

Camilla Anker-Hansen

## **On making the invisible visible**

A qualitative study of care partners of older people with  
mental health problems and home care services





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A qualitative study of care partners of older people with mental health problems and home care services

A PhD dissertation in  
**Person-Centred Healthcare**

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Faculty of Health and Social Sciences  
**University of South-Eastern Norway**  
Horten

**Doctoral dissertations at the University of South-Eastern Norway no. 57**

ISSN: 2535-5244(print)

ISSN: 2535-5252 (online)

ISBN 978-82-7860-414-4 (print)

ISBN 978-82-7860-415-1 (online)

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Print: University of South-Eastern Norway

Cover illustration: "Pusterom", by Lisa Aisato

## **Dedication**

*To Albert & Wiggo*

## Preface

Coming to the end of this project and looking back, I can see that the road has been long. I started in one place and ended up somewhere quite different, just like they said I would. My main supervisor, Associate Professor Siri Tønnessen, formulated the initial idea for the current project, but I had extensive leeway to shape it and make it my own. Yet I felt clueless in the beginning, using a tonne of energy to discern the difference between ‘phenomenological hermeneutics’ and ‘hermeneutical phenomenology’, what constitutes a ‘person’ and what ‘person-centredness’ is really all about. Table 1 provides an excerpt from the first paper I wrote for the mandatory course in the PhD programme, titled ‘The Science and Practice of Person-Centred Health Care’.

**Table 1.** Excerpts from my 2015 reflection paper.

<p style="text-align: center;"><b>Reflection paper</b></p> <p style="text-align: center;"><i>Camilla Anker-Hansen. November 2015</i></p> <p>In this paper, I will share my reflections on the philosophy and theory of person-centredness and how this relates to my research focus. Entering this course, I hope to develop a deeper understanding of the complexity of person-centred perspectives and to gain more knowledge about the strategies used for undertaking person-centred research. Having spent the last decade in the municipal health care sector and being a stay-at-home mother, I feel like a foreigner in a new country, where I need to learn a new language, a new way of thinking and ways to express myself. I find it difficult to navigate in ‘The flux and uncertainty of knowledge between and within paradigmatic or pragmatic approaches (...)’ (Martin &amp; Félix-Bortolotti, 2014, p. 1056), and sometimes, I feel a bit lost in the ‘(...) “unorder and disorder” in what is known and what it means’ (Martin &amp; Félix-Bortolotti, 2014, p. 1056), but I will share my current thoughts from the knowledge I have at this point.</p>
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Basically, I didn’t have a clue!<sup>1</sup> Three years later, I am convinced that person-centredness is the answer to many current and future challenges in the health care sector. I see this approach as crucial for practitioners, patients, and care partners, to feel seen, heard, and have their needs met in a way that confers confidence and security. This can be illustrated with a recent experience in my own life. Early on a Tuesday morning, I received a

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<sup>1</sup> Happy to discover Albert Einstein’s famous quote: ‘If we knew what it was we were doing, it would not be called research, would it?’

phone call from my son's kindergarten; my son had broken his arm. We went to the ER, where it soon was discovered the arm was broken in two places and he had to have surgery. A standard procedure for the practitioners, but not for a five-year-old boy and his mother. Upon arrival at the hospital, he was given a bracelet with his name and ID number. He could easily have been just another injured kid in the line, an object -but he was not. He was treated as a person, a child the staff quickly understood they could distract and make laugh by doing funny things. Albert fell into a narcosis sleep with a smile on his face, pretending he was wearing a pilot's mask. My heart was aching when I had to leave the operating theatre, but when the staff promised to take good care of him, I knew they would. For me, this experience demonstrates some of the core values of person-centred health care and helped me realise its significance in everyday caring practise.

### **Connecting identity, knowledge and creativity**

Green (2005) argues that doctoral education is just as much about identity formation as knowledge production. During the process of finding my own academic identity, one of the challenges was to find my authorial voice, both regarding creativity and how to situate myself in the text. However, the more I learned about person-centred research, the more I realised that this perspective provides space for creativity and for the researcher's values and beliefs to be visible and present throughout the research process (McCormack et. al., 2014; Titchen, Cardiff, & Biong, 2017). This resonated with the way in which I wanted to conduct research. Thus, the approach of this thesis is in line with the notion of values being central, explicit, considered and acted upon in person-centred research (Dulmen, McCormack, Eide, Skovdahl & Eide, 2017). As I will later argue, the concept of 'person' and recognition of the personhood of all individuals in a given context is central in the person-centred perspective (McCormack & McCance, 2010). These philosophical underpinnings of person-centredness have influenced my research process and are firmly located and integrated in the thesis. I realise, however, that there can be disharmony between this approach, and more established approaches to research in both this and other disciplines and fields of research. Dulmen, McCormack, Eide, Skovdahl and Eide (2017) argue that an evolution is happening in research, with a focus on person-centred principles being applied

with all stakeholders and in diverse programs of research. Hopefully this work can be seen to make a contribution to this new and evolving approach, by providing a critical lens through which we reflexively engage with the development of person-centred research methodologies.

## Acknowledgements

Writing a thesis is like travelling an endless road of digressions. One path leads to another, which leads to another, which leads to another, and so on. Without my main supervisor, Associate Professor Siri Tønnessen, I would have been lost. Thank you, Siri, for always keeping me on the right track while encouraging my need to explore. You have generously shared your thoughts and knowledge with everlasting enthusiasm. I appreciate you so much for the person you are and the way you have supported me. It has been an honour to be your first PhD student.

Throughout my work on this thesis, I found myself reaching ‘deeper levels of confusion’, as described by Christian Smith (2007). Thank you, Professor Brendan McCormack, for introducing me to this powerful book and so many others. Sometimes, in our lives, we meet special persons, ones who leave permanent marks on our souls. You are one of those persons for me, Brendan. Thank you for expanding my thoughts, knowledge, beliefs and understanding of research. I admire you for your professional achievements, but most of all, I admire you for your authenticity, your kindness and your genuine person-centred approach to everyone around you.

I also want to express my gratitude to Professor Kirsti Skovdahl; your thoughts and ideas have inspired me throughout this process. Thank you for all the great discussions and valuable suggestions, which have helped improve this thesis. Your encouragement and enthusiastic approach to my work were so important to me. Finally, thank you for your heartfelt support when I needed it the most.

Siri, Brendan and Kirsti. You have been such an amazing supervision team, and I truly can't thank you enough!

Associate Professor Astrid Skatvedt. You were not directly involved in my project, yet you have been there behind the scenes from the start. First, you were an opponent the first time I presented my project at the University of South-Eastern Norway, where you provided valuable feedback that helped shape this final product. Along the way, your work has been a great inspiration. Our roads crossed again at the very end of this project, not the way we planned, but still in an inspirational way. Thank you for your generosity, your compassion and your contributions to this thesis.



My very special thanks go to Associate Professor Wenche Falch, who supervised my master's thesis. Without your encouragement, I would never even have considered a PhD. Thanks for believing in me.

A big thanks also to Professor Annica Kihlgren for providing constructive feedback at both my midterm evaluation and in a PROFRES seminar.

A very special thanks goes out to everyone in PROFRES. I feel privileged to have been part of this great national research school. Lise Sæstad Beyene, Linda Horne Mæland, Heidi Dombestein and Marina Sletten deserve a special mention. I will never forget our trip to the monastery in Lesvos—such a lovely week! Also, a warm thanks to Camilla Melhuus Line and Kristin Humerfelt for your great work in PROFRES.

A million thanks to my fellow PhD student and former office mate Ingrid Taylor. Thank you for all the good moments we shared!! Thank you for inspiring and motivating me, for engaging in helpful discussions and for your continuous support; but most importantly, thanks for becoming a lifelong friend.

Veralia Gabriella Sanchez, I'm so happy our paths crossed and we had the chance to study and work together. You are truly one of my great examples; how do you get it all done? Thank you for your input on my project and for all the discussions that helped broaden my horizons.

I am grateful to the librarians at the University of South-Eastern Norway for their service, which was always fast and efficient. A special thanks to university librarian Jana Myrvold, who helped me conduct the literature searches for Study I, and Kristin Østerholt that helped with the final formatting details of the thesis before submission. During the last few months, the librarians at Østfold University College also provided crucial assistance, so thank you!

