale and aim. I brought my knowledge from the research into the dialogue meetings, where we openly discussed relevant topics. Throughout the process, it has been important to me to show imperials and acknowledge different views and experiences related to dementia healthcare services and acknowledge the potential conflict of interest between the municipality, voluntary organisations and research.

At the floor level, I have participated in field visits and more intensively participated in the social life of people and their work lives. Therefore, this field's character has been different; I have been oriented by grasping their experiences and observing their co-produced care practice. Especially where families were involved. I came close to the stories shared from their everyday life with dementia and their crisis. The stories told were harsh and emotional; showing my empathy, support, respect, and gratitude was therefore essential for me too.

3.19. METHODS FOR THE SCOPING REVIEW

This scoping review aims to provide an overview of how co-production is applied among older adult citizens, including persons with dementia and their relatives, and the gaps within the literature. A Scoping review aims to provide a broad coverage of the literature and a comprehensive exploration of the body of literature in relation to co-production (Levac et al., 2010) and was therefore chosen (Egilstrøð, Wegner, et al., 2025).

A six-stepped framework for scoping reviews by Levac et al., (2010) is applied for this scoping review(Egilstrøð, Wegner, et al., 2025). The Prisma guidelines for reporting and conducting scoping reviews (Tricco et al., 2018) , to structure the review process and to add transparency (Egilstrøð, Wegner, et al., 2025).

When reviews are conducted, a main methodological consideration is to balance reaching comprehensiveness and simultaneously adding precision to the process. There is 'an inverse relationship' between comprehensiveness and precision (A. Campbell et al., 2018). A comprehensive search strengthens the identification of all relevant studies in the field, but simultaneously it produces a high amount of unwanted, irrelevant hits, which makes the process less manageable (A. Campbell et al., 2018). In the following, the review process is reported, and the methodological considerations to reach comprehensiveness and precision are elaborated (Egilstrøð, Wegner, et al., 2025).

The six-stepped framework includes the following steps: (1) identifying the research question, (2) identifying studies, (3) selecting studies, (4) charting data, (5) collating and summarizing the results, and (6) consultation (Egilstrøð, Wegner, et al., 2025). To each step in the framework principals recommended by the Joanna Briggs Institute for scoping reviews are added to add precision to the review process (Egilstrøð, Wegner, et al., 2025; The Joanna Briggs Institute, 2015).

3.19.1. IDENTIFYING THE RESEARCH QUESTION

A broad research question with a clearly articulated scope of inquiry was set to summarise the breadth of the literature (Egilstrøð, Wegner, et al., 2025; Levac et al., 2010), reach comprehensiveness in the review process, and simultaneously make the review process manageable (A. Campbell et al., 2018)

The research question was formed by the inclusion criteria for this scoping review, which guides and structures the following steps in the research process, including the systematic search, the selection process, and the summarisation of the literature. This process was structured around principles recommended by the Joanna Briggs Institute for scoping reviews, and the research question was formed based on the PCC (Population, Concept and Context) principles recommended by the Joanna Briggs Institute for scoping reviews(Egilstrøð, Wegner, et al., 2025; Levac et al., 2010; The Joanna Briggs Institute, 2015).

*"How is **co-production** applied within **community health services** among **older citizens and citizens with dementia, including their relatives?**"*.

The inclusion criteria followed an iterative process. The inclusion criteria were developed based on the PCC principals, and inclusion and exclusion were applied post hoc to identify new familiarity with the study subject throughout the process (Egilstrøð, Wegner, et al., 2025; Levac et al., 2010).

Following the criteria in accordance with PPC, the formulated criteria, followed in table 3:

Table 3: The scoping review's inclusion criteria

	Inclusion	Exclusion
Population 1	*Informal caregivers* Defined as unpaid caregivers with any type of relation: Relatives of 1, 2, 3, etc. Degree, friends, neighbour	No exclusion criteria were sat in relation to the study population regarding to caregivers and volunteers
	Formal caregivers Who are paid for their service contribution	
	Volunteers Volunteers work without getting paid	
Population 2	Older citizens Mild Cognitive Impairment Dementia, any type Alzheimer's Disease	Other illnesses, such as Osteoporosis Lifestyle diseases, etc.
Content	Co-production as an applied concept	Other applied concepts than co-production, such as various terms of involvement (user, patient and public) Co-creation Citizen's engagement
Context	Community Health Services	Healthcare service in the hospital
Study characteristics	Studies based on empirical results Original articles No limitation on data collection methods or publication year	Abstracts Discussion papers Editorials Reviews

3.19.2. IDENTIFYING RELEVANT STUDIES

Relevant studies were search for and identified, through a systematic search conducted in seven databases (Cinahl, Embase, Google Scholar, ProQuest, PsycINFO, Scopus PubMed) from February 1st, 2022 to February 5th, 2022. All searches were updated, alarms were set, and studies were included until November 1st. A comprehensive literature search was conducted in collaboration with two information specialists (Egilstrøð, Wegner, et al., 2025).

The following elaborates on the development and use of the search. The search strategy follows Joanna Briggs' recommendation for conducting scoping reviews and is utilised in three steps: 1) an initial test search, 2) searching systematically across all databases, and 3) a chain search (identifying relevant studies through identified studies)(Egilstrøð, Wegner, et al., 2025).

Initially a limited research was performed in ProQuest to get a first-hand expression. First, index terms were identified, and text words were searched combined for index terms and text search. Index terms ensure a uniform indexation of the same topic (Buus et al., 2008), adding precision to the search strategy by identifying the relevant hits index within the (A. Campbell et al., 2018). Text searches ensure the capture of recent publications added to the database, identify studies which potentially are missed in the indexation process (Frandsen et al., 2014; Lund et al., 2014), and add comprehensiveness to the search strategy (Egilstrøð, Wegner, et al., 2025).

The initial test search was structured around the P (Population) C (Concept) C (Context) (PCC) recommended by Joanna Briggs Institute for scoping reviews based on Levac's principles (The Joanna Briggs Institute, 2015). The PPC model was initially adjusted and developed to P (Population 1), P (Population 2), C (Concept), and C (Context) (PPCC) to add precision to the search strategy, only study, where the citizens with dementia or older citizens were included was of interest. The population in the scoping review consist of citizens with dementia, older citizens, relatives, healthcare professionals and volunteers, and a division of the population was therefore needed, as illustrated below (Egilstrøð, Wegner, et al., 2025).

Table 4: The literature search string

AND			
P (Population 1)	**P (Population 2)**	**C (Concept)**	**C (Context)**
Relative *OR* Healthcare Professional *OR* Volunteers	Citizens with dementia *OR* Older Citizens	Co-production	Community Health services

Boolean operators (OR/AND) combine the search strategy. The Boolean operator OR adds comprehensiveness by searching synonyms within a single facet, where the union of studies is identified. AND adds precision by combining the terms across a facet, where the intersection of the studies is identified (Buus et al., 2008). After testing the facet search, the C (Context) was left out because the context rarely is explicated in the studies, and therefore, relevant studies were excluded when the facet was added (Egilstrøð, Wegner, et al., 2025).

The final search strategy was structured around PPC P (Population 1), P (Population 2), C (Concept) and all identified free texts words and index terms were applied and search for in each database.

Table 5: The modified literature search string

AND		
P (Population 1)	**P (Population 2)**	**C (Concept)**
Relative *OR* Healthcare Professional *OR* Volunteers	Citizens with dementia *OR* Older Citizens	Co-production

The index terms were specifically adjusted in each database due to individual indexation across databases. Truncation was applied on text searches, to capture word inflection, however PubMed automatically truncates text searches. All free text words were filtered with title and abstract (Egilstrøð, Wegner, et al., 2025).

Finally, the reference list of the included studies was screened for relevant studies.

Seven databases were applied as data sources to gather information about the application of co-production within community health services among older citizens and people with dementia including their relatives (Egilstrøð, Wegner, et al., 2025).

These databases were selected to ensure a comprehensive literature search within public health, which constitute a cross-disciplinary research area. Databases, which covers literature within public health, social science and humanities were selected. The selected databases were Cinahl, Embase, Google Scholar, ProQuest, PsycINFO, Scopus, and PubMed (Egilstrøð, Wegner, et al., 2025).

PubMed is the largest American database in the medical field and covers literature within public health, including the MEDLINE database (National Library of Medicine, 2025). The Medline is a bibliographic database with millions of citations derived from thousands of biomedical and life science journals (National Library of Medicine, 2025). Embase is a European database, covering European peer reviewed literature that complements PubMed, as both databases include the MEDLINE database (Elsevier, 2025). Cinahl with full text is considered the most important database for nursing and allied health (EBSCOhost, 2025). Cinahl therefore covers literature on interrelations and integrated care, which is a highly relevant data source to identify relevant studies for this scoping review (EBSCOhost, 2025). PsycINFO covers literature within the field of psychology, social and health science(Association American psychological, 2025). ProQuest covers 24 databases and covers literature within the field of the humanities, social science, and health science (Bibliotek Aalborg Universitets, 2025). Scopus and Google Scholar are bibliographic databases and covers peer-reviewed literature cited within the topic (ScienceDirect, 2025). These databases are therefore highly effective to identify relevant studies for the specific aim.

3.19.3. STUDY SELECTION

The screening selection process followed Levac et al., (2010) and The Joanna Briggs Institute (2015) recommendations for study selection(Egilstrøð, Wegner, et al., 2025). All authors held meetings at the beginning, middle, and end of the process to discuss any challenges or questions related to the study selection criteria. Two independent reviewers were responsible for reviewing each article, which ensured that at least two authors had handled each identified study. Initially, the independent reviewers met to test the full-text screening process and reduce any variations in the process, thus allowing for iterative refinement of the selection criteria. During the process, reviewers held meetings to resolve any disagreements. If required, a third reviewer was involved to make a final decision regarding eligibility (Levac et al., 2010).

All identified studies were screened for duplicates in the 'Rayyan Systematic Review Screening Software' (Egilstrøð, Wegner, et al., 2025).

3.19.4. CHARTING THE DATA AND COLLATING, SUMMARISING, AND REPORTING THE RESULTS

The included studies were summarised, organised, and thematically analysed to identify study characteristics and patterns of topics. A to-steps analysis was followed involving a descriptive numerical summery which covered the total number of studies, and included details such as author, year of publication, origin, study aim, design, methods, and results (Egilstrøð, Wegner, et al., 2025). Secondly, a flexible thematic analysis was conducted based on guidelines provided by Braun & Clarke, (2006, 2019) and (Levac et al., 2010). The aim was to capture the diversity of meaning related to the topic (co-production), and therefore a flexibility in the understanding of themes, as patterns were organized around shared topic rather than shared meaning. The thematic analysis followed a six-phase guide that included 1) familiarising with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining the themes and naming the themes, and 6) reporting the themes. Both deductive and inductive analysis techniques were applied to create "domain summary themes" as shown in Table 2 (Egilstrøð, Wegner, et al., 2025).

Table 6: The scoping review's analysis and processual description

Phases	**Description of the process**
1) Familiarising with the data	The familiarisation started in the descriptive analysis, articles were read thoroughly guided by the research question and the descriptive analysis, which lead to developing initial analytical questions as: • Who are the stakeholders in the applied co-production process? • What is the content of the applied co-production process? • What is the contribution of the applied co-production process?
2) General initial codes	Sentences and text passages were systematically coded related to the research questions and the analytical question derived from the descriptive analysis to identify patterns of topic within in the included studies
3) Searching for themes	Potential themes were sought by relationships between the codes and the text. All codes were considered, the analytical research questions were refined, and they began to form the structure of the analysis identifying main themes. A matrix was used in the process to organise the codes. The final research questions were: • What type of co-production is applied? • What is the aim of applying co-production? • How is co-production conceptualized? • What is the stakeholders' role? • What is the contribution of the applied co-production process?
4) Reviewing themes	The codes in each theme were revised to ensure coherent patterns of topics, but allowing to capture the diversity in-between the identified topics, according to the aim of identifying gaps in the literature
5) Defining and naming themes	The final revision of the themes disclosed the essence of each theme drawing the main patterns, still capturing the diversity in-

	between the identified topics, to identify the gap in literature
6) Producing the scoping review	Writing the analysis was a dynamic process, beginning in phase four, and continued covering the last three phases of six phases. Data were related to the research question during the process.

CHAPTER 4. FINDINGS

Chapter 4 briefly summarises the key findings from the three papers (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025; Egilstrøð, Wegner, et al., 2025), followed by a presentation of each sub-study. Hereafter, the PhD project's integrated findings are presented, involving an in-depth synthesis based additional analysis derived from the ethnographic fieldwork. This chapter addresses the overall research question and contributes with a more comprehensive understanding situated co-produced family caregiving to home-dwelling people with dementia.

4.1. SUMMARY OF THE PAPERS’ FINDINGS

The PhD study’s overall research objective was to investigate the situated co-produced family caregiving to home-dwelling people with dementia. Through three papers, I demonstrate the situated co-production, partly by investigating co-production as a concept, the underpinned theoretical understanding and application in practice within older adult citizens, including citizens with dementia and their relatives, investigated through sub-study I: Scoping review (Egilstrøð, Wegner, et al., 2025). The situated co-production was narrowed down into situated family caregiving investigated in two different contexts through two ethnographic papers. Firstly, in the meeting with healthcare professionals, sub-study II (Egilstrøð, Vardinghus-Nielsen, et al., 2025), and secondly, in the meeting with other family members demonstrated in sub-study III (Egilstrøð, Petersen, et al., 2025).

In cumulative, the analyses focus on situated co-produced family caregiving, by highlighting family caregivers' key role, and contribution to home-based dementia caregiving to home-dwelling people with dementia. Altogether, the findings demonstrate that co-production is situated differently, following different contextual logics. The Scoping review shows how co-production is applied as a collaborative approach, where all parties make a substantial contribution, and two main thematic were identified: 1) situated co-production and 2) co-production as an approach for stakeholder involvement, thereby being situated in different contextual logics, why different understandings and conceptualisations are drawn upon. The scoping review also demonstrate a lack of clarity and coherence on how the included studies understand co-production, the choice of definition, and conceptualisation in relation to its purpose and outcomes. From the ethnographic fieldwork, findings demonstrate the situated co-produced family caregiving related to the dementia's progression. Findings illustrate how family caregivers navigate their role in highly complex encounters and interplay nested in an ecosystem of social relationships in meeting with healthcare professionals, the Alzheimer's Association, and family and friends. It is highlighted how situated co-produced family caregiving evolves as a social process and is formed by socio-cultural interlinks related to normative expectations, social roles, social performances, and social identity. Situated co-produced family caregiving is, therefore, dynamic and ever-changing.

4.2. PAPER I: EXPLORING CO-PRODUCTION WITHIN RESEARCH ON COMMUNITY HEALTH SERVICES AMONG OLDER ADULT CITIZENS, INCLUDING CITIZENS WITH DEMENTIA AND THEIR RELATIVES: A SCOPING REVIEW

Paper I's findings show that there is a consensus among the empirical studies, that co-production is applied as a collaborative approach where all stakeholders contribute substantially to the process within community health services among older adult citizens, including citizens with dementia and their relatives. Three types of co-production were identified: 1) co-production applied in intervention and service development, 2) co-production applied in services provision, and 3) co-production applied in the design and process of research, illustrated in Figure 4. Across the three types, co-production was applied fundamentally differently, which impacts how co-production emerges in practice (Egilstrøð, Wegner, et al., 2025)

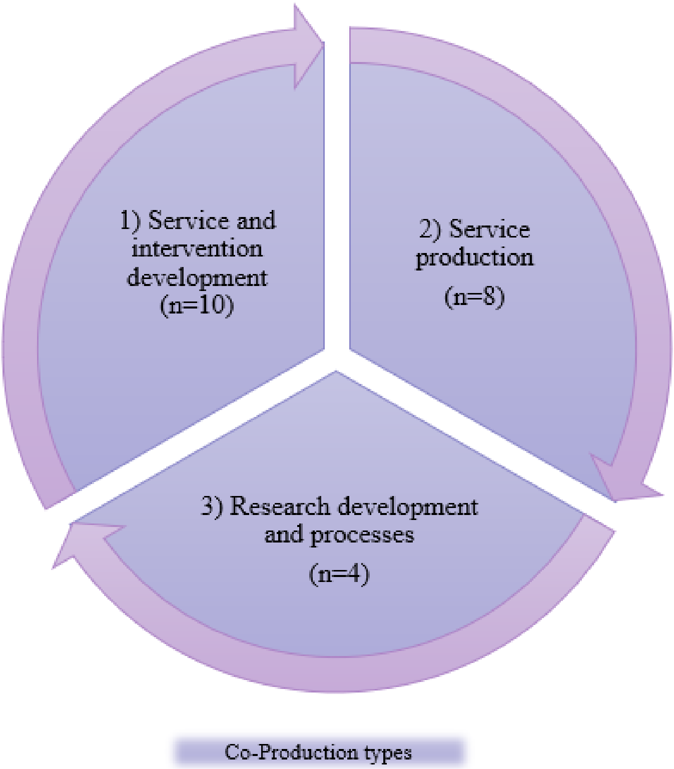

Figure 4: Types of co-production based on sub-study I, the scoping review's findings

The findings demonstrate that when interventions or services are developed through co-production, stakeholders are involved as innovators aiming to tailor interventions more effectively. This is a way to meet the needs of both users and providers, contributing to enhancing the implementation and meaningfulness of these interventions.

In contrast, when services are co-produced, stakeholders are involved as co-producers, engaging in mutual knowledge sharing and negotiations related to decision-making processes.

Finally, when co-production is integrated into the design and execution of research, stakeholders are involved as either innovators or co-researchers. This involvement aims to improve the quality of the research process and better equip co-researchers to conduct research that fosters co-produced knowledge sharing.

Identifying these three types of co-production reveals some ambiguity in the concept. In this study findings show how the term "co-production" is often mistakenly used in place of more appropriate terms like public involvement and co-creation (Egilstrøð, Wegner, et al., 2025). *Public involvement* refers to how the public can participate in *strategic decisions* regarding community health services (Egilstrøð, Wegner, et al., 2025). This can include activities where professionals engage the public, allowing them to influence and take part in direct decision-making processes (Egilstrøð, Wegner, et al., 2025; Florin & Dixon, 2004). Co-creation and co-production, on the other hand, are generally described as collaborative efforts between citizens and public sector professionals in initiating, planning, designing, and implementing public services (Brandsen & Honingh, 2018; Egilstrøð, Wegner, et al., 2025). *Co-creation* focuses on *the strategic level* during the overall planning of services. In contrast, *co-production* takes place in the later phases of the service cycle (Brandsen & Honingh, 2018; Egilstrøð, Wegner, et al., 2025), emphasizing the direct involvement of citizens in the *design and delivery of services* during the production phase (Brandsen & Honingh, 2018; Egilstrøð, Wegner, et al., 2025). When concepts are not clearly defined, it can lead to mistrust and confusion, which could negatively impact the effectiveness of service solutions (Egilstrøð, Wegner, et al., 2025; Masterson et al., 2022). This can moreover lead to unintended consequences, as the levels of involvement and the influence on decision-making processes, leading to involvement as tokenism (Egilstrøð, Wegner, et al., 2025; J. F. Pedersen et al., 2022). Although public involvement and co-creation share similarities in focusing on how services are shaped, they differ in the extent to which people contribute to the decision-making process (Brandsen & Honingh, 2018; Egilstrøð, Wegner, et al., 2025).

The findings also show a lack of transparency in relation to theoretical underpinnings, where studies, to a minor extent, defined or conceptualised co-production. Of those studies, that had an in-depth theoretical description, it was unclear how co-production theoretically underpinned the empirical data, and thereby the applied co-production (Egilstrøð, Wegner, et al., 2025).

Collectively, to succeed in applying co-production to promote healthy and active ageing, an articulation of the underlying principles of co-production is needed. These underlying principals comprise theoretical underpinnings, the co-production process, and the degree of involvement in decision-making processes (Egilstrøð, Wegner, et al., 2025).

The following gaps were identified within co-production:

- No studies focused on the involvement of older adult citizens, including people with dementia and their relatives, as co-producers in decision-making processes within service provision (Egilstrøð, Wegner, et al., 2025).
- Knowledge of co-produced services within health service among older adult citizens, including people with dementia and their relatives, is sparse (Egilstrøð, Wegner, et al., 2025).
- Clarification is needed on how co-production is applied and embedded in practice, and different co-production processes and their impact on different contextual practices (Egilstrøð, Wegner, et al., 2025).
- Knowledge is needed of how to structure co-production processes in practice across the three types of co-production (Egilstrøð, Wegner, et al., 2025).

Overall, paper I contributes to outline the landscape of co-production by highlighting the theoretical translation into applied practice, and finally the gaps in the co-production literature within health services among older adult citizens, including citizens with dementia and their relatives (Egilstrøð, Wegner, et al., 2025).

4.3. PAPER II: THE SOCIAL PROCESS AND CHANGED DYNAMICS IN THE CO-PRODUCED CARE AND SUPPORT TO PEOPLE LIVING WITH DEMENTIA WITHIN HEALTHCARE SERVICES: AN ETHNOGRAPHIC STUDY

In Paper II, a phase model, illustrated in Figure 5, was constructed to show how the co-produced care and support is negotiated over time in a triadic relationship between the person with dementia, the family caregivers, and the healthcare professional to family's everyday lives. The phase model consists of three phases 1) Negotiating participation in dementia assessment 2) Supported co-production 3) Negotiating receding home-based co-produced family caregiving. The phase model, thereby illustrate how different strategies are used to co-produce care and support over time (Egilstrøð, Vardinghus-Nielsen, et al., 2025).

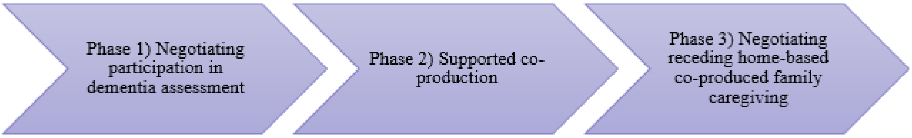

Figure 5: A phase model of co-produced care and support negotiations over time related to the progression of dementia, findings from sub-study II

Phase 1) Negotiating participation in dementia assessment demonstrates how the family caregivers use two main strategies to advance the official diagnosis of dementia. In the first strategy, the family caregivers bring their suspicion about dementia to the front stage and negotiates the symptoms in a dyadic relationship with the person with dementia. In the second strategy, the family caregivers use a backstage scene to advocate for the diagnosis involving a healthcare professional (Egilstrøð, Vardinghus-Nielsen, et al., 2025).

Phase 2) Supported co-production highlights how family caregivers enter a phase as supporters in the relationship between the person with dementia and the dementia service coordinator. After the healthcare professional suspects dementia or the diagnosis is confirmed, families are gradually eased into the municipal dementia service. Here, they are offered relevant services tailored to the families, involving a dialogue meeting, most often in the families' homes, where the family caregivers become valuable supporters in the dialogue. To support the co-production a backstage scene is used, allowing the use of face-saving strategies to spare the person with dementia from discussing specific topics and thereby avoid confrontation, which may harm the demented person's dignity of identity. This enables the family caregivers and the dementia service coordinator to lobby by agreeing on a script before entering the frontstage scene through the dialogue meetings. Consideration is shown for the person with dementia, and the person with dementia experience being a part of the conversation (Egilstrøð, Vardinghus-Nielsen, et al., 2025).

Phase 3) Negotiating receding home-based co-produced family caregiving highlights the re-negotiation and shift in the family caregiver's role towards home-based professional care. The family caregiver transitions from being the primary co-producer of care and support to a more secondary role (Egilstrøð, Vardinghus-Nielsen, et al., 2025).

Together these phases illustrate how co-producing care and support becomes situated, and how co-producing care and support is bound in a complex dynamic process related to the progression of dementia. As dementia progresses, co-production evolves and delimits as the capacity of the person with dementia to act as an independent and equal individual shrinks. Thus, there is a need to find new ways to practice co-produced care and support preserving the dignity of identity as an independent and equal individual. Throughout all phases, the interplay between frontstage and backstage serves a valuable function. Here, the healthcare professionals and the family caregiver coordinate a script to maintain the face of the person with dementia as an equal and autonomous individual, contributing to the dialogue and the negotiation of co-production of care and support (Egilstrøð, Vardinghus-Nielsen, et al., 2025).

Overall, paper II contributes to the perception of user co-production by highlighting the situated co-produced family caregiving, capturing the complex negotiation process and co-production roles over time. The findings contribute with knowledge of the complex co-production process as dementia advances and the capacity of the person with dementia to act as an independent and equal individual shrinks. This sets the open negotiations and the triadic relationships under pressure, raising dilemmas for the family. Additionally, the findings contribute to the perception of user co-production by extending the dyadic relationship between the service provider and service user by highlighting the family caregiver's key role. They moreover contribute with knowledge on the dynamics in the triadic relationship between the healthcare professional, family caregiver, and the person with dementia (Egilstrøð, Vardinghus-Nielsen, et al., 2025).

4.4. PAPER III: PROBLEM PERSPECTIVE AND PROBLEM-ASSOCIATED SOLUTIONS IN SITUATED CO-PRODUCED FAMILY CAREGIVING: AN ETHNOGRAPHIC FIELD STUDY

In paper III, three themes were constructed 1) It is on me, 2) I need help, and 3) We can’t help you, illustrating different approaches to situated co-produced family caregiving. Through family caregivers’ problems perspective and problem-solving complex interactional social dynamics are highlighted, when living with dementia. The findings demonstrate three different ways to handle situated co-produced family caregiving, formed by different normative expectations and roles in relation to caring resources available, and thereby activating different strategies to co-produce family caregiving (Egilstrøð, Petersen, et al., 2025).

Theme one 1) It is on me: highlights how the family caregiver's problem perspective is bound in a normative expectation of being the one handling the role by themselves, dealing with both the practicalities and the emotional distress that follows. The problem-associated solutions are, therefore, to use face-saving strategies, by using the backstage scene to prepare before performing in frontstage aimed to perform convincingly in their couplehood among others. In frontstage, the family caregiver and the person with dementia co-produced face-saving strategies, where the family caregiver assists the person with dementia in social performances (Egilstrøð, Petersen, et al., 2025).

Theme 2) I need help: highlights, how the family caregivers' problem perspective changes as the dementia progresses. There is a need for family caregivers to renegotiate the social script and the related normative expectations continuing to be a part of the normal life, because it becomes difficult to downplay or conceal the aberrant behaviour, also in frontstage. The renegotiation's success depends on the other family members' normative expectations and available caring resources to contribute to co-produced family caregiving, which influences the social roles. In this process two problem perspectives bound in normative expectations and available resources are at play, activating different problem-associated solutions for co-producing family caregiving: 1) face-saving strategies to maintain normalcy, and 2) face-challenging, involving direct confrontation, questioning the established roles and the amount of responsibility in situated co-produced family caregiving. The strategies activate different responses to family caregiver's expectations to contribute into the situated co-produced family caregiving. It always exists in a complex interaction between dementia's progression, the resources available and norms, and lasty the social roles (Egilstrøð, Petersen, et al., 2025).

Theme 3) We can't help you: highlights how it becomes difficult for other family caregivers to contribute into the situated co-produced family caregiving, and to live up to the normative expectations. We can't help you therefore also illustrate the limits for continuing to contribute to situated co-produced family caregiving. As the dementia continues to progress, it demands a high amount of caring resources. Dilemmas arise for family caregivers and friends, who previously shared the normative expectation and had the resources to contribute to the situated co-produced family caregiving. This influences the strategies used. Face-saving strategies are used towards the primary family caregiver, where evasive actions are used to recede to contribute into the situated co-produced family caregiving. Accordingly, to avoid direct confrontation with the primary family caregiver to set limits in the open. In this way, the primary family caregiver is again left alone bewildered, and distressed in the caring responsibility, as the primary family caregiver still acts upon the normative expectations and continuing the co-produced family caregiving in a shared constellation (Egilstrøð, Petersen, et al., 2025).

The findings demonstrate how situated co-produced family caregiving reflects dementia's progression. It is highlighted how these approaches are formed in an interplay between the progression of dementia, normative expectations, resources, and social roles in situated co-produced family caregiving. This activates different strategies to co-produce family caregiving. We highlight a dialectic between the severity of dementia on one side, and family caregivers' normative expectations, caring resources, and roles on the other side, which challenges the situated co-produced family caregiving. This fosters dilemmas as it becomes difficult to live up to the normative expectations and contribute into the situated co-produced family caregiving. This problem-associated solution reflects a compassionate effort not to abandon the primary family caregiver or confront the caring responsibility of supporting the primary family caregiver in a vulnerable situation of dementia (Egilstrøð, Petersen, et al., 2025).

Overall, paper III contributes with knowledge to enable reflections to guide family caregiving practice in the encounter with others. Three approaches for situated family caregiving are provided highlighting the complex interactional social dynamics when living with dementia, illustrated through three themes: 1) It's on me, 2) I need help, 3) We can't help you. It is illustrated how these approaches are formed by different normative expectations and resources available, activating different strategies to co-produce family caregiving. It is highlighted how dilemmas are fostered, due to a dialectic between the severity of dementia on one side and family caregivers' normative expectations, caring resources, and roles on the other side. Dilemmas arise as it becomes difficult to live up to the normative expectations and caregiving practices. This leads to different problem-associated solutions fostering barriers for supportive encounters, in situated co-produced family caregiving. These insights contribute to the discussion on moral and ethical caring practices towards people with dementia. These empirical insights add reflections to the ethical caring standards for people with dementia based on Kitwood's model for PCC. Furthermore, it adds new perspectives by highlighting the complex interaction in situated co-produced family caregiving, and challenge these principles as a standardised model for providing situated co-produced family caregiving as a part of home-based caregiving (Egilstrøð, Petersen, et al., 2025).

4.5. INTEGRATED FINDINGS: SITUATED CO-PRODUCTION WITHIN DEMENTIA IN A DYNAMIC PERSPECTIVE

The integrated findings depict co-production within dementia from a dynamic perspective and as situated in everyday life, thereby as a relational interplay forming the social process of situated co-produced family caregiving. I analyse how situated co-produced family caregiving as a social process is formed in the interlink between normative expectations, social roles, performances, and social identity, and thereby, how the situated co-produced family caregiving is formative, dynamic, and changeable over time. The situated co-produced family caregiving is demonstrated as a preventive caring practice within dementia, where strategies are put forward to maintain everyday life as 'normal' as possible and to promote personhood rather than illness despite the progression of dementia dominating everyday life. I analyse how this leaves the family caregivers with a pivotal role as contributors to the situated co-produced family caregiving as the 'normal' everyday life unfolds in an ecosystem of social interactions and relations entangled in social life and everyday obligations. In this analysis, I, therefore, focus on two contexts where situated co-produced family caregiving is formed and negotiated in the meeting with healthcare professionals and in the meeting with other family members, friends and others related, where the social scripts are changing due to the progression of dementia leading to different dilemmas and conflicts. Through problem perspectives and problem-associated solutions, this complexity is unfolded. In below, the relational dynamic of situated co-produced family caregiving is illustrated in Figure 6.

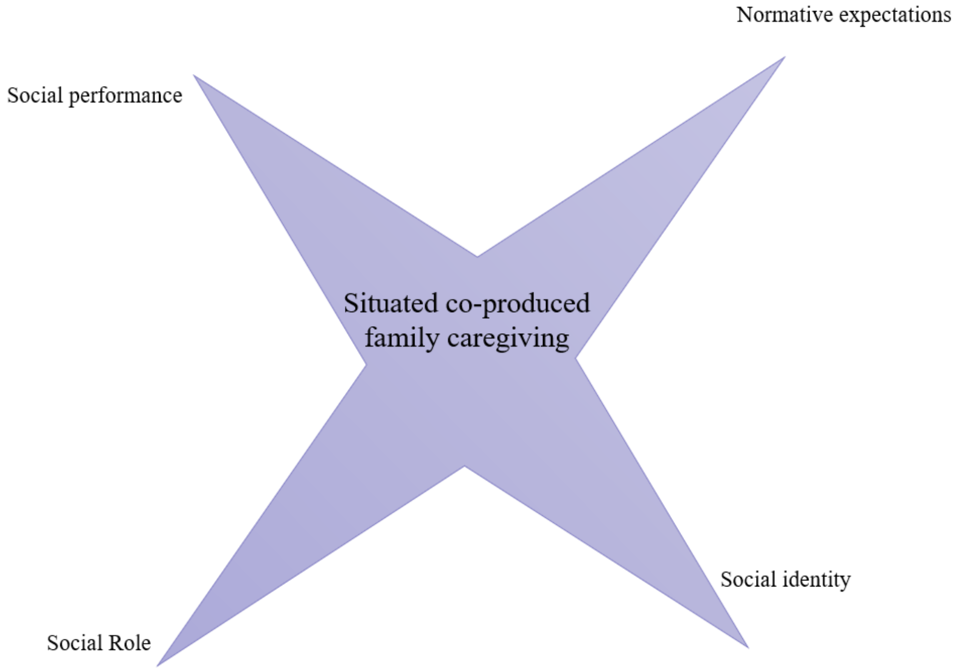

Figure 6: The relational dynamics of situated co-produced family caregiving, Integrated findings

4.5.1. THE DEMENTIA COORDINATORS PROBLEM PERSPECTIVE

Healthcare professionals' problem perspectives are bound by professional healthcare ethics, which form the normative expectation and thereby lead to the problem-associated solution to provide a co-produced preventive caring practice, by using face-saving strategies. In the following, the DSC’ problem perspective and everlasting dilemma are demonstrated, constituting the problem-associated solution as a co-produced preventive caring practice.