I am deeply indebted to computer engineer Andreas Løvås for saving my academic career twice by solving some really advanced PC mysteries. Thank you!

I cannot thank the participants in this project personally, but I am inexpressively appreciative of you all. Without your contributions, this thesis would not exist. It was a pleasure to meet and talk with you all!

Thanks to all my new colleagues at Østfold University College for the warm welcome last year and for encouragement and support in these last few months.

Thanks to the University College management, especially the Heads of the Faculty of Health and Welfare, Randi Sommerfelt and Eli-Anne Skaug, for giving me space to finish writing my thesis and supporting me in the process. A very special thanks to my 'corridor mates' in N3, the members of the PSOTEK project and my reflection group. You have all been truly supportive, and I honestly feel privileged to have you all as my colleagues.

Another thanks goes out to Odd Brendebekken at SIØ. Thanks for the good laughs and your extraordinary service. I hope you have noticed that everyone who leaves your bookshop are smiling.

To my close friends, thanks for your unconditional support and patience throughout this process, especially during this last year where I was almost totally absent, both physically and mentally. I can't wait to catch up with you all!

To my family, thank you for your continued support over the years, your encouragement and your love. A special thanks to my mom and stepfather for always being there and to my brother Thomas for being you!

Albert, my little bundle of joy and laughter. Together we have produced an extensive amount of work in my office at home: you drawings and I sentences. You have no idea how much I have appreciated this 'collaboration'. Thanks for your endless patience throughout this process—you are forever my sun, my moon and all my stars.

The last word goes to my husband, Wiggo: It's done! Thanks for always being there, believing in me and making me work hard. Without your love and support, I would be lost.

Camilla

## Abstract

The concept of *Ageing in place* implies that efforts are made to allow people to live at home for as long as possible. This is a political goal in aging policy, where care partners and home care services play significant roles. Due to this policy, older people live longer at home with increasingly complex disease states, both physical and mental. Hospitalisations are fewer, and the number of days spent in hospital has dropped. Consequently, responsibilities have increasingly shifted to home care services and care partners. In particular, the care partners of older people with mental health problems face major challenges, and they often feel unsupported in their role. Furthermore, there are indications that the collaboration between home care services and the care partners of older people with mental health problems does not function satisfactorily. The home care districts in this thesis are organised in accordance with efficacy norms and New Public Management (NPM) principles that create difficulties for staff and challenge their professional autonomy. Moreover, home care services' capacities are limited, and they struggle to meet legislative requirements and expectations.

The study takes place in the context of the Norwegian welfare state and is approached from a person-centred perspective. The two primary objectives are 1) to develop knowledge about the needs of care partners of older people with mental health problems and 2) to explore the collaborative relationship between the care partners of older people with mental health problems and home care services through the perspectives of care partners, home care staff and leaders in home care services. To answer these questions, this thesis examines the kind of support the care partners say they need, their experiences with being caregivers and, finally, how home care leaders and staff experience their collaboration with care partners. This introductory chapter<sup>2</sup> sets out to explore factors that enable and hinder the establishment of a well-functioning collaboration between care partners and home care services.

This thesis includes three studies (I–III). Study I is a systematic review that identifies and synthesises the needs of care partners of older people living at home with assistance

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<sup>2</sup> Known as 'Kappe' in Norwegian

from home care services. In Study II, the lived experiences and support needs of care partners of older people with mental health problems are explored through in-depth interviews with care partners. Study III evaluates whether a focus on personhood could help explain the collaborative relationship between home care staff and care partners; this is carried out through focus group interviews with home care staff and individual interviews with the leaders of these services.

Study I includes 16 reviewed studies; three main categories emerge from the analysis: the need for quality interaction, the need for a shared approach to care and the need to feel empowered. The findings show that care partners have several, continuously unmet needs. Furthermore, a knowledge gap concerning the care partners of older people with mental health problems in home care services is identified. The results from Study II reveal that few or no consistent avenues for collaboration exist between home care services and the care partners of older people with mental health problems, and that the care partners seem to have little knowledge of their legal rights; they request more information, spare time and the opportunity to remain in their original family role. However, their primary concern is that the patient receives the necessary help from home care. Study III demonstrates home care staff and care partners of older people with mental health problems do not engage in satisfactory collaborative relationships. There appears to be lack of facilitation of collaborative relationships throughout all levels of the home care organisation, producing situations in which neither the personhood of the care partners nor the staff members are respected.

Together, the studies indicate that the collaboration between home care staff and the care partners of older people with mental health problems often does not function satisfactorily. Under the prevailing conditions, home care staff find it difficult to fulfil all their obligations, including meeting the needs of care partners. The staff must be capable of identifying and meeting the needs of care partners, but first and foremost, they need an organisational framework that allows them to accomplish their duties. A rethinking of how to fill the gap between the espoused values of the organisation and the reality of everyday practice is required. The implementation of person-centred practice in home care services

can help staff to establishment of a well-functioning collaboration to better meet the needs of care partners of older people with mental health problems.

**Keywords:** Older people, health services for older people, home health care services, caregivers, care partners, collaboration, person-centred practice, person-centredness, mental health problems, family needs.

## List of papers

Papers omitted from online edition due to  
publisher's restrictions

### Article 1

Anker-Hansen, C., Skovdahl, K., McCormack, B., & Tønnessen, S. (2017). The third person in the room: The needs of care partners of older people in home care services. A systematic review from a person-centred perspective. *Journal of Clinical Nursing*, 27, e1309-e1326.

### Article 2

Anker-Hansen, C., Skovdahl, K., McCormack, B., & Tønnessen, S. (2018). Invisible cornerstones. A hermeneutic study of the experience of care partners of older people with mental health problems in home care services. *International Journal of Older People Nursing*, 14(1), e12214. doi:10.1111/opn.12214

### Article 3

Anker-Hansen, C., Skovdahl, K., McCormack, B., & Tønnessen, S. (2019). Collaboration between home care staff, leaders and care partners of older people with mental health problems: A focus on personhood. *Scandinavian Journal of Caring Science*. ISSN 0283-9318. doi: 10.1111/scs.12714

*Behind the mask of confidence and competence,  
behind the proud ideology of individualism and self-determination,  
perhaps every human being yearns to be truly cared for and to care.*

Tom Kitwood. Dementia reconsidered: The person comes first.

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# 1. Introduction

‘Begin at the beginning’ the king said gravely,  
‘and go on till you come to the end: then stop’.

Lewis Carroll, *Alice in Wonderland*

This chapter describes the background of the study and the rationale for conducting this research. The thesis aims and research questions are presented, and an overview of the three individual studies is provided. Finally, the structure of the thesis is outlined.

## 1.1 Setting the scene

The future of health care in Norway presents well-known challenges, including changes in the number of older people who need health care, new and younger user groups with different needs and preferences, and the number of professionals providing services (Gautun & Grødem, 2015; Ministry of Health and Care Services, 2013). As such, the Norwegian authorities have been tasked with developing new strategies for health care policy. One example is the Coordination Reform, which has led to the establishment of *Helsehus* (local hospital-like centres that fills the gap between specialist health services and primary care) and health centres focusing on preventive health care (Ministry of Health and Care Services, 2009). Another political strategy is the focus on care partners as resources, and the possibility of finding new avenues of collaboration within health care services (Directorate of Health, 2017; Jenhaug, 2018; Ministry of Health and Care Services, 2018). Care partners represent a significant resource in health care in Norway, both from a socioeconomic perspective and for the individual service user (Directorate of Health, 2017). Care partners provide almost half the total care in the health care sector (Rønning, Schanke, & Johansen, 2009), and it is difficult to imagine how adequate care could be given to service users without care partners’ efforts. Yet it is stated that the resource the care partners represent is not adequately utilised (Ministry of Health and Care Services, 2018). Recent government initiatives have granted care partners more rights, and municipalities are now

required to take action and realise these rights. Furthermore, policy guidelines emphasise the need for a person-centred approach to both service users and care partners (Directorate of Health, 2017; Ministry of Health and Care Services, 2018). It is also highlighted that older people with mental health problems should be offered assessment and treatment equal with younger adults; “Treatment and measures that can improve the quality of life, symptom and functional level of the elderly should not be limited due to high age per se” (Directorate of health, 2015, p.4).