> ”The DSC always considers ethical aspects before entering the family's home, particularly regarding how much to intervene in their daily life. The DSC explains that it is important for her to build a relationship with both the person with dementia and their family caregiver. She focuses on not talking too much about the dementia diagnosis but instead on how she can help make everyday life pleasant and comfortable (…) [and] (…) creating an everyday life that is as natural as possible. Ideally, in a way where you don’t constantly notice the dementia, at least for most people. The DSC adds: “For me, it’s about quality of life. We can’t do anything about the illness—perhaps delay its progression, but not cure it” (Fieldnotes and focus group interview).

DSCs reflect on how they can most properly downplay the aberrant behaviour in encounters with families and thereby use face-saving strategies to maintain personhood and a normal everyday life rather than focus on the illness during the dialogue meeting. They also reflect how it becomes important to include the person with dementia, as demonstrated in the focus group interview sequence.

> Annabell: It’s about ‘a loving packaging’ because I think it’s so important that the person who is ill feels included in the conversation. I mean, often they’re sitting close by, and for me, it’s really a struggle to avoid talking about them instead of with them in the forum they’re also a part of. It’s about ensuring they truly feel involved, included, and heard.
>
> Nathaly: And also, so they don’t feel like they’re constantly being tested and failing every single time. Like it’s always them making the mistakes.
> Annabell: Yes, but also supporting them so they’re not being talked about but talked with.
> Nathaly: Yes, that’s something I care deeply about. (A conversation from the focus group between Annabell and Nathaly, the DSCs)

The DSCs, however, describe how they always need to reflect upon how to convert the problem-perspective into problem-associated solutions, hence guiding situated co-produced family caregiving. The situated co-produced family caregiving is guided through a preventive caring practice, by using face-saving strategies as a means to maintain the dignity of identity and personhood. The problem-associated solutions and the use of face-saving strategies depends on the encounter with the family caregiver, and thereby the social interaction, the family structure, and the dementia’s severity. Thus, the co-produced preventive caring practice is constructed in different ways depending on the individual family situation.

> “I don't think there's anyone who's the same to be a care coordinator for. Because they all have different issues, no matter who they are. It's about reading those individual needs that exist in the specific family we're working with. Simply understanding what is required here. Because it can vary greatly depending on the resources already present in the home [and the need to refer to services] and being in a process together with the family" (Focus group interview with six DSCs)

The professionals' judgements and observations of the families' everyday needs become important and needs to be seen in relation to the dementia symptoms, the family structure, and the families' collective resources. The multipronged diversity across families and families’ structure, becomes important, when DSCs guide the family caregivers in contributing into situated co-produced family caregiving. It also becomes important, when

DSCs needs to assess, which services to offer to relieve the family caregiver. Additionally, it becomes important in the encounter with the family caregivers in the dialogue meetings, and, when assessing what to expect of families to contribute to the situated co-produced family caregiving.

Despite these individual differences, DSCs always strive to maintain the situation as normal as possible and try to manifest their problem perspective through preventive caring practices by using face-saving strategies.

4.5.2. MANIFESTATION OF THE DEMENTIA SERVICE COORDINATORS' PROBLEM-PERSPECTIVE IN THE MEETING WITH FAMILY CAREGIVERS

The dialogue meetings between the person with dementia, the family caregivers, and the DSCs demonstrate that the problem-associated solution is to co-produce preventive caring practices through face-saving strategies to maintain the person with dementia’s dignity of identity (Egilstrøð, Vardinghus-Nielsen, et al., 2025).

To practice the preventive caring practice, the DSCs open for backstage scenes, allowing the use of face-saving strategies. Here, family caregivers can address specific topics which can be difficult to address in front of the person with dementia due to their own insight into the severity of the symptoms (Egilstrøð, Vardinghus-Nielsen, et al., 2025). In this way, the family caregiver is spared from directly confronting the person with dementia and harming the dignity of identity. This enables the family caregivers and the healthcare professional to lobby by agreeing on a script before entering the frontstage scene in the dialogue meetings allowing protection of their faces in frontstage performances (Egilstrøð, Vardinghus-Nielsen, et al., 2025). As the symptoms of dementia become more severe, the interplay between the backstage and frontstage intensifies, where physical scenes are created (Egilstrøð, Vardinghus-Nielsen, et al., 2025). The backstage scene plays a more significant role in planning the script to continue cherishing the person with dementia's dignity of identity by applying face-saving strategies (Egilstrøð, Vardinghus-Nielsen, et al., 2025). In the frontstage scene, the person with dementia is involved by dosing the communication when all parts are physically present in the dialogue (Egilstrøð, Vardinghus-Nielsen, et al., 2025). Here, information is concealed by finding ways to communicate things that go unnoticed by the person with dementia, e.g., using clearing signs as face-saving strategies. In the backstage performance, the more difficult topics are addressed to spare the person with dementia from being in dialogue meetings to harm the dignity of dementia, and the experience of not being involved in the decision-making process. This could be when the family caregiver needs to recede from being the main provider in performing the situated co-produced (Egilstrøð, Vardinghus-Nielsen, et al., 2025). As the dementia symptoms become more severe, it becomes challenging to co-produce preventive caring practices and to preserve the person with dementia's dignity of identity as the dynamic is changing dramatically due to the dementia progression (Egilstrøð, Vardinghus-Nielsen, et al., 2025). Confrontations between family caregivers and their spouses with dementia become more visible without the use of face-saving strategies, and the backstage scenes are broken (Egilstrøð, Vardinghus-Nielsen, et al., 2025). When the face-saving strategies are unable to be maintained, the DSCs change strategy and introduce a new room for performing backstage scenes and offer dialogue meetings without the person with dementia attending (Egilstrøð, Vardinghus-Nielsen, et al., 2025). In this way, the DSC always holds on to the problem perspective to co-produce a preventive caring practice towards maintaining the dignity of identity for the person with dementia. The DSC finds problem-associated solutions to support providing preventive caring practices to allow the use of face-saving strategies.

4.5.3. FAMILY CAREGIVERS' DIFFERENT PROBLEM PERSPECTIVES CONSTITUTE DIFFERENT PROBLEM-ASSOCIATED SOLUTIONS.

In everyday life and in interactions with other family members and others, it can be difficult for the primary family caregiver to transfer their problem perspectives and problem-associated solutions from the dialogue meeting to the situated co-produced family caregiving. Family members often have different problem perspective, and the willingness to contribute into contribute into the situated co-produced differs.

Overarching, there two themes occur. On one hand, the primary family caregiver experiences the main responsibility of contributing to the situated co-produced family caregiving, and on the other hand, the primary family caregiver shares the DSC problem perspective to maintain personhood (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). Therefore, the primary family caregiver's problem-solution becomes to co-produce a preventive caring practice, where face-saving strategies are used to downplay and conceal the aberrant behaviour, and thereby to prevent the dignity of identity. As dementia progresses, and it becomes challenging to contribute to the situated co-produced family caregiving, the primary family caregiver seeks their family members and others to participate in the situated co-produced family caregiving (Egilstrøð, Petersen, et al., 2025). This changes the problem perspective from being the main person responsible to sharing the responsibility with others. For some family caregivers, this is easily done, as other family caregivers share the same problem perspective and are aligned to co-produce a preventive caring practice and use face-saving strategies to maintain personhood and normality in everyday life (Egilstrøð, Petersen, et al., 2025). However, as the dementia progresses, it becomes difficult to live up to the normative expectations as the contribution into the situated co-produced family caregiving becomes demeaning and demands considerable caring resources. It becomes difficult for other primary family caregivers and family members to negotiate a new social script in social gatherings, as their problem perspective differs from the primary caregiver's, thereby influencing which problem-associated solutions to apply (Egilstrøð, Petersen, et al., 2025). Other family caregivers recede as it becomes too demanding to contribute to the situated co-produced family caregiving, thereby setting the limit for contributing to the situated co-produced family caregiving. Therefore, the primary family caregiver is left alone in co-producing family caregiving but is also responsible for setting the limit (Egilstrøð, Petersen, et al., 2025). This dilemma is often negotiated with the healthcare professionals sharing the same problem perspective, nudging the family caregiver to recede their role (Egilstrøð, Vardinghus-Nielsen, et al., 2025). Healthcare professionals tend to nudge the family caregivers to recede from their role, when the healthcare professionals assess it as an unworthy life for the family caregiver and the person with dementia (Egilstrøð, Vardinghus-Nielsen, et al., 2025).

4.5.4. THE SITUATED CO-PRODUCED FAMILY CAREGIVER ROLE

The family caregiver's co-production role is dynamic, situated, and changes over time. The co-production roles are linked to the social scripts for performances and how the family caregiver engages with their roles. Therefore, their role performance is associated with both the normative expectation related to the social scripts, and their role engagement.

Family members tend to feel strongly committed to their co-production role without questioning. They feel responsible for entering their co-production role and provide situated co-produced family caregiving. This is illustrated through the family caregiver’s initial problem perspective, illustrated in the first theme in article 3: ‘It’s on me’ (Egilstrøð, Petersen, et al., 2025), manifested in their social performance. Family caregivers apply a preventive caring practice, both in the encounter with the families and in the encounter with the DSCs. This involves using the backstage scene as a preparation scene for controlling and adjusting impression management to prevent the dignity of identity for the person with dementia (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). In frontage, together with others, the family caregiver and the person with dementia coordinate their use of face-saving strategies in public with 'normal people' to support the person with dementia's role and social identity. Consequently, the couple can succeed to maintain their social identity as couples, and to a less extend a family caregiver and a person with dementia (Egilstrøð, Petersen, et al., 2025). This is an example on how family caregivers commit and engaged to their family caregiving role as they 'play along', supporting the person with dementia in performing convincingly.

The social script for a specific social context determines how family caregivers can outplay their co-production role and which social information can be disclosed. In the following I will demonstrate two different social contexts for the ability to embrace their role as family caregivers, dementia-related social gatherings, and social gatherings with families and friends.

In dementia-related social gatherings where the social scripts follow a normative expectation of being inclusive towards the aberrant behaviour of dementia and normalising the behaviour, the family caregiver can play their co-production role fully, which is demonstrated in the below.

> "That sense of community is really important because (…) when you're with others in a similar situation—other caregivers—it allows us to talk about the problems we're facing, big or small, depending on where we are in the process. For example, Frida, whose husband is in a care home now, was more private and had a different kind of marriage. But it was good for her to have both Margaret and me there, to reach out and ask, 'How are you doing?' It's that difficult barrier; you don't usually talk about very personal things, even with neighbours (…) We can share those kinds of things and say, 'I had a rough day,' or 'We argued over something,' because not every day is easy—just like in any marriage. But here, we're all dealing with the same symptoms, and that understanding matters (…). It really feels like we can lean on each other because we know what each other is going through. (Interview with Edna).

Here, the family caregiver expresses how the normative expectation for the social scripts allows them to perform in their co-production role, disclosing social information from their everyday lives. Family caregivers can commit, attach, and embrace their role as family caregivers, as they freely can share social information about everyday experiences related to their role, thereby contributing to providing situated co-produced family caregiving.

Contrary, in other social gatherings following the social scripts for normal behaviour and performance, aberrant behaviour that might draw negative attention needs to be minimised or hidden. It becomes difficult for family caregivers to outplay their co-produced family caregiver role. Below, the social scripts for role performances is illustrated.

> "We were at a bar, it was Friday, and we got a table in the back (…) and we were four couples out together. So, we're all sitting there (…). And Erw, have had it harsh lately… David has just been there for him. He's [Erw] got divorced (…) he's sitting here [pointing towards another table]. He [Erw] turns like this [pointing towards the table where David is sitting], (…) and then he says, 'Cheers, Allan. Cheers, Simon.' And says nothing [to David]. I just felt really, really upset. So Erw, he goes up to get beers. He gets one for Allan. He gets one for Simon. Then he comes to the table and says, 'Oh, did you also want one, David?' 'No, thanks,' says David. I can tell, I was so upset (…) Then David says, 'I know exactly who wants to spend time with me and who doesn't" (Interview with Hannah).

This is an example of how it becomes difficult for David to outplay his expected role convincingly, thereby following the social scripts for performance. David is being excluded due to his aberrant behaviour, as he is unable to minimise or hide the dementia symptoms. This also influences Hannah's ability to commit and enter her role as family caregiving, because an inclusive approach towards dementia is not a part of the social scripts. This may influence how Hannah is able to support David and share social information about the dementia.

In another example of social gathering, an opposite situation occurs. Here, the person with dementia can play his role convincingly, minimising his aberrant behaviour due to the dementia symptoms, and thereby it becomes challenging for the family caregiver to outplay their caregiver role in public.

"Then she says, 'It's not nearly as bad with Paul as you all go around saying. But he's SO good at hiding it when we're out somewhere. And then he just sits there a bit more passively, and then occasionally, when someone says something to him, he'll of course respond, right? But otherwise, he hides it. So, they just can't understand that it's so bad with Paul.'"

This is an example of how a person with dementia succeeds in downplaying the aberrant behaviour. Therefore, it becomes difficult for the family to share information, which are in contrast with the social performance, and the family caregiver needs to adjust to the person with dementia's social behaviour and thereby also downplay the family caregiver's role.

When family caregivers try to disclose social information about the severity of the dementia symptom, other family members or friends may react differently, and, thereby, family caregivers can be met in their role or rejected to enter their role as family caregivers in public.

"'But Dad, it's not like that at all, you really need to move on now (...) [The Children refer to not being too consumed by the illness role]... I also experienced that my children - this really surprised me - they didn't understand at all what I was saying to them. They just couldn't understand it, and their mother, she ... Not that she couldn't remember, because that's not how they experience it. But I'm honestly surprised that it could cause so many conflicts. (...) (Interview with James).

These examples demonstrate how it became difficult for family caregivers to embrace and outplay their role in social gatherings, when the normative expectations in relation to the situation are not aligned.

In another example, it becomes easier for the family caregivers to outplay their roles when they are met in their observations about the dementia's severity and acknowledged in taking on their role as family caregivers.

A female family caregiver told me how vacations abroad was spent as quality time with the family, but due to the severity of the dementia symptoms, they now found other ways to spend quality time as a family. The children often gave their father different kind of adventures adjusted to the dementia symptoms. Once, their daughter gave her father a day out on Father's Day and experienced how her father was changed.

> "And the daughter took him to a place in the city where they were going to sit and have a glass of wine and some tapas. She then says, 'Well, you're right, Mom. Dad doesn't say anything. It's always me who has to start the conversation. But when you ask him something, he does answer.'" (Interview with Catharine).

In this situation, the daughter acknowledges her mother's experience of the progression of the symptoms, and it becomes easy to embrace their role as family caregiver.

Altogether, different conditions influence the family caregiver's role attachment and role commitment. The family caregiver needs to adjust their co-production role to match the social situation, and, thereby, the co-produced family caregiving role is dynamic, changeable, and situated. This can make it difficult for a family caregiver to navigate their role, as they are forced to downplay the severity of dementia and deal with it themselves.

CHAPTER 5. DISCUSSION

In this chapter, I initially demonstrate the key findings of this PhD study from the ethnographic fieldwork, followed by a discussion in relation to the existing literature on home-based care for home-dwelling people with dementia and the contributions in this regard. This is followed by a demonstration of key findings from the scoping review and the contribution to existing literature on user co-production based on the knowledge gaps identified in the scoping review (Egilstrøð, Wegner, et al., 2025). Finally, the methodological strengths and limitations are discussed based on quality criteria for qualitative research and review.

5.1. THE PHD STUDY'S KEY FINDINGS

Overall, this PhD study demonstrates how co-produced family caregiving is situated, dynamic, and relational, illustrated through a 'preventive caring practice' as the dominant strategy for home-based caregiving to home-dwelling people with dementia. The preventive caring practice is co-produced through a range of face-saving strategies aiming at preventing the dignity of social identity for people with dementia. The focal point of situated co-produced family caregiving is to maintain everyday life as normal as possible and keep the dominant family story intact despite progress in the severity of dementia and, thereby, downplay the aberrant behaviour. The preventive caring practice and the face-saving strategy are, therefore, always co-produced in a highly complex social interaction interconnected with normative expectations, social roles, social performances in social situations, and social identity. Therefore, family caregivers must navigate the situated co-produced family caregiving in encounters with different social situations involving different people, healthcare professionals, other family caregivers, family members, and friends. Navigating and practicing situated co-produced family caregivers differ across social situation. In the encounter with healthcare professionals and patient association, as the Alzheimer Association, it is easier to the primary family caregivers and the person with dementia to discuss the symptoms of dementia openly, and to disclose aberrant behaviour as the social script is built to be inclusive towards the dementia symptoms (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). However, in the encounter with family and friends, the social script for social gatherings is initially not built upon being inclusive towards dementia, and in some social situation this can be negotiated, and not in others. It depends on the social scripts and social performances flexibility

(Egilstrøð, Petersen, et al., 2025). Therefore, performing in social situations with family and friends often results in a downplay of the dementia symptoms, as highlighted in paper III (Egilstrøð, Petersen, et al., 2025). Furthermore, the findings demonstrate a doubleness, as the face-saving strategies are not only performed to preserve the dignity of identity but are also used to delimit the contributions into the situated co-produced family caregiving by others than the primary family caregiver. This typically outplays when the severity of dementia progresses, and it becomes difficult to maintain normality in everyday life. In paper III, it is highlighted how other family caregivers and friends use evasive actions to reduce their contribution into situated co-produced family caregiving and to avoid direct confrontation. This reflects a compassionate effort not to abandon the primary family caregiver or confronting to fail the caring responsibility in supporting the primary family caregiver in the vulnerable situation which dementia is (Egilstrøð, Petersen, et al., 2025). These findings underscore the complexity in providing situated co-produced family caregiving and contributing into home-based caregiving to home-dwelling people with dementia.

In the following, a discussion is raised about the contribution in relation to providing a preventive caring practice when providing home-based care for home-dwelling people with dementia, the roles related to being a family caregiver, and the match between home-based care services and family caregivers' needs for support. The section ends with a wrap up on the contribution to home-based caregiving practice.

5.2. HOME-BASED CAREGIVING TO HOME-DWELLING PEOPLE WITH DEMENTIA AS A PREVENTIVE CARING PRACTICE

The main findings from this PhD study revealed how a preventive caring practice becomes the dominant strategy for providing home-based caregiving for people with dementia. Additionally, the findings show how the preventive caring practice continuously is co-produced by healthcare professionals, the primary family caregiver, and other family members aimed at preserving the dignity of the identity of the person with dementia as an autonomous individual (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). In the encounter with healthcare professionals, other studies highlight how encouraging the autonomy and involvement of a person with dementia becomes essential to engaging the person with dementia (Tuijt et al., 2021). As demonstrated in this PhD study, a double bind exists where an encouragement of the dignity of identity leads to co-produced preventive caring practices, where the symptoms and aberrant behaviour is downplayed for others. This conceals the true severity of dementia and the extensive caregiver burden, which often falls on the family caregiver, invisible for the surroundings (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). The findings also demonstrate how the primary family caregiver plays a key role in orchestrating the daily life and keeping things as normal as possible, with support from healthcare professionals and sometimes other family members. These findings reflect other studies within family caregiving in relation to maintaining normality. Previous studies highlight how keeping things normal becomes a strategy for family caregiver when coping with dementia emotionally and practically (Boylstein & Hayes, 2012; Egilstrod et al., 2018; Egilstrød & Petersen, 2021; Hellström, 2014). The findings from this PhD elaborate on previous studies by broadening the perspective on interactions by highlighting how family caregivers navigate the situated co-produced family caregiving in meeting with others and by adding how face-saving strategies become the dominant strategy for navigating normality, despite dementia. Our findings underscore that co-producing a preventive care practice in the provision of home-based care for home-dwelling people with dementia is a valuable strategy to preserve the dignity of social identity and maintain normality for as long as possible, both in the encounter with healthcare professionals and in the encounter with other family caregivers and friends (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). It underpins the philosophy of person-centred care, acknowledging and valuing people with dementia as unique human beings with the right to self-determination, irrespective of their condition. It emphasises focusing on personhood rather than the illness, organising care and support around the individual's perspective, life history, habits, and psychosocial needs (Kitwood, 2019). However, these PhD findings also highlight a range of ethical dilemmas when preventive caring practices are used in services close to home, where the primary family caregiver becomes the key co-producer in orchestrating the preventive caring practice (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). These PhD findings highlight how the preventive caring practice becomes paramount, and it becomes more challenging for the family caregiver to perform face-saving strategies to continue the situated co-produced family caregiving and continue to provide a preventive caring practice (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). Especially as dementia progresses, there is a need to find creative face-saving strategies to keep things as normal as possible in a tolerable way, both in encounters with healthcare professionals and with friends and families (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). The encounter with healthcare professionals involves an interplay between backstage and frontstage performances, where the frontstage constitutes a negotiation room for discussing the family's need for support due to dementia. However, the family caregiver and the healthcare professional use a backstage scene to re-negotiate and agree on the social script for the dialogue meeting, and as dementia progresses the backstage scenes are used more manipulative and strategic, as it becomes more and more difficult to involve the person with dementia in decision-making processes (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). Here, the preventive caring practice is double-sided as it both aims at protecting the family caregiver to reveal their experiences of the severity of dementia and the need for support and to avoid to directly confront the person with dementia with their experiences (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). In the encounter with family members and friends, the creative use of face-saving strategies changes character compared to the encounter between professionals and family caregivers. In these encounters, where appearing in accordance with the social script is paramount, and, therefore, face-saving strategies are employed to adjust the impression management to align the social norms (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). Initially, the backstage scene plays a significant role in adjusting the aberrant behaviour and downplaying the symptoms of dementia, but as dementia progresses, it also becomes necessary for the primary family caregiver to support and assist the person with dementia in performing convincingly (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). As dementia progresses, it becomes difficult to keep the aberrant behaviour in-house, and the family caregiver needs to reach out to other family members and friends. The collective face-saving strategies are used to maintain normality and depending on their normative expectations and employed resources (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). The primary family caregiver and other family members or friends find ways to apply face-saving strategies when providing situated co-produced family caregiving (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025).

As dementia progresses, it becomes gradually more challenging to keep things normal, and the symptoms of dementia and aberrant behaviour become gradually more challenging to downplay and conceal (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). In the encounter with the healthcare professionals, it becomes difficult for the primary family caregivers to continue to use face-saving strategies, which leads to a direct confrontation between the family caregiver, the person with dementia, and the healthcare professionals (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025).

Goffman highlights how social interactions are idealised, and how people need to live up to idealised standards. Thus, people will always try to idealise their behaviour, and, therefore, their appearance will always be finished, polished, and packaged (Goffman, 1959). The present PhD findings indicate idealised standards, both in relation to normative expectations of being a good spouse contributing into the situated co-produced family caregiving, and to meet the outside world polished when using backstage scenes as a preparation scene for performance (Egilstrøð, Petersen, et al., 2025). This underpin to keep the severity of the symptoms under the radar both in the encounter with healthcare professionals, family members, and friends, as the primary family caregiver and the person with dementia successfully downplay the severity of dementia by using face-saving strategies. Moermans et al., (2022) have revealed how healthcare professionals underestimated the severity of caring for a person with dementia, leading to a lack of emotional support for family caregivers in decision-making processes. Paper III highlights how other family members and friends set limits to contribute to the situated co-produced family caregiving, because it demands considerable resources, and when a co-produced preventive care practice becomes the dominant strategy for situated co-produced family caregivers, the primary family caregiver is often left alone to handle the practical and emotional distress (Egilstrøð, Petersen, et al., 2025). Consequently, family caregivers are often reluctant to reduce their role as primary family caregiver (Egilstrøð, Petersen, et al., 2025). Co-producing preventive caring practice can be seen as a contributory factor in the experienced caregiver burden. Notably, it is evident that family caregivers experience a high caregiver burden and an increased risk of developing psychosocial illnesses, such as stress, anxiety and depression, ending up as patients themselves (Chiao et al., 2015; Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025).

The findings about the co-produced preventive caring practice can also be reflected in family caregivers' unmet needs. Family caregivers generally experience their needs being unmet both by professional healthcare dementia services and by friends and family (Allen et al., 2017; Black et al., 2013; Mansfield et al., 2017; Pinto et al., 2016; Queluz et al., 2020). Clemmensen et al., (2020) have identified how family caregivers' needs originate from an interactional relation with the person with dementia but also from being a family caregiver. The findings from this PhD study contribute to understanding the family caregivers' needs arising in highly complex encounters, which are dynamic and contextual situated (Egilstrøð, Petersen, et al., 2025). In the following, the findings on family caregiver situated co-produced family caregiver role is outlined and discussed to understand the complexity in understanding the family caregiver's needs followed by a discussion about the family caregivers' unmet needs in situated co-produced family caregiving

5.3. THE SITUATED CO-PRODUCED FAMILY CAREGIVER ROLE WHEN PROVIDING HOME-BASED CAREGIVING

The findings from this PhD study highlight how situated co-produced family caregiving is dynamic and ever-changing, and thereby forms the situated co-produced family caregiving roles. The co-production roles are linked to the social scripts for performances and how the family caregivers engage with their roles. Therefore, their role performance is associated with both the normative expectation related to the social scripts and their expected role and their role engagement.

Other studies reflect this complexity. Johansen et al. (2024) have highlighted how being a family caregiver emerges from different kinds of relational connectedness and how the term "family caregiver" especially becomes relevant in the meeting with the healthcare system. These findings are in line with the findings from this PhD. In encounters with healthcare professionals or with the patients organisation, Alzheimer's Associations, the family caregiver can embrace and unfold their family caregiver role (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). Contrary, in encounters with family members and friends, the family caregivers roles needs to be adjusted according to the social scripts (Egilstrøð, Petersen, et al., 2025). Adjusting their social role to the social script can be highly complex as face-saving strategies are 'normally' to use in everyday life. According to Goffman, all interactions with others in daily life involves impression management concerning the ability to present a 'normal performance' involving impression management strategies (Egilstrøð, Petersen, et al., 2025; Goffman, 1959). To avoid aberrant behaviour, face-saving strategies are used. Aberrant behaviour refers to actions that deviate from the social script. These can range from minor missteps that are quickly corrected, such as apologizing when someone accidentally enters the wrong room, which helps restore the expected social appearance. In such cases, face-saving strategies are a typical response. (Goffman, 1959). Dementia is insidious and families tends to adjust without noticing (Egilstrød & Petersen, 2021). From a Goffman optic, family caregivers adjust by using face-saving strategies.

Firstly, this involves using backstage as a preparation scene for downplaying the aberrant behaviour and the dementia symptoms (Egilstrøð, Petersen, et al., 2025). Secondly, it involves the active use of face-saving strategies in frontstage, where the person with dementia can convincingly downplay the aberrant behaviour and the severity of dementia, often with help from the primary family caregivers to preserve their social identity (Egilstrøð, Petersen, et al., 2025; Egilstrøð, Vardinghus-Nielsen, et al., 2025). However, the use of face-saving strategies also undermines the severity of family caregivers' role.

The findings also emphasise different problem perspectives related to the family caregiver role, which implicate perception and expectation to contribute into the situated co-produced. The roles are dynamic and will differ across families. This is supported by the three different approaches to handle situated co-produced family caregiving, revealed in paper III (Egilstrøð, Petersen, et al., 2025). Brodaty & Donkin, (2009) found different motivational factors for taking on a family caregiver role, which involves a wide range of combined feelings, a sense of love and/or reciprocity, a sense of duty, guilt, and social pressure (Brodaty & Donkin, 2009). In Goffman’s optic, this can influence the role attachment, commitment, embracement, and distance (Goffman, 1959). Role distance was also highlighted within this PhD study’s findings, resulting in reduction to contribute into the situated co-produced family caregiving, as it became too demanding. When providing supportive services as a part of the home-based caregiving, these complexities become important to address and reflect on, as the capability to contribute into the situated family caregiving vary. These insights can play a crucial role in meeting the needs of family caregivers.

5.4. SUPPORTING SITUATED CO-PRODUCED FAMILY CAREGIVING

Within research, family caregivers generally experience unmet support needs, both in encounters with healthcare professionals and in encounters with family and friends, manifested by a lack of self-care and referrals to appropriate community resources (Black et al., 2013; Pinto et al., 2016; Queluz et al., 2020). The unmet needs originate from different situations, which adds complexity to understanding and supporting family caregivers sufficiently. Clemmensen et al., (2020a, 2020b) found how family caregivers oppress their own needs as they are obtained about the needs of the person with dementia (Clemmensen et al., 2020a, 2020b). In line with the present PhD study’s findings, there is a caring paradox, as the dominant strategy is to provide a preventive caring practice to preserve the social roles and normality in everyday life, thereby downplaying the symptoms of dementia.

Concurrently, it is the family caregiver who needs to set the limit and ask for help (Egilstrøð, Petersen, et al., 2025). In line with a study by Egilstrød & Petersen, (2021), family caregivers follow along and try to cope with dementia by adjusting to everyday life as dementia progresses. Furthermore, family caregivers are not always aware of the changes, because the symptoms appear processual and change in intensity from being more severe in one week followed by being better the next week, and the family caregivers' main focus is to adjust changes (Egilstrød & Petersen, 2021). On the longer trajectory, the need for support changes as dementia progresses. However, it becomes difficult for family caregivers to assess and see the situation from the outside, as they are part of the process 24/7 (Clemmensen et al., 2020b; Egilstrod et al., 2018; Roberts, 2018). It is, therefore, crucial to support family caregivers in assessing their own needs.

Moermans et al., (2022) highlight how family caregivers often feel a lack in emotional support in the decision-making process from professional caregivers, as the professional underestimated the severity of caring for the person with dementia, which impacts the provision of timely support (Moermans et al., 2022). In line with the PhD study's findings, it can be difficult to support family caregivers sufficiently when the dominant strategy is to downplay or conceal the severity of the symptoms to maintain life as normal as possible in a co-production process. Clemmensen et al., (2020b, 2020a) highlight how professionals mostly offer practical support matching the service level, although this is not in line with the family caregivers' needs. Family caregivers' consume their concerns around the clock in feeling safe (Clemmensen et al., 2020a). Safety as a challenge has also been explored by Moermans et al., (2022), where family caregivers struggle to find the right balance in prioritising safety and supporting the person with dementia's autonomy. As dementia's severity advances, finding the right compromise between safety and autonomy becomes more difficult (Moermans et al., 2022). In line with the PhD study's findings, it is highlighted how the preventive caring practice aims to preserve the dignity of social identity as the dominant strategy. Safety was not a theme raised within findings from this PhD. Based on the findings, it can be difficult to focus on safety, when the primary focus is on providing a preventive caring practice and using face-saving strategies in the encounter with healthcare professionals and with family and friends. Particularly, if this is an overseen need as outlined by Clemmensen et al., (2020a). The findings from this PhD study confirm that dialogue meetings are held once to four times a year, depending on the severity of dementia, and the dialogue meetings are held where the family caregiver and the person with dementia attend unless there is a risk to harm the person with dementia’s dignity of identity (Egilstrøð, Vardinghus-Nielsen, et al., 2025). From these insights, support services should focus on providing emotional support, and healthcare professionals should be reflective about how to reveal ‘the dirty work – hidden from the outside’. Another need addressed is the continued need to be supported with knowledge about dementia as dementia progresses (Black et al., 2013; Clemmensen et al., 2020b).