Nevertheless, older people with mental health problems and their care partners are often invisible in the health landscape. These persons often first receive help when somatic problems arise, but in many cases, they have together with their care partners experienced significant challenges due to mental health problems for a number of years (Skatvedt & Baklien, 2017). Research shows that while being a care partner can be rewarding, it is often burdensome. Care partners are more vulnerable to both physical and mental health problems than the general population (Hansen, Jakobsen, & Slagsvold, 2017), and being a care partner can represent a threat to that individual’s quality of life (Poulin et al., 2010 p. 108).

There is a considerable amount of knowledge about how care partners experience their caring roles, including their needs and how their situations can be improved; studies typically concentrate on distinct patient groups, such as people with dementia, cancer and palliative care (Aasgaard, Disch, Fagerström, & Landmark, 2014; Lee & Loke, 2013; Stajduhar, 2013). However, there is limited knowledge about the needs of care partners of older people with mental health problems and their collaborative relationships with home care services. Given that life expectancy is increasing globally, leading to a rising number of older people with mental health problems, and considering the current trend of community-based health care, this specific group plays a crucial role in health services and should be treated as such (United Nations, 2015). Hence, knowledge about these care partners’ individual needs and experiences is needed.

## 1.2 Aims and research questions

The thesis consists of three studies (Study I, Study II & Study III) with two primary aims:

1. Develop knowledge about the needs of care partners of older people with mental health problems in home care services.
2. Explore the collaborative relationship between care partners of older people with mental health problems and home care services through the perspectives of care partners, home care staff and the leaders of home care services.

The research questions are as follows:

1. Do the care partners of older people with mental health problems experience collaboration with home care services?
2. What do care partners of older people with mental health problems need from home care services in order to cope with their responsibilities?
3. How do leaders and staff in home care services experience collaboration with care partners of older people with mental health problems?

Together, these research questions form the basis for the three studies, as well as the overall discussion in Chapter 6. Based on the findings of Studies I, II and III (appendix), the overall aim for the introductory chapter is to explore factors that enable and hinder the establishment of a well-functioning collaboration between care partners of older people with mental health problems and home care services.

A schematic overview of the studies and their aims, research questions, methods for data collection and analysis is presented in Table 2.

**Table 2.** Overview of Studies I, II and III together with the overall aim for the introductory chapter.

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>
<b>Title of paper</b>	The third person in the room: The needs of care partners of older people in home care services. A systematic review from a person-centred perspective.	Invisible cornerstones: A hermeneutic study of the experience of care partners of older people with mental health problems in home care services.	Collaboration between home care staff, leaders and care partners of older people with mental health problems: A focus on personhood.
<b>Aim</b>	To identify and synthesise the needs of care partners of older people living at home with assistance from home care services.	To explore the lived experiences and support needs of care partners of older people with mental health problems living at home with assistance from home care services.	To explore whether a focus on personhood can help explain the collaborative relationship between home care staff and care partners.
<b>Research question</b>	<ul style="list-style-type: none"> <li>• What do the care partners of older people living at home need from home care services?</li> </ul>	<ul style="list-style-type: none"> <li>• Do the care partners of older people with mental health problems experience collaboration with home care services?</li> <li>• What do the care partners of older people with mental health problems need from home care services to cope with their responsibilities?</li> </ul>	<ul style="list-style-type: none"> <li>• Does a focus on personhood help to make sense of the nature of the collaborative relationship between home care staff, home care leaders and care partners?</li> </ul>
<b>Data collection and analysis method</b>	<ul style="list-style-type: none"> <li>• Systematic literature review of 16 studies.</li> <li>• Qualitative content analysis.</li> </ul>	<ul style="list-style-type: none"> <li>• In-depth interviews with six care partners.</li> <li>• Hermeneutic analysis.</li> </ul>	<ul style="list-style-type: none"> <li>• Two focus group interviews with eight home care staff members, and in-depth interviews with three home care leaders.</li> <li>• Thematic framework analysis.</li> </ul>

<p><b>Connection to overall aim</b></p>	<ul style="list-style-type: none"> <li>• Develop knowledge<sup>3</sup> about the needs of care partners of older people with mental health problems in home care services.</li> </ul>	<ul style="list-style-type: none"> <li>• Develop knowledge about the needs of care partners of older people with mental health problems in home care services.</li> <li>• Explore the collaborative relationship between care partners of older people with mental health problems and home care services through the perspectives of care partners, home care staff and leaders in home care services.</li> </ul>	<ul style="list-style-type: none"> <li>• Explore the collaborative relationship between care partners of older people with mental health problems and home care services through the perspectives of care partners, home care staff and leaders in home care services.</li> </ul>
<p><b>Connection to overall research question</b></p>	<ul style="list-style-type: none"> <li>• What do care partners of older people with mental health problems need from home care services in order to cope with their responsibilities?</li> </ul>	<ul style="list-style-type: none"> <li>• How do care partners of older people with mental health problems experience the collaboration with home care services?</li> <li>• What do care partners of older people with mental health problems need from home care services in order to cope with their responsibilities?</li> </ul>	<ul style="list-style-type: none"> <li>• How do the leaders and staff in home care services experience the collaboration with care partners?</li> </ul>
<p><b>Overall aim for the introductory chapter</b></p>	<p>To explore factors that enable and hinder the establishment of a well-functioning collaboration between care partners and home care services.</p>		

<sup>3</sup> During the review process, it became apparent that the knowledge gap in this area concerned care partners of older people with mental health problems, which is why this thesis concentrates on this specific group rather than care partners in general.

### **1.3 Thesis structure**

Chapter 2 provides the background for the thesis, and gives an overview of the development of home care services. The term 'care partner' and the policy guidelines attached to this group is outlined, before the chapter describes the mental health problems of older people and consequences for the care partners. Chapter 3 contains the theoretical perspective of the thesis, which is person-centredness. Chapter 4 presents the methodology and the ethical considerations, as well as a discussion of who I am and my preunderstandings. The results of the studies are summarised in Chapter 5. In Chapter 6, factors that enable and hinder the establishment of a well-functioning collaboration between care partners and home care services are discussed. Further, the methodological considerations, implications for policy and practice, and suggestions for further research are described. Chapter 7 outlines the conclusions and offers some final reflections on the research as a whole.

## 2. Background

There are only four kinds of people in this world:  
those who have been caregivers;  
those who currently are caregivers;  
those who will be caregivers;  
and those who will need caregivers.

Rosalynn Carter

This chapter discusses home care services in Norway, its background and how the service functions today. It provides an overview of the concept of 'care partners' before examining mental health problems in older people.

### 2.1 Home care services in the Norwegian welfare state

#### 2.1.1 Background

Norway is a parliamentary democracy operating at three administrative levels: state-wide, regional, and municipal. Civil rights, including the right to access health and welfare, apply equally to all members of the community (Eriksen & Weigård, 1993). The country ranks fourth amongst Organisation for Economic Co-operation and Development (OECD) nations for health expenditures per capita (OECD, 2017). In 2016, Norway expended 10.5% of its GDP on health, and the government covered 85% of the expenses related to health care. Since World War II, the Norwegian health care sector has been characterised by strong growth in employees, tasks and monetary resources (Otnes, 2012; Tingvoll, Kassah, & Kassah, 2014). For nearly 70 years, the goal has been to provide as much care as possible in the patient's home; in 1959, government subsidies were introduced for setting up home care services (Otnes, 2012, 2015). Guidelines for the establishment and operation of home care services were established in 1971, and in 1984, the Health Services Act required all municipalities to establish public home care service organisations (Fjørtoft, 2012; Ministry of Health and Care Services, 2006). Home care services increased rapidly, and the number of



users more than tripled from 24,000 to 75,000 from 1965 to 1980 (Borgan, 2012). Around the turn of the century, services expanded to include care for people of all ages and for those with complex needs. During this time, policymakers also acknowledged the need to increase the efficiency and quality of the services, which is a continued focus (Ministry of Health and Care Services, 2006). Quality assessments shifted toward user experience, and the intention was to consider the needs and preferences of each user when further developing the service (Ministry of Health and Care Services, 2006).