The findings from this PhD study also highlight how the family caregivers approach situated co-produced family caregiving differently, due to different problem-perspectives, bound in different normative expectations and resources available to contribute to the situated co-produced family caregiving (Egilstrøð, Petersen, et al., 2025). From the integrated findings in the present PhD study, this was highlighted as being a key concern for healthcare professionals. However, it is not possible based on our findings to assess how healthcare professionals manage this in their caring practice, and how they support families when different resources are available. St-Amant et al., (2012) highlight how the home care structures and processes shaped the enactment of decision-making patterns, following the system's needs rather than the family’s needs, where the burden of meeting the timeline becomes the family’s problem.

Providing supportive services embedded in a welfare state contributes to qualitative reasoning, where some societal challenges possess a complexity which exceeds the individual capacity to manage the challenges, as outlined by Roar Hagen as *collective solidarity* (Hagen, 2006; Nissen & Harder, 2008). The welfare state investment in dementia caring services is seen as valuable, as it can support people with dementia and their families to better cope with dementia. Here, the dementia symptoms can be addressed, they can seek advice and be included in dementia-friendly activities, supporting their quality of life (National Knowledge Center for Dementia, 2023). However, there is a need to continuously reflect on the services provided, and whether the services match the needs of the citizens. Otherwise, the qualitative reasoning diminishes in value.

When providing services to support family caregivers as part of home-based caregiving, more emphasis should be placed on the family caregivers' caring practice to better target their needs and guide them in providing situated co-produced family caregiving. The welfare sector could also critically reflect on how to support families with limited capacity to contribute into the situated co-produced family caregiving. The currently provided service could indicate that a well-established capacity is needed to handle and live well with dementia. Home-based caring service seems beneficial to support families to live with dementia and maintain their social life, but it concurrently seems to negatively influence the family caregiver's health, potentially ending as patients themselves. Speculatively, it is particularly hard for those families with limited capacity to provide situated co-produced family caregiving. The PhD findings indicate that family caregivers are mostly left alone in providing home-based caregiving.

5.5. CONTRIBUTION TO HOME-BASED CARING PRACTICE FOR HOME-DWELLING PEOPLE WITH DEMENTIA

The PhD study contributes to the existing literature on home-based caregiving to home-dwelling people with dementia by introducing situated co-produced family caregiving illustrated through a co-produced preventive caring practice. Thereby, the findings contribute by highlighting home-based caregiving to home-dwelling people with dementia as highly complex, dynamic, and situated involving an ecosystem of social relationships and social interactions. The situated co-produced family caregiving is unpredictable and temperamental, which exceeds individual competencies to manage dementia.

Approaching the analysis of home-based dementia care through the lens of co-production reframes the perspective towards the dynamic interplay between the family caregivers and healthcare professional's active contribution into services, rather than focusing on them as separate units. This perspective emphasizes the active contributions of both service providers and service users, including family members in their dual role supporting service provision and being service co-users. This knowledge contributes with adding reflections to practice on guiding family caregiving navigating the complexity in providing home-based caregiving for home-dwelling people with dementia.

5.6. CONTRIBUTIONS TO THE USER CO-PRODUCTION CONCEPTUALISATION

Overall, this PhD study contributes with empirical insights and to a deeper understanding of co-production and contributes with examples on co-production as a dynamic ever-changing concept in home-based care to home-dwelling people with dementia.

Co-production is argued to be dynamic and ever-changing, as it is situated in practice. Practices are infiltered in different contextual logics, and therefore the definitions depends on the purpose to which why they are put (Loeffler & Bovaird, 2021). When working with co-production, an important reflection becomes to consider which definitions suit, and consider its adaptability into practice (Loeffler & Bovaird, 2021). Whether co-production appears as a part of service provision, research or a third.

Findings from the Scoping review highlight a consensus in applying co-production as a collaborative approach, where all parties make a substantial contribution into the process. Two main thematics were identified: 1) situated co-production and 2) co-production as an approach for stakeholder involvement, thereby being situated in different contextual logics, why different understandings and conceptualisations are drawn upon. However, the scoping review also highlighted a lack of clarity and coherence how the included studies understand co-production, the choice of definition, and conceptualisation in relation to its purpose and outcomes (Egilstrøð, Wegner, et al., 2025).

Accordingly, the findings from the scoping review highlight how the lack of consensus can lead to speculation about using co-production as a buss word for involving public. When concepts are blurred and not clearly defined or conceptualised, it can foster mistrust and confusion, affecting the service solution, whichever co-production is applied in the development phase, in services, or research (Masterson et al., 2022). This can moreover lead to unintended consequences, as the purpose of the involvement becomes unclear, leading to tokenism where their participation is superficial and lacks genuine impact (J. F. Pedersen et al., 2022).

The empirical insights from the fieldwork contribute by unpacking the complexity of co-production and contributing with examples about how co-production can be situated in a highly complex dynamic interactional process. These findings also contribute with a deeper insight into the understanding on co-production, and thereby add reflections to the knowledge gaps identified in the scoping review.

The following gaps were identified within the scoping review on co-production:

- No studies focused on the involvement of older adult citizens, including people with dementia and their relatives, as co-producers

in decision-making processes within service provision (Egilstrøð, Wegner, et al., 2025)
- Knowledge is sparse about co-produced services within health service among older adult citizens, including people with dementia and their relatives (Egilstrøð, Wegner, et al., 2025).
- Clarification is needed on how co-production is applied and embedded in practice, and different co-production processes and their impact on different contextual practices (Egilstrøð, Wegner, et al., 2025).
- Knowledge is needed on how to structure co-production processes in practice across the three types of co-production (Egilstrøð, Wegner, et al., 2025).

The outlined knowledge gaps also reflect that co-production is a concept taken down from a shelf and being applied, either as an involvement strategy or as an analysis concept to investigate practice. In most of the studies, which drew on co-production as an analytical concept, there was a poor link to the empirical studies. Therefore, based on the scoping review, it was difficult to gain insight into the situated co-production. However, the PhD findings from the ethnographic fieldwork succeed to study the situated co-production and highlight the complex ever-changing dynamic related to the conception, as co-production always involve ongoing interactions. Thereby, these findings contribute into existing literature within health service among older adult citizens, including people with dementia and their relatives.

The knowledge gaps are therefore also modified accordingly to the empirical insights. Leding to the followed knowledge gaps identified:

- The purpose on choosing co-production within studies are unclear, and likewise the process on the active involvement in co-production processes in pre-determined services, following the co-production phases from co-designing, co-delivery, and co-assessment. A better understanding of co-production across different contextual logics within health services towards older adult citizens, including people with dementia and their relatives, is still needed.
- Few studies focus on situated co-produced services, and we lack knowledge in relation to understand co-production as a dynamic, ever-changing concept. More studies are needed to provide a better understanding of situated co-production within older adult citizens, including people with dementia and their relatives.

This PhD study has an analytical standpoint based on user co-production (Loeffler & Bovaird, 2020), exceed the service-provider and service-user relationship, by involving the family caregiver. The findings demonstrate that user co-production is situated and dynamic and changes over time; it unfolds in a complex social process involving multiple actors. The PhD study's findings indicate that user-co-produced services only constitute an analytical frame for interactions between professionalised service providers and service users, and thereby only guides the direction for the dyadic relationship between a service-provider and a service user. Based on this PhD study, I argue to redefine the presented current definition of user and community co-production by Loeffler & Bovaird, (2020)

User and community co-production defined as:

"The provision of services through regular, long-term relationships between professionalized service providers (in any sector) and service user or members of the community, where all parties make substantial resource contribution" (Bovaird, 2007, p. 84).

In the following, I will argue for the need to redefine and refine the current definition. Initially, I argue to separate user and community co-production as these two contexts involve different contextual logics and, from a Goffman perspective, different normative expectations constituting the social behaviour. Secondly, I argue to cross out 'long-term relationships', as it can be difficult to define when there is a long-term relation. The definition of service provision should neither be restricted to long-term relationships, as suggested by the current definition. Dementia often involves intense, short-term interactions that are no less significant. Thus, the definition should be flexible enough to encompass both short- and long-term relationships, recognising that the nature of care—such as the urgency and intensity of dementia—can require more immediate or temporary forms of support. Thirdly, I argue to extend the definition to involve the complex ecosystem of social relations, involving both professionalised service provider, the service user, but also those who do not directly use the services but support the service-provider and service user, therefore also being co-users of the service. This complex dynamic needs to be considered when understanding user co-production within healthcare, where family or informal caregivers are substantial contributors to the co-produced services.

I argue to define user co-production in a triadic relationship as follows:

User co-production defined as:

“The provision of services through regular relationships between professionalised service providers (in any sector), service user, and other members supporting the service providers and service user in co-producing services, where all parties make substantial resource contribution."

A refined definition could also support academia and service organisation in choosing a suitable definition.

CHAPTER 6. METHODOLOGICAL STRENGTHS AND LIMITATIONS

In this chapter, I discuss the study's methodology and methodological considerations throughout the research process. To discuss the methodological strengths and limitations, quality criteria for qualitative research outlined by Lise Justensen and Nanna Mik-Mayer are applied (Justesen & Mik-Meyer, 2012). The overall ethnographical fieldwork strengths and limitations are discussed from quality criteria coherence, transparency, and reflexivity applied throughout the research process. In contrast, the scoping review's methodological strengths and limitations are discussed by applying coherence and transparency, and additionally, only for scoping reviews, precision and recall as quality criteria.

6.1. COHERENCE AND TRANSPARENCY IN THE ETHNOGRAPHICAL FIELDWORK

To strengthen my PhD study, I have strived to adhere to coherence and transparency throughout the research process. Coherence refers to a logical connection between the components in the study and, thereby, a logical connection between the research question, philosophy of science, data collection, analysis strategy, and presentation of findings and conclusion (Justesen & Mik-Meyer, 2012). Transferability refers to a high degree of explicitly of the research choice made in the research process (Justesen & Mik-Meyer, 2012). Applying Carter and Little's relational model to research coherence is seen as a strength to support reaching coherence and transparency in the research process and, thereby, the validity of the results (Carter & Little, 2007; Justesen & Mik-Meyer, 2012). The model has contributed with a continuous reflection on being explicit about the methodological choices through the research process and how epistemology, methodologies and methods, and analysis influence each other and the knowledge production. This study has its strength in its coherence and has its pitfalls in handcrafting the ethnographic fieldwork and thereby executing the PhD study and bringing the different ethnographical skills into play at once, covering the participant, the observer, the pragmatist, the diplomat, and the analyst all at once. Strengths and limitations in this regard will be elaborated below.

6.2. ETHNOGRAPHIC FIELDWORK WITH A SOCIAL CONSTRUCTIVIST APPROACH

Considering the overall objective of this study, choosing ethnographic fieldwork with a social constructivist approach strengthens the ability to gain in-depth knowledge of the situated co-production processes as a social phenomenon. The ethnographic fieldwork has allowed a flexible approach to modelling the research process and exploring situated co-production processes. Co-production has conceptual ambiguities that implicate ambiguity in the situated co-production processes. The ethnographic fieldwork allowed me to follow the phenomenon and be interactive and in dialogue between my observation, interaction with the participants, and the development of the research process. This is seen as a strength as it has allowed a knowledge production both towards the conceptualisation of co-production and the situated co-production processes and contributing with insight to situated co-produced family caregiving for home-dwelling people with dementia. Moreover, a strength has been to support the ethnographic fieldwork being inspired by Sarah Pink and Jennifer Morgan (Pink & Morgan) Short-Term theoretically informed ethnographic. This has supported the continued focus on the ethnographic-analytical-theoretical dialogue, moving between the theoretical and previous empirical insights and bringing them into play during my observations and vice versa (Pink & Morgan, 2013). Enabling this process, I combined a scoping review with field visits, which strengthened the focus to gain knowledge on how co-production as a theoretical concept is applied to practice, but also delve situated co-produced family caregiving by centring about these three sub-objectives.

- To identify and chart the application of co-production within research in community health services among older adult citizens, including people with dementia and their relatives (Paper I).
- To explore how co-produced care and support for persons living with dementia is negotiated over time in a triadic relationship between the family caregiver, healthcare professional, and the person living with dementia (Paper II).
- To explore situated co-produced family caregiving by analysing the problem perspective and problem-associated solutions approaching situated co-produced family caregiving (Paper III).

Applying social constructivism allowed to stay flexible in the research process, and to continuously adjust the PhD study's rational and aim in the practice where the study is embedded, together with relevant and affected actors, family caregiver, dementia service provider's representatives, and Alzheimer's Association's representatives. One of the core assumptions within social constructivism is that knowledge and meaning are not fixed entities, but are continuously created and reshaped through social interaction (Burr, 2015). Moreover, a social constructivist perspective has allowed a scientific contribution of social constructivist perspective to enrich my understanding of co-production as a social phenomenon. Social constructivism offers significant contributions to understanding co-production as a dynamic social phenomenon shaped by interactions and contextual practices. Through a social constructivist lens, co-production is studied as deeply embedded in social encounters and evolving relationships between healthcare professionals and family caregivers (K. B. Pedersen, 2012). This has been a strength in this study because it allowed to study the situated co-production processes as a dynamic and ever-changing concept swayed by social interactions.

The scoping review and the ethnographic fieldwork will be discussed separately in the following, as they require different logical connections to reach coherence. First, the ethnographic field is elaborated, followed by the scoping review's methodology.

6.3. METHODS FOR DOING ETHNOGRAPHIC FIELDWORK

Applying ethnographic fieldwork with a social constructivist perspective and employing participant observation, including ethnographic interviews, field notes, and field journals, is seen as a strength for reaching coherence in the research process. Moreover, combining different methods that complement each other and contributes with a deeper and nuanced understanding of situated co-produced family caregiving strengthens the study (Tjørnhøj-Thomsen & Whyte, 2012). Inspired by the Short-Term Ethnography, the field visits were executed within approximately four months. The Short-Term Ethnography works with a compromised time intensity lasting for weeks- or months rather than years in opposition to long-term ethnographic fieldwork (Pink & Morgan, 2013). In research studies where the research question can be set precise and delimit, this way of conducting fieldwork may be a strength. However, in the present study, the choice of this time frame can be discussed, as it becomes questionable whether I reached sufficient analytical insights in situated co-produced family caregiving and studying the complex social processes, which is one of the strengths in conducting ethnographic fieldwork. This PhD project could benefit from prolonging the fieldwork and balancing a dialogue between the participant observation with continued analytical insights. In closing, hanging around becomes an important method for recruiting participants in vulnerable groups, and when reducing the timeframe for the field visits also implicates the possibility of hanging around and building trust between the researcher and the family caregivers in opening their homes and hearts (Tjørnhøj-Thomsen & Whyte, 2012). Adding this time frame may, therefore, be a limitation within this PhD study.

6.4. ANALYSING CO-PRODUCED FAMILY CAREGIVING

Applying Braun and Clarke's flexible analysis strategy to analyse patterns of shared meaning units is a strength of this PhD study. It supports its coherence for this PhD study and contributes with transparency and stringency through the analysis process. Moreover, this analytical strategy has been applicable as it allows for flexibility and accommodates multiple analytical approaches. This helps prevent a one-dimensional analysis that reduces decontextualized data to a purely thematic treatment, instead enabling their recontextualization within a new framework of categories (Atkinson, 2015). Therefore, combining different analysis strategies, such as a diachronic and functional analysis strategy, strengthens this PhD study as it supports analysing the complexity of the data regarding the temporality and contextual information.

6.5. RECRUITMENT STRATEGY AND ACCESS TO THE FIELD

A strength of this study was the recruitment of diverse families varying in age, educational level, socio-economic position, and residential areas. However, most of the families participating were middle-class families. Most of the family caregivers were female, specifically 17 out of 23 family caregivers. This reflects the prevalence of female family caregivers in Europe, where it is estimated that approximately 83% of family caregivers are female while 17% are male (Alzheimer Europe, 2018). While the high percentage of female participants may seem unbalanced, it is representative to the caregiving demographic. There was no variety in ethnicity, as no ethnic minorities participated in the project nor in the services where I visited. Some of the eligible participant groups have, therefore, not been recruited for this project, e.g., lower and higher classes and ethnical minority groups, even though their voices are important in understanding situated co-produced family caregiving and the complex dynamics at play. Including these groups could have strengthen the analysis on the different approach in handling situated co-produced family caregiving, as it could deepen the analysis highlighting families' capability to provide situated co-produced family caregiving to home-dwelling people with dementia, explored in paper III (Egilstrøð, Petersen, et al., 2025).

Parts of the recruitment were challenged during this project. This comprised recruiting participants with resource constraints and the COVID-19 lockdown.