### 2.1.2 Home care services today

The Coordination Reform was implemented in 2012, creating major changes in the municipalities; more responsibility for health care was transferred from secondary to primary care. Procedures and treatments reserved for use in hospitals just a few years ago are now performed by nurses in home care, such as intravenous delivery of medications and fluid replacements, the monitoring and use of central venous catheters, and the monitoring of patients with tracheostomies, which has led to an increased task-oriented home care organisation (Birkeland & Flovik, 2014). One of the goals of the Coordination Reform is to ensure the patient receives the proper treatment—at the right place and the right time—through improved coordination and collaboration between primary and secondary care. Further, the reform promotes person-centred values and principles, such as greater user involvement, closer proximity to services and more coherent health care services (McCormack & Skatvedt, 2016; Ministry of Health and Care Services, 2009). However, the measures are also intended to be cost-effective and contribute to greater socioeconomic cost-effectiveness (Ministry of Health and Care Services, 2009). Thus, the reform is in line with the New Public Management ideology, and the efficiency norm that characterizes most home care service districts in Norway (Kassah, Tønnessen & Tingvoll, 2014; Klijn, 2012), including the two districts that participated in this project. Consequently, the reform has led to increased pressure on home care services. Home care staff have not only taken over many of the tasks previously provided by secondary care, but the number of days that patients spend in the hospital has also decreased (Grimsmo, 2013). The same applies to mental health services, where the number of people staying in mental health institutions has been

considerably reduced, and care tasks are transferred to the municipalities (Borg & Karlsson, 2017).

There is no unified, global definition of 'home care'; the concept is defined differently from country to country (Genet et al., 2011). Furthermore, because the content of the services is continuously changing, the definition also changes according to the time and context (Birkeland & Flovik, 2014). A suitable definition that captures key aspects is, 'Home care is an offer of nursing and care at home when illness, impaired health, old age or life situation leads to a need for help for shorter or longer periods of time' (Fjørtoft, 2006, p. 15). In Norway, home care services are divided into categories. *Health care in the home* (previously called *home care*), is where professional carers such as registered nurses and care assistants provide nursing, health care, medical help and assistance with activities of daily living (ADL). In *practical assistance* (previously called *home help*), ADL, user-assisted personal assistance and domestic aid are provided, mostly by care assistants and people without higher education. Respite solutions, rehabilitations at outside institutions and care benefits<sup>4</sup> fall under the umbrella term *home care services* (Abrahamsen, Allertsen, & Skjøstad, 2016). This thesis focuses on health care in the home, which is referred to as 'home care' and 'home care services' throughout.

The decentralisation of health care tasks from the state to the municipal level has increased the need for the state to oversee local budgets and ensure the services provided by the municipalities are relatively consistent. This governmental oversight can occur through legislation, the setting of national standards or by tying municipal funding to specific purposes (Stamsø, 2005). However, the municipalities are assuming more responsibilities for health care services without receiving sufficient financial resources (Tønnessen, 2011; Vabø, 2007). One instrument used to increase the effectiveness of health care services and get maximum care out of every penny is the system known as New Public Management (Nyseter, 2015). The introduction of NPM in the early 1980s brought management and organisational principles usually found in the private sector to the public sector in order to encourage economic efficiency (Klijn, 2012). With a strict focus on results, the goal of NPM

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<sup>4</sup> 'Care benefits' is economic compensation paid to care partners who perform particularly demanding care work on a private basis (Municipal Health Service Act, 2011, Section 3-6.).

was to streamline production and increase the quality of services. NPM has not been implemented as rigorously in Norway as it has been in other European countries. Goal- and result management is the part of NPM that has been given most focus in both the Norwegian administration and the other Nordic countries. Thus, these elements in the public sector are often associated with NPM, despite being only one part of the original model (Biel-Larsen, Harsvik & Skulberg, 2013; Stamsø, 2005). One issue with results-based evaluations is how the results are to be measured. This is particularly difficult in the health care sector, where the target is not a financial surplus (Stamsø, 2005). It is difficult to measure the effectiveness of the home care staff and the care provided, while it is simple to measure whether the rules and procedures are followed. Thus, this is what health care workers are often measured and checked on (Feiring, 2014).

Although NPM strategies are widely criticised within the health care field, NPM has contributed to the development of a more accountable system that emphasises the patient's rights and distribution of power, customer choice, and tailoring public services to individual needs (Pierre, 2009). However, it is uncertain whether the benefits outweigh the disadvantages. The British researcher Christopher Hodd, credited for launching the term 'New Public Management' in an article published in 1991, reviewed evidence from a thirty-year period; he and his colleague conclude the reform has failed in its efforts to create more efficiency and quality (Hodd & Dixon, 2015; Nyseter, 2015, 2016).

The two home nursing districts included in this thesis have different degrees of NPM features in their organization. This will be explained under *the research field* in Chapter 4.3. The understanding of NPM as outlined here will be the starting point for the later discussion.

### 2.1.3 Laws and regulations in home care services

Home care services are regulated by the Municipal Health and Care Service Act (2011), which states that anyone who lives in or stays temporarily in a Norwegian municipality has a legal right to necessary health care services. Necessary health care is defined as the treatment of disease, emergency medical services, medical habilitation and rehabilitation, preventive health services, and nursing and care services. This right applies to

all people, including people with somatic or mental health problems, substance abuse problems, injuries, disorders, disabilities, or social problems (Municipal Health Service Act, 2011, Section 3). This universalistic approach to health care is also called the Nordic or Scandinavian welfare model (Barth, Moene, & Wallerstein, 2003). All municipalities in Norway are required to offer home care services, and certain standards must be followed in each home care services district. The law regulates the quality of care provided to ensure people receiving care services get help for their basic needs while having their autonomy, personhood and way of life respected (Ministry of Health and Care Services, 2004). Meanwhile, the purpose of the Dignity Guarantee Regulations (2010) is to organise the care of older people in a way that contributes to a dignified, safe and meaningful way of ageing. Health professionals are required to provide care that respects the individual's self-determination, self-worth and way of life. For example, conversations about existential questions should be undertaken (The Dignity Guarantee Regulations, 2010, § 3). Furthermore, staff working for home care services are subject to the Health Personnel Act (1999), which contributes to the safety of patients, quality of health care services and trust in health workers and health care services (§ 1). Finally, the rights of patients and users are regulated by the Patient and User Rights Act (1999), which provides for equal access to quality health care services (§1-1).

To access services from home care, patients apply for help and an executive officer assesses the application against the applicable legislation and its criteria. The arguments for granting assistance or refusal are justified in a legal administrative decision, which may be appealed (Municipal Health Service Act, 2011). Based on the statutory requirements and national policy documents, each municipality organises a home care service suited to the local conditions within the available financial framework (Vike, Bakken, Brinchmann, Haukelien, & Kroken, 2002). Thus, services vary from municipality to municipality.

## 2.2 Care partners

Words have power. Labels used to describe specific issues affect how things are defined, perceived and experienced by the people affected, and by the people around them. This work consistently uses the term 'care partner' rather than the more commonly used 'caregiver' or 'caretaker'. This is in line with the person-centred approach taken in the current project, as 'care partner' suggests a more two-sided relationship between the parties in the care situation; '[C]are partner implies equality, trust, a give and take attitude, and a shared experience' (Eilers, 2013, p. 61). Thus, the use of the term 'care partner' conveys the importance of a partnership approach to the care relationship rather than the traditional paternalistic approach, where the provision of care is seen as a one-way transaction.

Bennett and Wang (2017) contend that the concept of a care partner may be an under-recognised component of the movement toward patient-centred care, while Eilers (2013) argues that the endorsement of 'the idea of care partners' signals a real paradigm shift. This may be somewhat over-optimistic, but it is reasonable to assume the use of the term has the potential to advance the person-centred approach.

This paper focuses on the care partners of older people with mental health problems who receive help from home care services. To make the text more readable, the full description is used only when the referenced group requires clarification.