Dementia is one of the illnesses that need time-intensive support (Alzheimer Europe, 2018). Family caregiving involves significant responsibilities and complexities in providing care and support, including logistical tasks entwined with emotional challenges (Egilstrod et al., 2018). Therefore, family caregivers often lack resource constraints to participate in research (Ellard-Gray et al., 2015). Combining these conditions with the aftermath of the COVID-19 lockdown – during which both municipal and voluntary services struggled to reach family caregivers and people with dementia and involve them in available services – challenged the recruitment process. In this context, it has been challenging for family caregivers to open their homes and hearts as they struggle to manage everyday life. Participant resource constraints are a well-known phenomenon in research, where people faced with the stresses of daily life often deprioritise participating in research (Ellard-Gray et al., 2015). To address this challenge, different sampling strategies were applied, along with a few simple participation criteria, in order to meet and recruit as many family caregivers as possible and ensure broad participant eligibility (Ellard-Gray et al., 2015). A pallet of recruitment strategies were applied to reach as many families as possible, combining purposeful, maximum variation, gatekeeping, snowballing, and hanging around. The planning of the recruitment strategies is a strength, considering the vulnerability. However, the practical challenges of involving families with dementia in research can be seen as a limitation in itself. I was unable to recruit people from disadvantaged neighbourhoods or families with complex social challenges. However, these families are not only difficult to reach in research but also for public health programs and services in general (Shaghagi, Bhopal, Sheikh 2011). The recruitment strategies where I succeeded were through a top-down approach. I recruited the families through representatives who were already in touch with the families: The Knowledge Center for Dementia, and thereby through the municipality recruitment services, the Alzheimer Associations, and the DanChurchSocial. This both represents a strength, but may also have been a limitation of the study, as the organisation acts as a gatekeeper and influences whom I could get in contact with.

6.6. THE SCOPING REVIEW'S COHERENCE AND TRANSPARENCY

Conducting a scoping review has strengthened this PhD study by exploring the comprehensiveness of the body of literature, assessing the nature of research activity on co-production in health services for older adult citizens, including people with dementia and their family caregivers, and identifying knowledge gaps. We systematically followed Levac et al., (2010) guidelines for conducting a scoping review to structure the review process and reach coherence and transparency in the research process. These guidelines support a logical cohesion between the research processes, the type of review, the methodologies and analysis strategy (Levac et al., 2010). Levac et al., (2010)'s work adds to the work by Arksey & O'Malley, (2005), where the guideline is tested to refine and enhance the methodology for conducting scoping reviews, and to add precision to the research process and, thereby, add validity.

We added transparency to the process by following Levac guidelines for conducting reviews and PRISMA's procedures for reporting scoping reviews, and we additionally added a search protocol (Levac et al., 2010; Tricco et al., 2018). The framework is systematically followed, describing each step and visualising elements involving the search strategy and the analysis process to enrich the transparency. I especially sought to describe the analysis process in detail, as Levac et al., (2010) have criticised the lack of description. Applying these guidelines and the search protocol supported being explicit throughout the review process, thus adding transparency.

6.7. BALANCING PRECISION AND RECALL THROUGHOUT THE REVIEW PROCESS

Approaching the scoping review process with high comprehensiveness represents a strength in this PhD study, because it enhances the identification of the comprehensiveness of the body of the literature and the nature of research activity within co-production in health services among older adult citizens, including people with dementia and their family caregivers.

Precision and recall are critical quality criteria for evaluating the precision and relevance of retrieved information in all types of literature reviews. These two concepts refer to the accuracy of the search in terms of finding relevant publications and number of publications retrieved. Recall indicates the ratio between the number of relevant publications found and the total number of relevant publications in a database, while precision indicates the ratio between the relevant publications found overall in relation to the selected literature (Butt & Hussain, 2021; Buus et al., 2008).

There is an inversely proportional relationship between precision and recall. If the search precision increases, recall decreases, and a growing number of relevant references are not found. Conversely, an increase in recall leads to identifying more potentially relevant, but also produces more irrelevant results, reducing the precision and creating 'noises' (Buus et al., 2008).

In the first screening process, two-thirds (67%) were excluded while one-third (33%) was included for further investigation. This resulted in a large number of unwanted, irrelevant hits that had to be manually processed, increasing the risk of overlooking relevant references in the review process (A. Campbell et al., 2018). An additional strength of this scoping review is the careful consideration of balance in the review process, along with thorough planning to align the process with the study's aim and the suitability of databases for retrieving relevant references. The aim of this study calls for a comprehensive search strategy with a high recall and low precision. Moreover, the aim covers a cross-disciplinary research domain, comprising health and social science. Reaching comprehensiveness in information sources, covering six databases across biomedical science and social science, represents a strength. Databases in social science are often less stringent, as the use of controlled terms are not applied across the social science databases with the same rigour as medical databases (Papaioannou et al., 2010). Adding more databases can strengthen more relevant studies, accepting a higher comprehensiveness and a lower precision in the search (Papaioannou et al., 2010).

To balance and ensure to retrieve all relevant hits and minimizing unwanted hits (A. Campbell et al., 2018), precision was added to the search strategy following the recommendation by Jonna Briggs Institute, focusing the research question and operationalize it into the P*(Patient)* C*(Concept)* C*(Context)* process.

Throughout the review process, I have been in dialogue with a librarian with expertise in search strategies and in conducting reviews. This has qualified the review process, refining the systematic search, and supporting the selection on search databases. I was also in dialogue with previous family caregivers, with service-provider's representatives from the municipality, and the Alzheimer's association discussing the findings and their practical value, which strengthens and helps to qualify the scoping review (Levac et al., 2010; The Joanna Briggs Institute, 2015).

CHAPTER 7. PRACTICAL IMPLICATIONS

The findings presented in this PhD thesis are particularly relevant as a reflection to practice working within home-based caregiving for home-dwelling people with dementia, where family caregivers play a key role as contributors to home-based caregiving. This involves healthcare professionals encountering the family caregiver and the person with dementia, and those who work at an administrative level facilitating and designing the home-based caregiving services.

Given the importance of supporting family caregivers to provide home-based family caregiving to home-dwelling people with dementia, there is a need to reflect upon the double bind in co-producing a person-centred caring practice, where a co-produced preventive caring practice becomes dominating. On one hand, it enhances the person with dementia's ability to maintain everyday life routines and participate and engage in social life; on the other hand, it puts a pressure on the family caregiver being the one who needs to deal both with managing the dialogue meetings and providing home-based family caregiving. Family caregivers are at increased risk of developing psychosocial illnesses, such as stress, anxiety, and depression, and end up as patients themselves. Even though the preventive caring practice is meant to be helpful and support the whole family living well with dementia, it is paramount to reflect that this can oppress the actual severity of dementia, hindering the healthcare professionals from providing sufficient support to the family.

On a relational level, in the meeting with families, healthcare professionals must reflect on how to address the family caregiver’s needs, as it tends to go under the radar, and how to navigate uncovering the family caregiver’s needs, as it involves a high complexity. Family caregiver’s needs for support originates differently as emphasised in the findings. Situated co-produced family caregiving is approached differently due to conflicting normative expectations to family caregiver’s co-production roles, and the capacity to contribute into the situated co-produced family caregiving. It is especially important to pay attention to the primary family caregiver, who is often the spouse, as other family caregivers tend to reduce their involvement long before the spouse. As a result, spouses often end up providing home-based care and support alone, leading to self-isolation. However, this places high demands on the DSCs, who are main responsible for assessing the families’ support needs. Therefore, there is a need on a service system level to support the DSCs.

On a service system and organisational level, policies could reflect on how to organise services to support healthcare professionals in the encounter with family caregivers to discuss and share reflections about ethical dilemmas and caring responsibilities, which arises as dementia progresses. In this way, family caregivers could receive better emotional support and have opportunities to discuss how to best support people with dementia while also prioritizing their own well-being, which often is an unmet need by family caregivers. When the challenges get out of control, healthcare professionals seem to be left alone in supporting family caregivers emotionally, provided as an ad-hoc service. It is recommended to intervene early and provide one-on-one dialogues to address the actual, allowing family caregivers to speak freely without constantly worrying about avoiding direct confrontations that could harm the person with dementia. Accordingly, emotional challenges and caring-related challenges can be addressed, notably as dementia progresses, at it becomes too sensitive for the person with dementia to participate. This could also function as a way to show consideration both towards the person with dementia and the family caregiver. In this way, the preventive caring practice can be maintained simultaneously as there is a reflection towards the unintended consequences of this caring practice oppressing the severity of dementia. When designing services to support family caregivers, it could be beneficial to involve them. This could also be former family caregivers to better targeting services towards the family caregiver. Former family caregivers have often processed some of their experiences and gained a distance from their experiences living with a person with dementia, allowing them to reflect retrospectively on the entire journey. Many family caregivers go unnoticed because there is a paramount focus on supporting personhood and maintaining a sense of normalcy in everyday life, often overlooking the challenges they face. Involving the family caregivers could create a better understanding of situated co-produced family caregiving and how family caregivers contribute to home-based caregiving to home-dwelling people with dementia.

The findings also provide an important societal contribution by offering insight into the significance of raising public awareness about dementia. By spreading knowledge about dementia, it can become easier for families to participate in social settings and maintain their citizenship within society, embracing the aberrant behaviour that follows instead of constantly downplaying to appear ‘normal’.

CHAPTER 8. CONCLUSION

This PhD study contributes with knowledge on how family caregivers contribute into the home-based dementia care, through situated co-produced family caregiving. This study contributes knowledge on how family caregivers' dominant strategy in situated co-produced family caregiving is provided through preventive caring practices in their encounters with others.

Preventive caregiving practices are co-produced through face-saving strategies aimed at protecting the social dignity of people with dementia. The primary goal is to maintain everyday normality and preserve the dominant family narrative despite the progression of dementia and associated behaviours. These strategies emerge within complex social interactions influenced by normative expectations, social roles, and social identities.

Family caregivers navigate different social contexts, including interactions with healthcare professionals, family members, and friends. Encounters with healthcare professionals and patient associations like the Alzheimer Association often allow for open discussions of dementia symptoms due to an inclusive social script. In contrast, social gatherings with family and friends are often less accommodating, requiring negotiation or concealment of dementia symptoms.

To maintain social harmony in such settings, dementia symptoms are often downplayed. This face-saving practice not only preserves dignity but also limits contributions from other caregivers as dementia progresses. Findings in the present PhD study also highlight how other family caregivers and friends use evasive actions to reduce their contribution into situated co-produced family caregiving, and to avoid direct confrontation. This reflects a compassionate effort not to abandon the primary family caregiver or confronting to fail the caring responsibility.

These dynamics reflect the complex and often vulnerable situation of providing situated co-produced family caregiving for home-dwelling individuals with dementia.

Co-producing preventive caring practice can be seen as a contributory factor in the experienced caregiver burden. However, it is evident that family caregivers experience a high caregiver burden and an increased risk of developing psychosocial illnesses, such as stress, anxiety, and depression, potentially becoming patients themselves.

In light of the findings from this PhD study, supported services embedded within the welfare state become essential, as dementia exceeds the capacity of individuals and families to manage on their own. However, it is essential to continuously subject services to critical scrutiny and strive to align the services to match the needs of family caregivers if the welfare state's services are to fulfil their purpose.

There is a need to focus on the double bind of co-producing a preventive caring practice to maintain normality in a progressive illness involving aberrant behaviour, which becomes difficult and complex to manage.

Although preventive caring practices are intended to be helpful and support the entire family in living well with dementia, it is crucial to recognize that this may oppress the actual severity of the condition. This can hinder healthcare professionals from providing adequate support to the family and may also contribute to psychosocial illnesses among family members, such as stress, anxiety, and depression.

The PhD study contributes with practical implications by providing knowledge on how to guide family caregivers in navigating the complex compass of normative caregiving expectations and associated strategies for providing situated co-produced family caregiving to home-dwelling people with dementia. This is achieved by addressing and reflecting on dilemmas that arise early in the caregiving process when a preventive caring practice becomes the dominant caring strategy. Addressing and reflecting on these dilemmas can support both healthcare professionals and family caregivers. Both for healthcare professionals and for family caregivers, addressing and reflection upon dilemmas that arise when using a preventive caring practice can give rise to acting differently.

When family members become co-users of a service that is not directly aimed at them but is provided out of necessity, it is important to consider whether family caregivers receive sufficient support through available services.

These findings can also be analytically generalised to other illnesses where co-produced preventive caring practice is a widespread caregiving strategy. This could include other chronic diseases and disorders, particularly mental health conditions, where aberrant behaviour is often invisible and tends to go unnoticed. As a starting point, people will always present themselves as a finished product – polished, finished, and packaged. The long, tedious hours of labour will remain unseen, and all evidence of the 'dirty work' will be concealed, as outlined by Goffmann.

Future research should continue to deepen the understanding of situated co-production processes, with a focus on the highly complex social interactions involved in providing home-based caregiving. Exploring these processes from different perspectives, across both healthcare professionals and family caregivers, could be beneficial. Additionally, further studies are needed on situated co-production in triadic encounters between family caregivers, individuals with dementia, and healthcare services, aiming to organise services to better meet the needs of families living with dementia.

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Appendix A. Interviewguide for semi-structured interviews

Interview guide		
Themes	Questions	Supplementary questions
Dementia diagnoses	Can you tell me about, which type of dementia (name) has?	
Diagnostic assessment	Did (name) get a diagnostic assessment? And when was that? Alternative questions were: When is the diagnostic assessment planned? Some people never get the dementia assessment but are diagnosed based on their symptoms. In these cases, this question was asked.	
The everyday life experience of the initial observations of dementia / the diagnostic phase /	Can you tell me a bit about how you noticed something was changing? How did you contact the healthcare system or municipality concerning your suspicion?	What happened next? Can you tell me more about this?
Changes in daily life leading to changes in the role	I want to return to your daily life. How has it changed, especially for you?	
Changes in the role	Can you recall what you did when (name) had been diagnosed and you became a caregiver and the transformation in your life?	
Preparing for the future	Generally, when unexpected things happen, people can go into crisis mode, planning and preparing for the future. I mean, how were things for you?	

	Many people start thinking about the future when serious illness arises. Have you given it any thought?	
Support from the Health system: Municipality, Dementia Unit, and General Practitioner	How did you experience the meetings with the healthcare units? Can you describe what your role has been?	If it is difficult to talk about 'the role' supplementary questions were used: - What kind of services do you participate in? - Can you tell me about these meetings?
Background information	I'd like to ask a few questions about your age, family relationships, employment, etc. How old is (name)? How old are you? How long have you been together, and are you married? Do you have children? Where do they live? Employment: Retired/working?	
Informal network	How did your experience with your network react when the diagnosis was disclosed? How are things now? Is there anyone you can ask for help?	
Participatory social network map: 1) mapping the social network 2) understand the social network		
Informal network	Mapping: We'll start by creating a 'network map.' Let's begin with the two of you – we'll place you here (I'll show them where to draw). If we start with family members, friends, and acquaintances first, and then move on to local community associations and, finally,	Understanding: Guiding the dialouge: Where do ou know him/her/them from? Where do they live? What is your relationship – are they friends, family, or acquaintances? How long have you known them? How often are you in contact? What do you do together?