### 2.2.1 Care partners in health care policy

In Norway, a care partner is defined in the Patient and User Rights Act (1999) as the person the patient designates, and this person is granted defined rights in the Health Personnel Act (1999), Mental Health Care Act (1999), the Patient and User Rights Act (1999), and the Municipal Health Services Act (2011). The attention on care partners has never been greater, partly because of the increased focus within health care policy. Governmental guides and white papers acknowledge care partners as important contributors in health care, emphasising that their needs must be met. The white paper 'Future Care' (Ministry of Health and Care Services, 2013) describes how care partners are entitled to receive training, respite options, support and guidance, and to become more involved in the care process. The paper also invokes the term 'co-creation', used to describe the collaborative relationship

between care partners and the welfare state (Ministry of Health and Care Services, 2013). Co-creation is further described as a method that ‘does not act for, but with people’ that will deepen relationships, such as the interaction between care partners and staff in home care services, through creative and interactive processes (Ministry of Health and Care Services, 2013, p. 51). Jenhaug (2018), in her analysis of the white paper, illuminates the expectations the authorities have for care partners as co-creators. The findings indicate the government wants to increase co-creation to establish a sustainable welfare state, but will not necessarily permit care partners to influence health services.

A similar message about collaboration is reinforced in the white paper ‘Living All Life’, describing a quality reform for older people and care partners (Ministry of Health and Care Services, 2018). One of the reform’s aims is to facilitate closer collaboration between care partners and health care services. The intention is to reduce the burden on care partners, thus enabling them to provide consistent care (Ministry of Health and Care Services, 2018, p. 10). The paper describes care partners as ‘a renewable resource, provided we succeed with a sustainable resource utilisation in line with the older persons’ and the care partners wishes and needs’ (Ministry of Health and Care Services, 2018, p. 47). In October 2017, a new section of the Municipal Health Services Act came into effect, aiming to clarify the municipality’s duty to offer care partners support; those with particularly demanding care work should be offered necessary support such as training, respite options and care benefits (Municipal Health Services Act, 2011, §3-6).

### **2.3 Mental health problems in older people**

The World Health Organisation (WHO) use the following definition on health: ‘Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (WHO, 2007). This definition has been criticised since it was released, especially because of the absoluteness of the word ‘complete’ concerning well-being (Huber et al., 2011). Additionally, the representation of physical and mental health as equals does not in general reflect reality. Hummelvoll (2012) objects to the definition and suggests the following modification: ‘Health is a state and a process of the best possible physical, mental, spiritual and social well-being and not merely the absence of disease or infirmity’ (p. 35). Hummelvoll (2012) argues this is a more realistic perception of health, where good health

can be experienced even with ailments and symptoms present. However, physical and mental health is an individual experience. Certain symptoms can be stressful for one person, while another person can be unaffected by the same symptoms. Thus, health is distinct to the individual, which requires practitioners to see the person behind the diagnosis and recognise how this individual person defines and experiences his or her health.

The term *mental health problems* refers to a variety of conditions or diagnoses such as schizophrenia and bipolar disorder that are characterised by affecting people's cognitive, social and emotional functioning (Public Health Institute, 2016). Knowledge of mental health has increased over the last few decades. As with care partners, people with mental health problems have gained more rights. WHO (2013) developed an action plan for mental health; the goal is 'to promote mental well-being, prevent mental disorders, provide care, enhance recovery, promote human rights and reduce the mortality, morbidity and disability for persons with mental disorders' (p. 33). The action plan also includes a life course approach, which states that strategies concerning mental health needs must apply to all stages of life, including older age. Nationally, the Norwegian action plan for mental health (1998–2008) helped direct attention to mental health problems. This plan was compiled after a report was submitted to the Norwegian Parliament in 1997 (Ministry of Social Affairs and Health, 1997). It acknowledges that the services given to people with mental health have been unsatisfactory: 'The patients do not get all the help they need, the staff do not feel that they are doing a good enough job, and the authorities are unable to provide the population with adequate service' (Ministry of Social Affairs and Health, 1997, p. 16). However, an evaluation of the action plan concluded that although mental health services in the municipalities had been strengthened, mental health care services for older people had not been prioritised and remained inadequate (Norwegian Research Council, 2009). The report emphasised the need to focus on older people with mental health problems in the future (Norwegian Research Council, 2009). After the implementation of the 1998–2008 action plan, it was not until 2017 that a new strategy was launched. This new plan covered the entire mental health field, but focused on children and young people (The Ministries, 2017).

Arguably, most mental health policies do not satisfactorily account for the needs of older people, and recent research has highlighted issues such as ageism and the low priority given to mental health problems (Briseid, 2017; McCormack & Skatvedt, 2016; Skatvedt &

Baklien, 2017). An example of this is how depressive disorders have a tendency to increase in old age, but somehow are under-identified and under-recognised (Crowther, Scogin & Norton, 2010; Pradeep & Sutin, 2015). Ageism is a notion that it is normal to become inactive and passive in old age, and that aging means living an empty and meaningless life. This negative view of older people is not correct, and may be one of the causes of underdiagnosing depression in this age group (Engedal, 2003). Daatland (2010) describes in a chronicle society's tendency toward ageism, viewing older persons as having lesser value than younger individuals:

In the public space, the older person appears to be a stranger and the greatest burden of the welfare state. Through language forms like 'the old and the sick', a distance between them and us is created, as if it could hide the fact that we are one of them, just a few steps behind in the queue'.

This quote identifies how older people can be seen in society: as people of lesser value than younger ones. When adding mental health problems on top of old age, the stigma becomes even clearer. Album and Westin (2008) examined disease prestige and found that mental health disorders such as neurosis, depression, schizophrenia and anxiety disorders are located on the lower part of the prestige ladder, together with diseases common in older people, like arthritis and apoplexy (p. 185). It is apparent that the mental health of older people is not prioritised; older people's mental health is relegated to the fringes of the health service due to both stigma and discrimination. This also has consequences for the care partners of this patient group. Godfrey and Denby (2004) claim that in addition to physical and practical demands in the caring role, these care partners also have to deal with interpersonal difficulties due to inability to motivate their family member, loss of intimacy and companionship and general feelings of hopelessness and powerlessness (p.6). Furthermore, Hunt, Greene, and Whiting (2016) found that several care partners found it difficult to talk to others about their family member's mental health issues, due to the ongoing stigma. This difficulty was also apparent in relation to health care providers, and the care partners reported on general difficulties in navigating the care system and access support functions (Hunt, Greene & Whiting (2016).





### 3. Theoretical Perspectives

In theory there is no difference between theory and practice.  
In practice there is.

Yogi Berra

This chapter begins by describing different concepts of person-centredness and its importance, before presenting the Person-centred Practice Framework. The Norwegian approach to person-centredness is then examined, before looking at the concept of ‘personhood’.

#### 3.1 Person-centredness

‘Person-centred care’ is a term used in health care around the world (van der Cingel et al., 2016), although various related terms are used interchangeably in the literature to describe this individualised approach to care, such as ‘patient-centred’, ‘people-centred’, ‘person-oriented’, ‘client-centred’ and ‘individual-focused’<sup>5</sup> (Buetow, 2016; Kitson, Marshall, Bassett, & Zeitz, 2013). Such terms can be perceived as self-explanatory, but the concept is understood differently in various contexts (Rokstad, 2014), and it is even claimed that the modern use of the term is a neologism (Wilberforce, 2017). However, a recent review identifies seven core themes of person-centredness: honouring the person; being in a relationship; facilitating participation and engagement; social inclusion/citizenship; experiencing compassionate love; being strength/capacity focused; and organisational characteristics (Waters & Buchanan, 2017). Evidence indicates person-centred care contributes to improved outcomes for both patients and health care organisations, including decreasing costs, decreasing readmission, better use of resources, affecting positive lifestyle