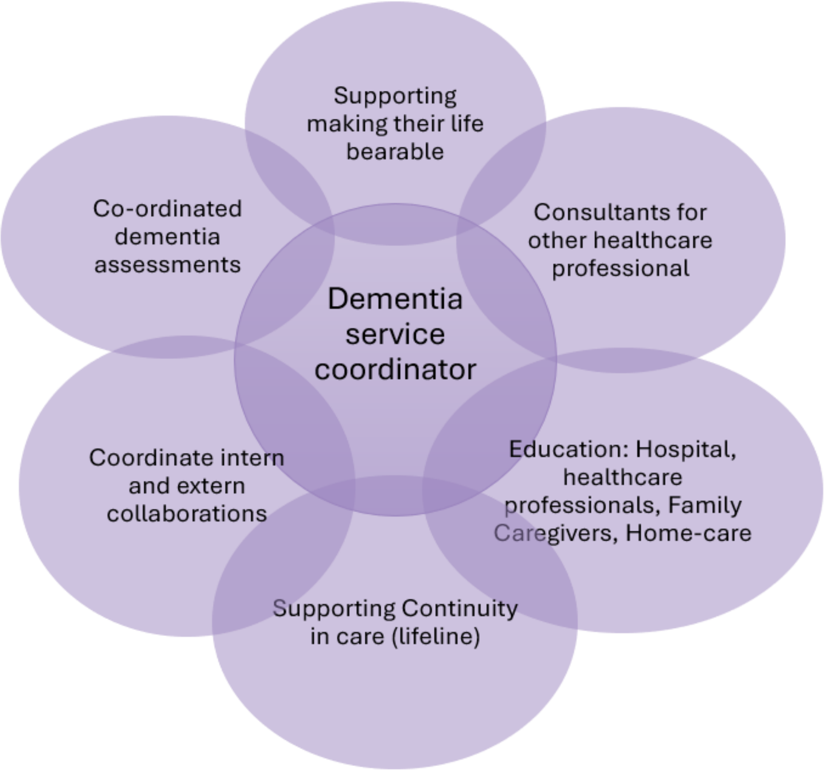
	health professionals/volunteer organizations. Place those closest to you who you feel belong here. Once you've placed the first one, I'll ask some questions about them.	Do they help with practical matters like support or relief? Have you lost contact with anyone during the progression of dementia? Do any of these people know each other?
Formal network	I'd also like to hear about your relationships with professionals and the quality of those relationships. Do you feel heard, supported, seen, and included? Do you feel the professionals understand your situation? I know you are in touch with a dementia coordinator. And a doctor. Are there others who come to your home in a professional capacity? What about organizations like the Alzheimer's Association or the Dane Age Association? If you had to describe the dementia dialogue meetings, what do they typically like? How often do they visit? How would you describe your relationship with them? How do you prepare for a meeting with the dementia nurse? Is there room for you to bring up what you need? Do you feel the dementia coordinators understand your concerns? How do you find the support and services relevant to you? And who makes the decisions?	What about your (specific service relation)? How often are you in contact? Can you tell me a bit about how you experience your relationship with your (specific service relation)?

Appendix B. Interviewguide for focus group interview

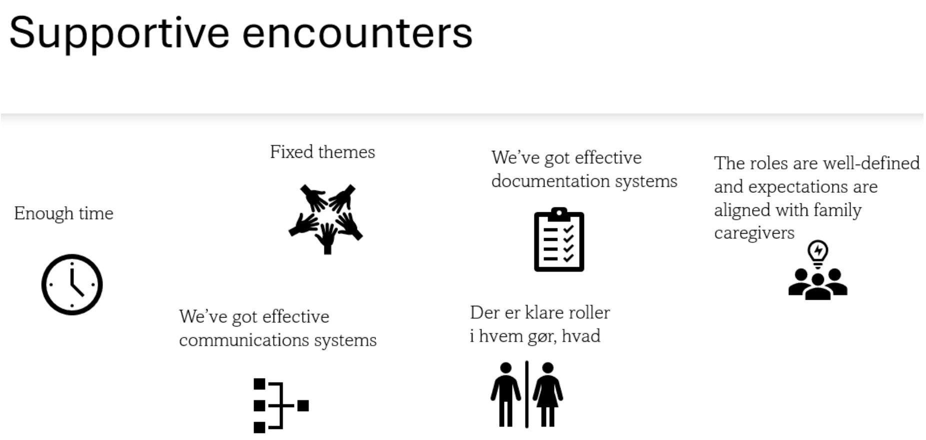
Themes	Main question	Exercises to facilitate the group discussion
The Dementia Service Coordinator's role when supporting situated co-produced family caregiving	What is your core role as dementia coordinators?	Exercise 1: Open discussion about their core role Thematising the core role (se illustration of exercise 1).
	Could you describe three situations, where you act as boundary spanners within the system?	Exercise 2: Posted were handed out to write three main situations Discussed in plenum
	Could you describe some supportive encounters? Could you describe some barrier to supportive encounters?	Exercise 3: The dementia service coordinators were given some illustration, where they should choose those illustration, who they could identity as supportive encounters
Matching of expectations when supporting the situated co-produced family caregiving	How do you match the expectations in family encounters?	Exercise 4: The dementia coordinators plots x's in a coordinate system (no limit on amount of x's) The coordinate systems are discussed in plenum with follow up questions: What plays a significant role in terms of aligning expectations? How does it manifest?
Supporting Family caregivers in providing situated co-produced family caregiving	How do you describe support? Can you describe when you experience a supportive encounter, an especially focus on the interaction?	Exercise 5: Three key words on a post-it Mutual discussion in plenum The dementia service coordinators are given

	What is important for a supportive encounter, and a good interaction? What do you wish for family caregiver? What services are needed?	pictures to discuss, what is most important in relation to family caregiving support.

Exercise 1



Exercise 2



Supportive encounters

Enough time

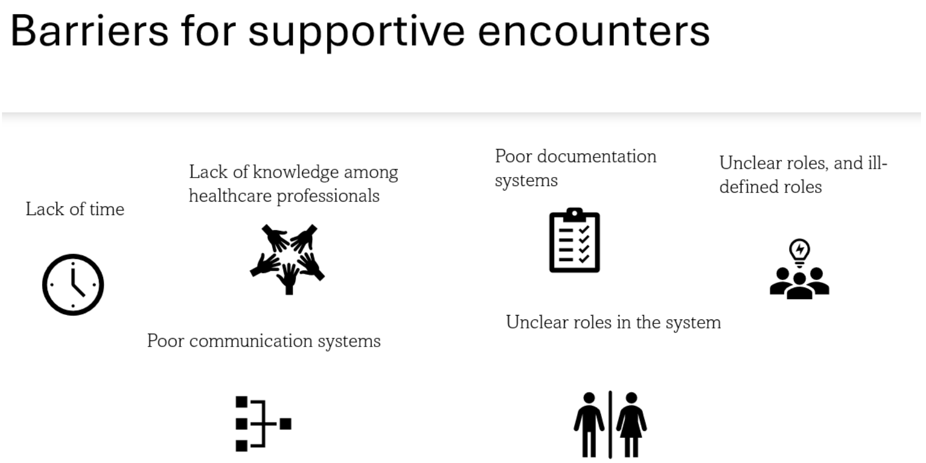
Fixed themes

We've got effective communications systems

We've got effective documentation systems

Der er klare roller
i hvem gør, hvad

The roles are well-defined and expectations are aligned with family caregivers



Barriers for supportive encounters

Lack of time

Lack of knowledge among healthcare professionals

Poor communication systems

Poor documentation systems

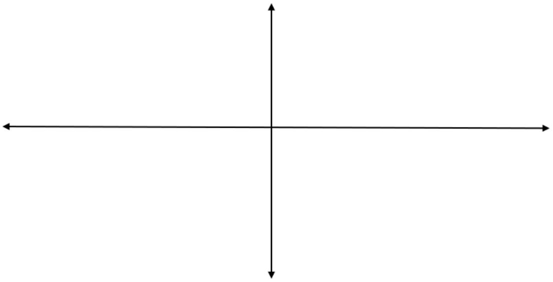
Unclear roles in the system

Unclear roles, and ill-defined roles

Exercise 4

Matching exportations

What's your approach?



Informal conversation

Tool to support the conversation

Intuitive approach

Formel samtale

Exercise 5

What is important when supporting family caregivers?

To listen

To take the family's daily life as a starting point

To consult

To help guide in daily life

To involve the family in decision-making

To ensure knowledge sharing

To ensure proper documentation

Whishing well!

- What services would you wish were available for family caregivers?
  - What do you often find yourselves lacking?

Appendix C. Information material for participants

Vigtig information til dig som deltager

- Din deltagelse i forskningsprojektet sker anonymt og frivilligt.
- Du kan altid fortryde og trække dig fra undersøgelsen.
- Oplysninger og datamateriale, som indsamles i undersøgelsen, vil blive opbevaret i overensstemmelse med databeskyttelsesloven.
- Alle oplysninger behandles fortroligt af mig og mine vejledere. Det, du bidrager med, vil ikke kunne ledes tilbage til dig som deltager i det endelige projekt.
- Du er altid velkommen til at kontakte mig med spørgsmål til projektet eller om din egen deltagelse.

Om mig…

Jeg er PhD studerende på Aalborg Universitet, og er i gang med at undersøge pårørendestøtte i livet med demens. Projektet vil forløbe over en tre-årig periode. Projektet har været i gang siden februar 2021 og forløber til januar 2024.

Kontaktinfo:

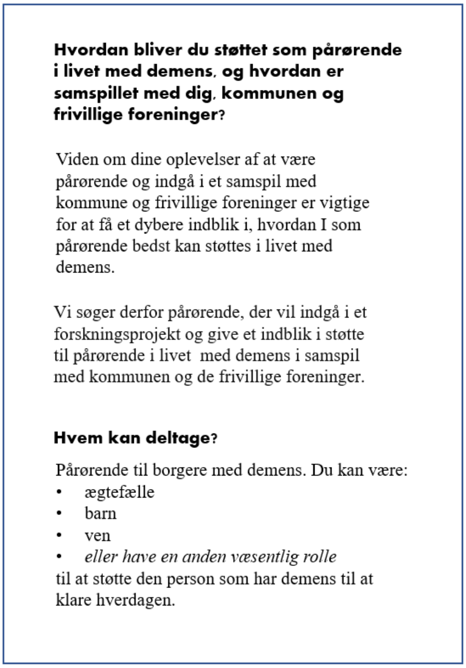
Barbara Egilstrøð

Tlf. nr: 41 83 49 84

Mail: be@hst.aau.dk

Forskningsprojekt

Støtte til pårørende i livet med demens
i samspil
med kommune og frivillige foreninger



Hvordan bliver du støttet som pårørende i livet med demens, og hvordan er samspillet med dig, kommunen og frivillige foreninger?

Viden om dine oplevelser af at være pårørende og indgå i et samspil med kommune og frivillige foreninger er vigtige for at få et dybere indblik i, hvordan I som pårørende bedst kan støttes i livet med demens.

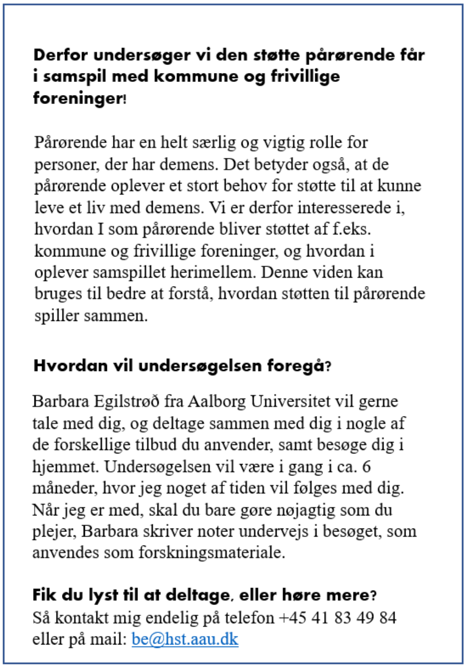
Vi søger derfor pårørende, der vil indgå i et forskningsprojekt og give et indblik i støtte til pårørende i livet med demens i samspil med kommunen og de frivillige foreninger.

Hvem kan deltage?

Pårørende til borgere med demens. Du kan være:

- ægtefælle
- barn
- ven
- *eller have en anden væsentlig rolle*

til at støtte den person som har demens til at klare hverdagen.



Derfor undersøger vi den støtte pårørende får i samspil med kommune og frivillige foreninger!

Pårørende har en helt særlig og vigtig rolle for personer, der har demens. Det betyder også, at de pårørende oplever et stort behov for støtte til at kunne leve et liv med demens. Vi er derfor interesserede i, hvordan I som pårørende bliver støttet af f.eks. kommune og frivillige foreninger, og hvordan i oplever samspillet herimellem. Denne viden kan bruges til bedre at forstå, hvordan støtten til pårørende spiller sammen.

Hvordan vil undersøgelsen foregå?

Barbara Egilstrøð fra Aalborg Universitet vil gerne tale med dig, og deltage sammen med dig i nogle af de forskellige tilbud du anvender, samt besøge dig i hjemmet. Undersøgelsen vil være i gang i ca. 6 måneder, hvor jeg noget af tiden vil følges med dig. Når jeg er med, skal du bare gøre nøjagtig som du plejer, Barbara skriver noter undervejs i besøget, som anvendes som forskningsmateriale.

Fik du lyst til at deltage, eller høre mere?

Så kontakt mig endelig på telefon +45 41 83 49 84 eller på mail: be@hst.aau.dk

FORSKER PÅ BESØG

i 'Aktiv med demens'

I forbindelse med et forskningsprojekt, der handler om at kortlægge og få dybdegående viden om samspillet imellem pårørende, kommuner og frivillige foreninger, er jeg på besøg hos jer.

Jeg vil være til stede i hele ugen og følge de aktiviteter, som 'Aktiv med demens' tilbyder. Det gør jeg for at få dybdegående viden om de aktiviteter, der foregår i 'Aktiv med demens', med det formål at undersøge hvordan 'Aktiv med demens' er med til at støtte familier i livet med demens.

Hvordan påvirker projektet mig? |

Du anses for at være en vigtig del af dette projekt, da det er gennem dig oplysningerne til forskningsprojektet skal komme. Jeg vil være til stede hele ugen, og vil være med i samtlige aktiviteter i 'aktiv med demens'. Vi skal dyrke sport sammen, være kreative, hygge os i caféen og alt det som tilhører. Ved at jeg får lov til at være med kan jeg danne mig et indtryk af, hvordan i som familier bliver støttet i livet med demens. Jeg vil derudover spørge ind til nogle af de ting jeg ser og er med til under mit besøg. Det er nok altid lidt anderledes, når der er nye med på holdet, men gør præcis som du plejer, selv om jer er der.

Ved at deltage bidrager du med viden til forskning!

- Hvordan støtte frembringes i et samspil, når flere aktører bidrager med værdifulde ressourcer, hvor pårørende og borgere med demens også er særlige nøgleaktører.
- Viden er til gavn for pårørende og borgere med demens, kommuner samt frivillige foreninger, da denne viden kan bidrage til at få dybdegående viden om værdien af et samspil samt eventuelle udfordrende forhold, når aktører indgår i et samspil.
- Denne viden bidrager til en helhedsorienteret forståelse af, hvordan pårørende støttes i livet med demens, som vil være med til at give input til, hvordan fremtidig støtte kan tilrettelægges for pårørende til ældre borgere, herunder også borgere med demens, som følge af den demografiske udvikling.

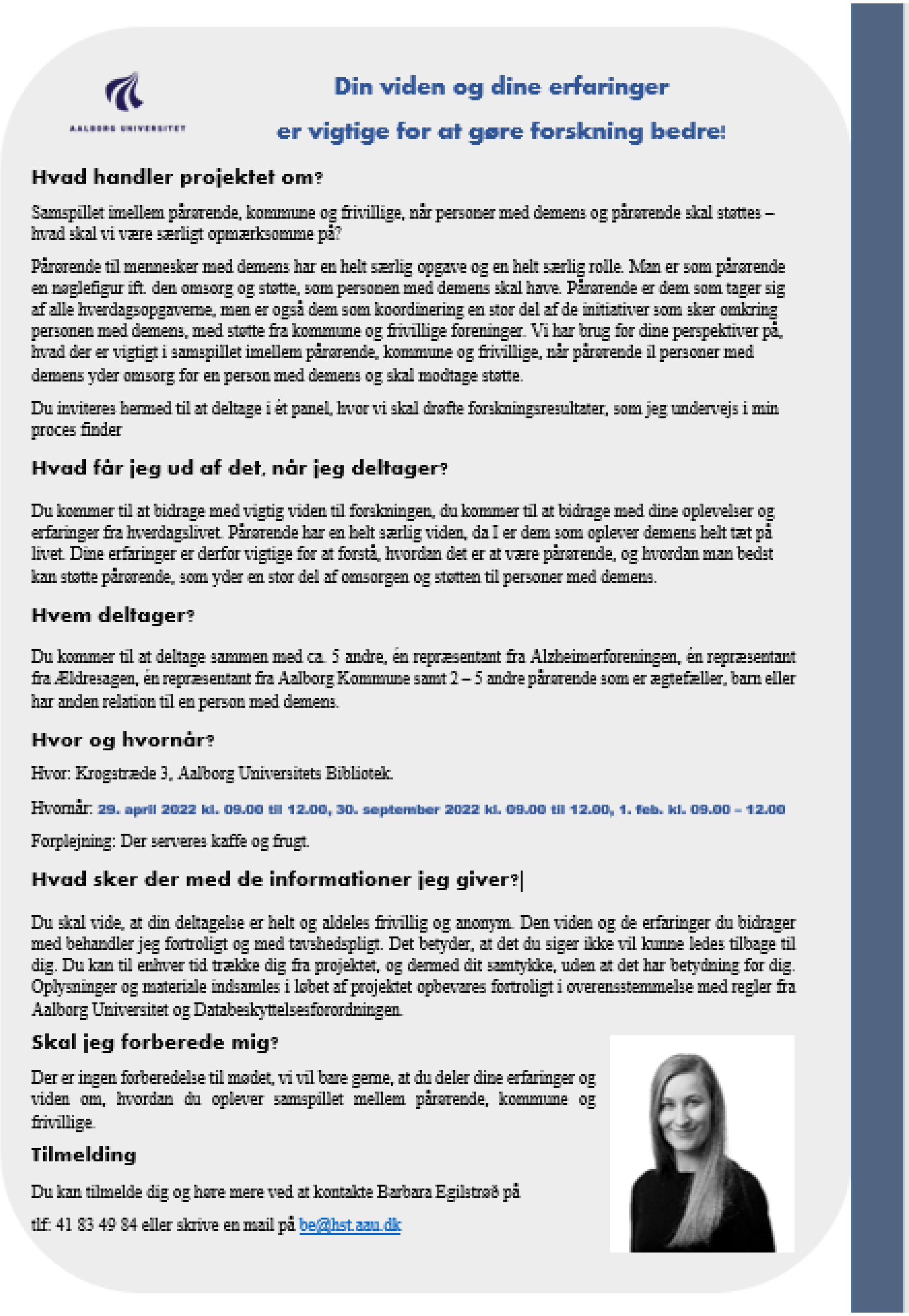
Jeg ville sætte rigtig stor pris på din deltagelse!