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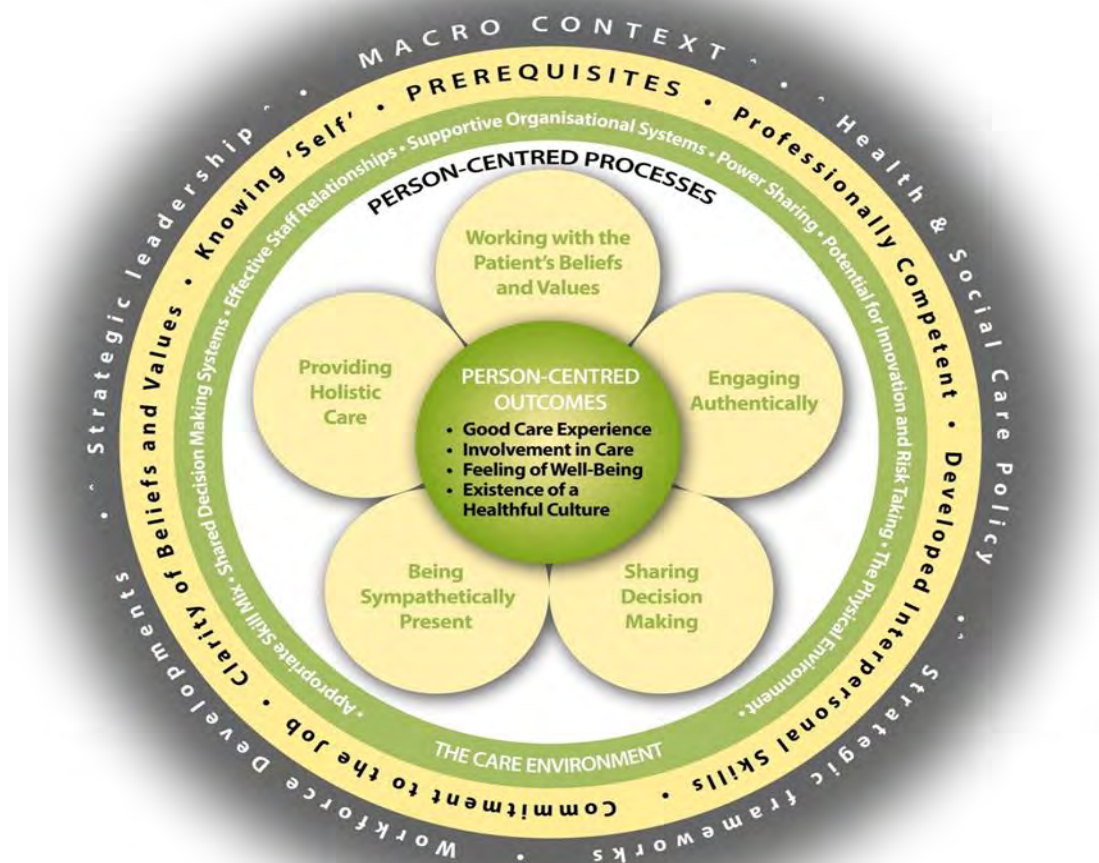
<sup>5</sup> The term ‘person-centred’ is consistently used in this thesis, except where reference is made to text that uses other terms, such as ‘patient-centred’.

changes and increasing satisfaction with care (Delaney, 2018; Gluyas, 2015). Indeed, the United States National Academy of Medicine identifies patient-centred care as one of six attributes of health care quality, alongside safety, timeliness, effectiveness, efficiency and equity (WHO, 2007, p. 5). Glasby (2017) explains the need for person-centred care on a personal level, stating that people—not surprisingly—want care that is focused on and tailored to their needs, and is delivered in a compassionately way.

While exploring these concepts, it is important to keep in mind that the notion of person-centredness does not only concern person-centred care. Person-centredness should be seen from a broader perspective of person-centred practice that is enabled by the development of person-centred cultures. According to McCormack and Skatvedt (2016) there are four underpinning principles of person-centred practice, which can be summarized as being concerned with treating people as individuals, respecting their rights as persons, building mutual trust and understanding and developing collaborative relationships (p. 103). In order to capture this broader perspective of person-centred practice, this thesis is based on the Person-centred Practice Framework (Figure 1) (PCP framework), developed by McCormack and McCance (2017). This is an internationally recognised theoretical framework (Slater, McCance, & McCormack, 2017), building on more than 20 years of empirical research focusing on person-centred practice with older people and experiences of caring in nursing. The framework was first developed in 2006 (McCormack & McCance, 2006), and further developed in 2010 (McCormack & McCance, 2010), before the last version came in 2017 (McCormack & McCance, 2017). The Person-centred Practice Framework is based on the following definition of person-centredness, which captures the complex nature of the concept:

Person-centredness is an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood), individual right to self determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development. (McCormack & McCance, 2017, p. 3)

Figure 1. Person-centred Practice Framework (McCormack & McCance, 2017, p. 264)



The framework comprises five constructs, which highlight the contextual, attitudinal and moral dimensions of humanistic caring practices needed to deliver positive outcomes for all individuals in the care process (McCormack & McCance, 2017, p. 61), including the practitioners. This resonates with Buetow (2016), who claims that in the person-centred approach, clinicians should be treated as moral equals, as person-centredness puts the person first, and the clinicians are persons too. Furthermore, the framework offers an understanding of how these dimensions can be operationalised in practice (McCormack & McCance, 2017; Slater et al., 2017). The PCP framework is developed around the following five constructs:

1. **Macro context**, which concerns political and strategic influences. It consists of the following components: Health and social care policy, strategic frameworks, workforce developments and strategic leadership. This construct was added in the last version of the framework, where it is emphasised that the framework as a whole is situated in a macro context that influence how it can be used within practice, education, research and policy (McCormack & McCance, 2017, p. 263).
2. **Prerequisites**, which focus on the attributes of the staff and consist of the following components: Being professionally competent, having developed interpersonal skills, being committed to the job, being able to demonstrate clarity of beliefs and values, and finally, knowing self.
3. **Care environment**, which focus on environmental factors of the context where practice takes place, and consist of the following components: Appropriate skill mix, shared decision making systems, effective staff relationships, supportive organisational systems, sharing of power, potential for innovation and risk taking and the physical environment.
4. **Person-centred processes**, which focus on the delivery of care through different activities, and consists of the following components: Working with patient's beliefs and values, engaging authentically, sharing decision making, being sympathetically present and providing holistic care.

- 5. Person-centred outcomes**, which represent the expected outcome of effective person-centred practice, and consist of the following components: Good care experience, involvement in care, feeling of well-being and the existence of a healthful culture.

(Dewing, McCormack & Titchen, 2014; McCormack & McCance, 2017).

The model focuses on person-centredness as a cultural construct, meaning that person-centred outcomes can only be experienced if all features in the care setting or organisation are person-centred (McCormack & McCance, 2017). The constructs in the framework are connected in such a way that to reach the inner circle, the person-centered outcomes, the outer structures must first be accommodated. That is, first the prerequisites and the care environment must be considered, as they are both essential in providing effective care through the care processes. This leads to more holistic person-centred processes, and thus to person-centred outcomes, which are the expected results from effective person-centred practice (Dewing, McCormack & Titchen, 2014; McCormack & McCance, 2017). It is worth noticing that McCormack and McCance (2017) emphasize that the practitioners (staff) need appreciation for their work and experience feelings of well-being in order to effectively provide person-centred care. Thus, this is also a key aspect of outcome evaluation in the framework (McCormack & McCance, 2017).

The authors of the framework claim that person-centredness should be operationalized based at the level of principle, since no individual tools, procedures or methods can be transferred to every context (McCormack & McCance, 2017). This understanding is transferable to the person-centred practice framework as well. Although the key constructs are well explained, it will always be the local context that determines what, how and whether they can be implemented in practice. However, when it comes to the philosophical underpinnings of the framework, there is no difference in the level of being person-centred towards a person with mental health problems compared to a person with a somatic condition. The core person-centred processes apply whether the context concern a critical care unit, or a person with depression living at home –or their care partner.

### 3.1.2 Person-centredness in the Norwegian context

In the previous section I have accounted for different perspectives of person-centredness. Much of the debate about person-centredness, person-centred care and person-centred practices on the global scale was initially situated within the field of gerontology (McCance, McCormack, & Dewing, 2011). These approaches have now found their way into practically all dimensions of care. However, when it comes to Norway, most of the research in this domain concerns person-centred *care* in gerontology, particularly within dementia care<sup>6</sup> (Grøndahl et al., 2017; Helgesen, Fagerli & Grøndahl, 2019; Rokstad, 2014; Rummelhoff, Smebye, & Tombre, 2016). In particular, the VIPS model developed for person-centred dementia care (Brooker, 2013) is widely known and used, and is one out of few academic works concerning person-centredness translated and/or published in Norwegian.