Hvad sker der med de informationer jeg giver?

Du skal vide, at din deltagelse er helt og aldeles *frivillig* og *anonym*. Den viden og de erfaringer du bidrager med, behandler jeg fortroligt og med tavshedspligt. Det betyder, at det du siger ikke vil kunne ledes tilbage til dig eller de familier vi besøger sammen. Du kan til enhver tid trække dig fra projektet, og dermed dit samtykke, uden at det har betydning for dig og mulig fremtidig deltagelse i forskningsprojekter. Oplysninger og materiale, som indsamles i løbet af projektet, opbevares fortroligt i overensstemmelse med regler fra Aalborg Universitet og Databeskyttelsesforordningen.

Kontakt

Navn: Barbara Egilstrød | Tlf: 41 83 49 84 | Mail: be@hst.aau.dk



AALBORG UNIVERSITET

Din viden og dine erfaringer er vigtige for at gøre forskning bedre!

Hvad handler projektet om?

Samspillet imellem pårørende, kommune og frivillige, når personer med demens og pårørende skal støttes – hvad skal vi være særligt opmærksomme på?

Pårørende til mennesker med demens har en helt særlig opgave og en helt særlig rolle. Man er som pårørende en nøglefigur ift. den omsorg og støtte, som personen med demens skal have. Pårørende er dem som tager sig af alle hverdagsopgaverne, men er også dem som koordinering en stor del af de initiativer som sker omkring personen med demens, med støtte fra kommune og frivillige foreninger. Vi har brug for dine perspektiver på, hvad der er vigtigt i samspillet imellem pårørende, kommune og frivillige, når pårørende il personer med demens yder omsorg for en person med demens og skal modtage støtte.

Du inviteres hermed til at deltage i ét panel, hvor vi skal drøfte forskningsresultater, som jeg undervejs i min proces finder

Hvad får jeg ud af det, når jeg deltager?

Du kommer til at bidrage med vigtig viden til forskningen, du kommer til at bidrage med dine oplevelser og erfaringer fra hverdagslivet. Pårørende har en helt særlig viden, da I er dem som oplever demens helt tæt på livet. Dine erfaringer er derfor vigtige for at forstå, hvordan det er at være pårørende, og hvordan man bedst kan støtte pårørende, som yder en stor del af omsorgen og støtten til personer med demens.

Hvem deltager?

Du kommer til at deltage sammen med ca. 5 andre, én repræsentant fra Alzheimerforeningen, én repræsentant fra Ældresagen, én repræsentant fra Aalborg Kommune samt 2 – 5 andre pårørende som er ægtefæller, barn eller har anden relation til en person med demens.

Hvor og hvornår?

Hvor: Krogstræde 3, Aalborg Universitets Bibliotek.

Hvornår: **29. april 2022 kl. 09.00 til 12.00, 30. september 2022 kl. 09.00 til 12.00, 1. feb. kl. 09.00 – 12.00**

Forplejning: Der serveres kaffe og frugt.

Hvad sker der med de informationer jeg giver?

Du skal vide, at din deltagelse er helt og aldeles frivillig og anonym. Den viden og de erfaringer du bidrager med behandler jeg fortroligt og med tavshedspligt. Det betyder, at det du siger ikke vil kunne ledes tilbage til dig. Du kan til enhver tid trække dig fra projektet, og dermed dit samtykke, uden at det har betydning for dig. Oplysninger og materiale indsamles i løbet af projektet opbevares fortroligt i overensstemmelse med regler fra Aalborg Universitet og Databeskyttelsesforordningen.

Skal jeg forberede mig?

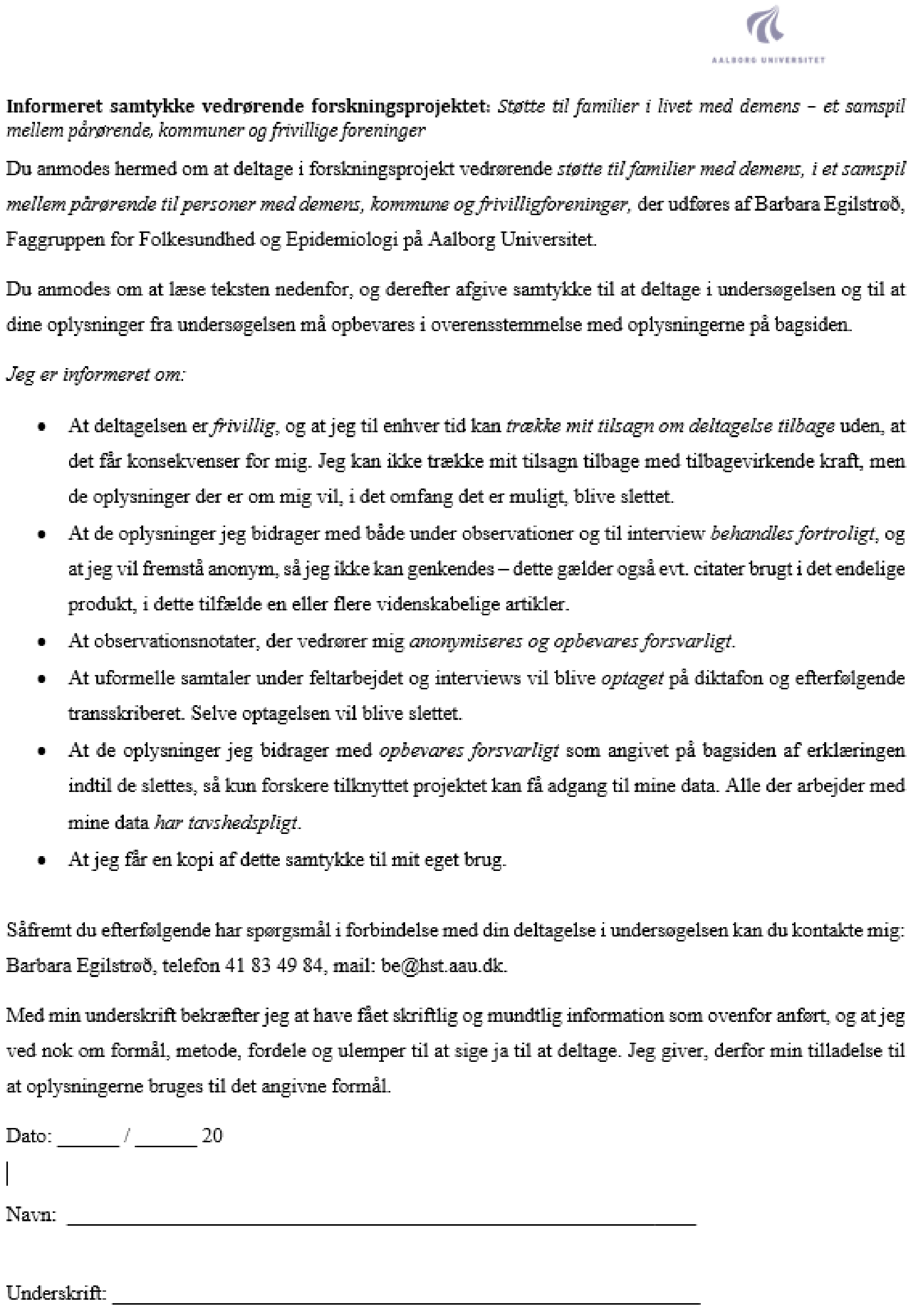
Der er ingen forberedelse til mødet, vi vil bare gerne, at du deler dine erfaringer og viden om, hvordan du oplever samspillet mellem pårørende, kommune og frivillige.

Tilmelding

Du kan tilmelde dig og høre mere ved at kontakte Barbara Egilstrød på

tlf: 41 83 49 84 eller skrive en mail på be@hst.aau.dk

Appendix D. Written consent



Informeret samtykke vedrørende forskningsprojektet: *Støtte til familier i livet med demens – et samspil mellem pårørende, kommuner og frivillige foreninger*

Du anmodes hermed om at deltage i forskningsprojekt vedrørende *støtte til familier med demens, i et samspil mellem pårørende til personer med demens, kommune og frivilligforeninger,* der udføres af Barbara Egilstrøð, Faggruppen for Folkesundhed og Epidemiologi på Aalborg Universitet.

Du anmodes om at læse teksten nedenfor, og derefter afgive samtykke til at deltage i undersøgelsen og til at dine oplysninger fra undersøgelsen må opbevares i overensstemmelse med oplysningerne på bagsiden.

Jeg er informeret om:

- At deltagelsen er *frivillig*, og at jeg til enhver tid kan *trække mit tilsagn om deltagelse tilbage* uden, at det får konsekvenser for mig. Jeg kan ikke trække mit tilsagn tilbage med tilbagevirkende kraft, men de oplysninger der er om mig vil, i det omfang det er muligt, blive slettet.
- At de oplysninger jeg bidrager med både under observationer og til interview *behandles fortroligt*, og at jeg vil fremstå anonym, så jeg ikke kan genkendes – dette gælder også evt. citater brugt i det endelige produkt, i dette tilfælde en eller flere videnskabelige artikler.
- At observationsnotater, der vedrører mig *anonymiseres og opbevares forsvarligt*.
- At uformelle samtaler under feltarbejdet og interviews vil blive *optaget* på diktafon og efterfølgende transskriberet. Selve optagelsen vil blive slettet.
- At de oplysninger jeg bidrager med *opbevares forsvarligt* som angivet på bagsiden af erklæringen indtil de slettes, så kun forskere tilknyttet projektet kan få adgang til mine data. Alle der arbejder med mine data *har tavshedspligt*.
- At jeg får en kopi af dette samtykke til mit eget brug.

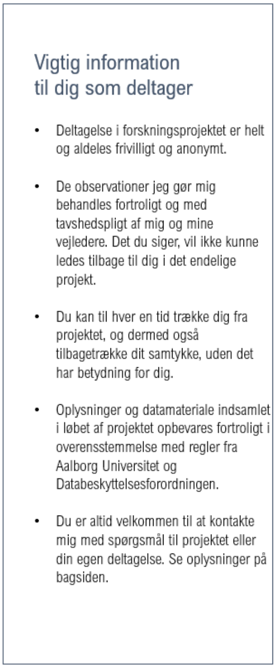
Såfremt du efterfølgende har spørgsmål i forbindelse med din deltagelse i undersøgelsen kan du kontakte mig: Barbara Egilstrøð, telefon 41 83 49 84, mail: be@hst.aau.dk.

Med min underskrift bekræfter jeg at have fået skriftlig og mundtlig information som ovenfor anført, og at jeg ved nok om formål, metode, fordele og ulemper til at sige ja til at deltage. Jeg giver, derfor min tilladelse til at oplysningerne bruges til det angivne formål.

Dato: ______ / ______ 20

Navn: ____

Underskrift: ____



Vigtig information til dig som deltager

- Deltagelse i forskningsprojektet er helt og aldeles frivilligt og anonymt.
- De observationer jeg gør mig behandles fortroligt og med tavshedspligt af mig og mine vejledere. Det du siger, vil ikke kunne ledes tilbage til dig i det endelige projekt.
- Du kan til hver en tid trække dig fra projektet, og dermed også tilbagetrække dit samtykke, uden det har betydning for dig.
- Oplysninger og datamateriale indsamlet i løbet af projektet opbevares fortroligt i overensstemmelse med regler fra Aalborg Universitet og Databeskyttelsesforordningen.
- Du er altid velkommen til at kontakte mig med spørgsmål til projektet eller din egen deltagelse. Se oplysninger på bagsiden.

Hvem er jeg?

Om mig….
Jeg er ansat som forsker på Aalborg Universitet og er projektansvarlig for projektet omtalt i denne brochure.

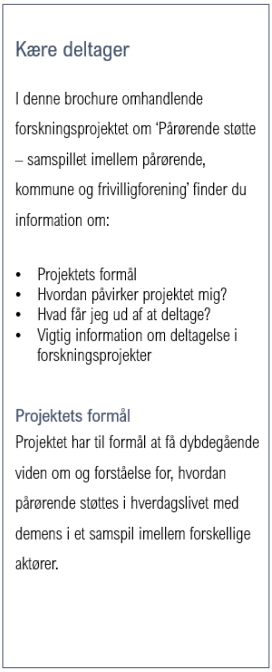
Jeg har en kandidatuddannelse i folkesundhedsvidenskab fra Aalborg Universitet

Kontaktinfo
Navn: Barbara Egilstrøð
Tlf.: 41834984
Mail: be@hst.aau.dk

AALBORG UNIVERSITET
Niels Jernes Vej 14
1.sal, lok. 3-220
9220 Aalborg Øst

Deltagelse i forskning

Pårørende støtte – Samspillet imellem pårørende, kommune og frivillige foreninger



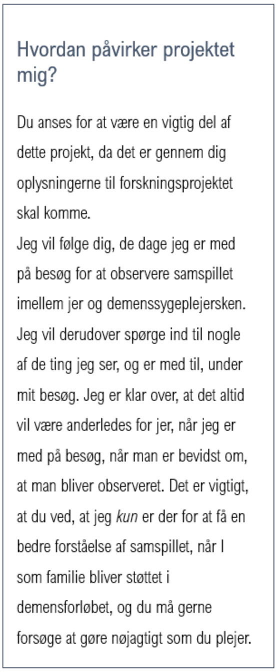
Kære deltager

I denne brochure omhandlende forskningsprojektet om 'Pårørende støtte – samspillet imellem pårørende, kommune og frivilligforening' finder du information om:

- Projektets formål
- Hvordan påvirker projektet mig?
- Hvad får jeg ud af at deltage?
- Vigtig information om deltagelse i forskningsprojekter

Projektets formål

Projektet har til formål at få dybdegående viden om og forståelse for, hvordan pårørende støttes i hverdagslivet med demens i et samspil imellem forskellige aktører.



Hvordan påvirker projektet mig?

Du anses for at være en vigtig del af dette projekt, da det er gennem dig oplysningerne til forskningsprojektet skal komme.

Jeg vil følge dig, de dage jeg er med på besøg for at observere samspillet imellem jer og demenssygeplejersken. Jeg vil derudover spørge ind til nogle af de ting jeg ser, og er med til, under mit besøg. Jeg er klar over, at det altid vil være anderledes for jer, når jeg er med på besøg, når man er bevidst om, at man bliver observeret. Det er vigtigt, at du ved, at jeg *kun* er der for at få en bedre forståelse af samspillet, når I som familie bliver støttet i demensforløbet, og du må gerne forsøge at gøre nøjagtigt som du plejer.

Hvad får jeg ud af at deltage?

Du bidrager med vigtig information til forskningsprojektet, og er dermed medvirkende til at sætte fokus på livet med demens, og hvordan i bliver støttet af forskellige aktører. Denne viden vil til gavn for andre familier med demens, kommuner og frivillige foreninger.

Jeg sætter stor pris på din deltagelse!