Person-centredness is, however, slowly gaining a stronger position within education, research and policy. The establishment of a PhD program in person-centred health care at the University of South-Eastern Norway in 2014 is one example of this. Another example is how the notion of person-centredness is reflected in current health care policy developments (Ministry of Health and Care Services, 2018; Ministry of Health and Care Services, 2015). Current reforms are based on person-centred values, in which service contributions concentrate on what is important for the individual. There is a particular focus on safeguarding older people as a whole, rather than simply treating their illnesses and functional failures. It is a stated political goal that the individual's life stories, values and wishes are to form the basis for the health and care services offerings (Ministry of Health and Care Services, 2018, p.25). Nevertheless, person-centred health care research can still be characterised as pioneering work in the Norwegian context (Briseid, 2017). The fact that there is no consensus on how the term 'person-centred' should be translated into

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<sup>6</sup> As a curiosity, it can be mentioned that a search on google for person-centred practice in Norwegian ("personsentret praksis"/ "personorientert praksis" (person-centredness is translated to Norwegian in two different ways)) only yields 159/116 hits. A similar search in English ("Person-centred practice") yields 68600 hits (Date of search: 08.10.19).

Norwegian<sup>7</sup> can be seen as a sign that certain elements of person-centredness have been incorporated into the Norwegian context without a profound translation and interpretation process.

### 3.1.3 Personhood

This section examines personhood, which, by virtue of its importance in person-centredness, holds a central place in my studies. Due to the concept's centrality in person-centred health care (Dewing, 2008), and the complexity of the term I will briefly summarise it here, then elaborate on different theories involving personhood. These theories have influenced my subsequent perceptions of, and reflections on, the concept.

What is a person? The answer to this may immediately be seen as obvious: I who write and those who read these words are all persons and can easily identify others as persons; 'I am a person, and so are you' (Dennett, 1976, p. 175). However, seen through the lens of philosophical glasses, what it means to be a person becomes more complicated. Dewing, Eide and McCormack (2017) raise a number of intriguing questions:

Is a human being who is a foetus a person, is a child with severe learning disabilities a person, is a human being who is in a persistent vegetative state a person? Is an older adult with advanced Alzheimer's disease a person? Is a human being who has had some of their legal rights formally removed a person? (p. 22).

The answers to these questions have far-reaching implications, because to hold the title 'person' entitles the holder to certain moral, ethical and legal rights. Thus, these questions point at moral dilemmas in controversial issues such as abortion, euthanasia and the death penalty. Throughout history, many great thinkers have contributed to what constitutes a person. Different attributes such as cognition (e.g., intelligence, rational decision-making), consciousness, free will, self-awareness, a capacity to understand or speak

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<sup>7</sup> The terms 'personorientert' (person-oriented) and 'personsentret' (person-centred) are often used interchangeably, sometimes within the same text (see, e.g., Kirchhoff, Grøndahl, & Andersen, 2015), although these are two different concepts.



a language, the ability to make moral judgements and the existence of a soul are a few suggestions (Dewing et al., 2017, p. 23).

Many authors have tried to capture the concept of personhood, in different ways. The most well-known is probably Kitwood (1997b), who saw personhood as a relational concept, defining it as:

[A] standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood, and the failure to do so, have consequences that are empirically testable (p. 8).

Though this is a commonly used definition regarding person-centredness, it is important to be aware that it denotes clear parameters. Positioning personhood through a relational perspective implies it is dependent on the recognition of others, which clearly imposes potential limits on personhood as an absolute moral value.<sup>8</sup>

Noonan (1970), on the other hand, claims personhood starts at conception. By possessing the genetic code of human beings, the being is a person:

The positive argument for conception as the decisive moment of humanization [Personhood (Walker, 2014)] is that at conception the new being receives the genetic code. It is this genetic information which determines his characteristics, which is the biological carrier of the possibility of human wisdom, which makes him a self-evolving being. A being with a human genetic code is man. (p. 15)

However, several philosophers have problematised the implications of this conservative view. Fink (2017, p. 63) identifies one glaring issue: If a human being is anything with a complete human genetic code, then every cell of a person's body is a human being. Kent (2017) illustrates another problem, suggesting that if there are no morally relevant differences between a human embryo and human adult, it may also mean that there are no

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<sup>8</sup> More on this in Study III.

morally relevant differences between Homo sapiens and other species (p. 10). Similarly, Singer (1979) argues the title 'person' is not reserved for human beings only: 'There could be a person who is not a member of our species. There could also be members of our species who are not persons' (p. 76). It is interesting to note that Singer believes certain Homo sapiens may not be people. According to Singer, characteristics of personhood (as applied to a human or animal) are attributed to a rational and self-conscious being that 1) is aware of itself as an extended body existing over an extended period of time; 2) has the ability to make plans and formulate desires; 3) maintains, as a necessary condition for the right to life, the desire to continue living; and 4) is an autonomous being (Hymers, 1999, p. 127). Based on this definition, Singer (1979) controversially supports selective infanticide or after-birth abortion, defending the possibility of killing a new-born baby under certain circumstances. This has created strong resistance to his work (McKenna, 1994), despite the fact that many believe he is one of the greatest philosophers of the present day. Hymers (1999) contends that those opposed to Singer have read little of his works or heard his views second-hand. However, Singer's distinction between the 'human being' and the 'person' grounds his position on infanticide. This debate demonstrates how crucial the definition of personhood can be, transferred to important value-based matters.

Smith's (2003) capacity theory of personhood holds that human persons are moral, believing animals whose motivation for action is to sustain moral order. He asserts that humans' unique capacities are abilities to evaluate our beliefs, desires and feelings, and to be able to transform them. Smith (2003), too, questions whether all human beings automatically deserve the status of 'person'. He uses the example of individuals diagnosed with antisocial personality disorder, who are unable to follow social norms, are manipulative and destructive, show no empathy for others, and are unable to feel guilt over the pain they inflict on others. Smith (2003) alleges they have less personhood: 'We know that something has gone very deeply wrong with their humanity, that even though they are genetically humans, they have become in a sense somehow something less than human' (p. 14). Such arguments reinforce once again how important the definition of personhood is. If we bestow individuals with different degrees of personal value, would they also be afforded different rights? It is unlikely this is what Smith intended, but such a discussion illustrates the challenges of the concept of 'personhood', and the implications it carries.

Determining which criteria constitute a person or what approach to personhood is the most plausible is beyond the scope of this paper. However, reflecting on these perspectives has helped me gain a deeper understanding of the concept of personhood. Personally, I believe in the absolute and intrinsic worth of every person, regardless of recognition by others or the self, which aligns with the person-centred approach taken by McCormack and McCance (2010, p. 9).

## 4. Methodology

What we see will depend on what we are interested in,  
what we are trained to see  
and what we are trained to not see.

Dag Ingvar Jacobsen, *How to conduct surveys*.

This chapter describes the philosophical underpinnings of the study, and the different methodologies used throughout the different stages of the project.

### 4.1 Qualitative research

As the purpose of the current project was to gain insight into the care partners' and home care staffs' life experiences and their own interpretations of these experiences, a qualitative approach was chosen. According to Denzin and Lincoln (2011), all research is interpretive: It is 'guided by a set of beliefs and feelings about the world and how it should be understood and studied' (p. 13). The authors state that the net containing the researcher's epistemological, ontological and methodological premises can be called a paradigm (Denzin & Lincoln 2011). Creswell (2013) emphasises that researchers must 'position themselves' to acknowledge how their backgrounds influence their interpretations. I position myself within a social constructionist, interpretive paradigm, drawing on hermeneutics. In the social constructionist<sup>9</sup> worldview, people seek to understand the world and develop subjective meanings of their experiences, which are complex and varied. According to Creswell (2013), these views or subjective meanings are often negotiated socially and historically; they are socially constructed through interactions with others, which again come under the influence of historical and cultural norms. Guba (1990) claims '[R]ealities exist in the form of multiple mental constructions, socially and experientially based, local and specific, dependent for their form and content on the persons who hold

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<sup>9</sup> Also described as interpretivism, see Denzin and Lincoln (2011).

them' (p. 27). This implies that multiple realities exist; taking this view acknowledges that even the most rigorously conducted study will still be a product located in one specific reality influenced and interpreted by all those involved in the project, both the participant(s) and researcher(s). As Geertz (1973) states, 'What we call our data are really our own constructions of other people's constructions of what they and their compatriots are up to' (p. 9). Indeed, reality and "truths" are fluid and changeable.

The way I construct and interpret my life world—both its private and professional aspects—depends on my own lived experiences, which include my social, cultural and historical background. As such, I have chosen a hermeneutic orientation for this thesis<sup>10</sup>. Gadamer (1960/1998) remarks that 'the work of hermeneutics is to illuminate the circumstances under which understanding takes place rather than to develop a process for understanding' (p. 295). Historical and social phenomena exist by virtue of being understood; a greeting is just a greeting insofar as it is understood as a greeting, so the more familiar we are with the basic features of human consciousness and the better we know the context, rules, and conventions, the more adequate and complete our understanding will be (Johannessen, 1994). However, this understanding will still remain a product of the interpreter's construction.

In other words, the interpretations, results and conclusion of this thesis must be seen as located in this current period of time, in the local context of the participants and through the subjective interpretations made by the author. By outlining the context, my personal background and descriptions of the research process, the goal is to make the reader better able to ascertain on which conditions the results were reached.

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<sup>10</sup> A pure hermeneutic approach was only used in Study II, however, through the research process I discovered that this perspective resonates best with me, and it forms a natural starting point for the work on this part of the thesis (the introductory chapter).

## 4.2 Participants

A purposive sample was recruited from two municipalities. Purposeful sampling, where the inquirer selects persons especially knowledgeable about or experienced in the phenomenon under investigation, is widely used in qualitative research (Creswell, 2013; Creswell & Plano Clark, 2011). This research involves two groups with these qualities: care partners of older people with mental health problems and home care staff/leaders.

### 4.2.1 Care partners of older people with mental health problems

Home care staff and leaders recruited the care partners, and they did not provide exact figures on the number they asked to participate. Securing the participation of care partners of older people with mental health problems proved to be a challenge. Most potential participants declined to become involved, as they did not have time or were too exhausted. This is an important element regarding the findings of this thesis. It might be that the care partners who experienced the greatest burden of being in these roles are not included. Furthermore, it is possible that their experiences would be different from those who had enough resources to participate in the interviews. This identifies a challenge researchers often encounter in the face of vulnerable groups - how to get them to speak and let their voice be heard?

The recruitment process itself may also have led to bias in the sample in the sense that it may have been the care partners who were most satisfied with the services offered by the home care staff who participated. The home care staff/leaders assessed who was eligible to participate, thus it was inevitable that their opinions on the suitability did not influence the process. Sanghera and Thapar-Björkert (2008) highlight challenges regarding employees assuming roles as gatekeepers while arranging the contact between participants and the researcher, and how this can determine the researcher's access to participants. It might have been the case in this study that participants were carefully selected by the home care staff and leaders, that not *all* the care partners of older people with mental health problems were asked about participation. It is reasonable to assume that they may have attempted to protect the care partners they knew were particularly tired and/or facing challenging situations. It is also possible that some care partners were not asked to participate for other reasons. However, it is important to assess the participants against the purpose of the study

and research questions. As I consider it, the persons who participated contributed with unique stories of their experiences as care partners of older people with mental health problems.

In addition to this recruitment process, I also got access to previously collected data from the action research project, 'Collaborative Practices with Older people Living at Home with Mental Health Problems: A Person-Centred Approach'.<sup>11</sup> These data are referred to in the thesis as secondary data, and are used in Study II. Secondary data can be defined as "further analysis of an existing dataset to address a different research question or to conduct research with data that was not collected for research purposes" (Windle, 2010, p. 322). Heaton (2008) points out that there are three main modes of secondary analysis; formal data sharing, informal data sharing and re-use of own, self-collected data (p.35). In this study, the first option was used, as the accessed data were independently collected by other researchers and deposited in the USN's archives where they met the necessary ethical and legal requirements for being shared (Windle, 2010). I also had the chance to consult with the primary researchers during the analysis process.

The secondary data were collected during 2012–2013. Three care partners who participated in that project met the inclusion criteria for the current project, and the collected data were compatible with the aim of this study. Furthermore, the data were evaluated for the methodology, purpose of collection and content of the data. The data did not contain any identifying information (Tripathy, 2013). It was concluded that the data were suitable for use in this project. However, there are some weaknesses in using secondary data. In this case, the data are relatively old, as they were collected 6-7 years ago. Furthermore, it was a comprehensive undertaking to get insight into the material, and it was difficult to reach the same level of understanding of the secondary data as the primary data. Nevertheless, the disadvantages were undoubtedly offset by the benefits, especially in terms of getting more data on a group of people who was difficult to recruit for participation.

The final sample consisted of six male care partners between 44 and 89 years of age; three from the municipality where I collected data during 2016, and three from the

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<sup>11</sup>This is the name of the project, and not the published material from it, which is why it is not cited. Permission to use the data was obtained from its legal owner, the University of South-Eastern Norway.

municipality where the secondary data were collected. The inclusion criteria were: 1) being a close care partner of an older person (>65 years) with mental health problems living at home and receiving home care services; 2) having some kind of interaction with home care services; and 3) being able to understand the given information. The family members of the care partners primarily experience anxiety and/or depression. Additional characteristics of the care partners are presented in Table 3.

**Table 3.** Demographic characteristics of care partners.

Care Partners (N = 6)		
Age	Range	44–89 years (mean age 61.3 years)
Gender	Male	6
	Female	0
Relation to service user	Spouse	3
	Son	3

#### 4.2.2 Home care staff/leaders

After receiving oral and written information about the project, eight home care staff members and three leaders agreed to participate. Details of the leaders are omitted in order to ensure greater anonymity within this home care district. The inclusion criterion for participation was employment in home care services as either a leader or care staff. Additional characteristics of the home care staff and leaders are presented in Table 4.

It is debatable whether more home care staff and leaders should have been included in this study. More participants would have contributed to a richer data material, and perhaps given a more nuanced picture of the reality as presented here. However, this was not feasible within the scope of this dissertation. Accessing the field was a rather



straightforward task. However, the challenges consisted in carrying out information meetings, as well as organising and conducting the interviews. As stated in this study, home care services is an arena with very limited resources, and it was difficult to take time from the daily tasks for both the staff and leaders. The solution was to use the lunch break for information meetings, and partly their spare time to conduct the interviews. Following this experience, the question of including more home care districts was not only a question of practical matters, but also became an ethical concern.

**Table 4.** Demographic characteristics of home care staff/leaders.

<b>Home care staff/leaders (N = 11)</b>		
Age	Range	25–65
Gender	Male	0
	Female	11
Profession	Nurse	4
	Nurse assistant	4
	Leader	3
Years of experience in home care services	Range	1–28 years

The rationale for including the leaders in Study III was rooted in the principles of person-centredness in which all persons are seen as persons with an equal voice and thus should have an equal opportunity for their voice to be heard. Furthermore, there was a belief that the leaders could help shed light on the research question. The leader's participation proved to be an important contribution in that regard, but the way in which

they were included in the study also contributed to some methodological challenges, which are discussed under methodological considerations in chapter 6.3.

### 4.3 The research field

The research setting involved two rural home care districts in southeast Norway; one large municipality and one small.<sup>12</sup>Of the two districts, the large municipality is the most organized according to NPM principles, where the purchaser-provider split (PPS) model has been implemented. This service delivery model implies a distinction between the purchaser and the provider in which third-party payers are kept organizationally separate from service providers (Tynkkynen, Keskimäki & Lehto, 2013; Vabø, 2007). The purchasers are responsible for care provision decision making, while the provider offers services according to legal administrative decisions. The goal of this model is to create competition between providers, which together with other incentive structures is believed to lead to better service delivery in terms of improved cost control, efficacy, flexibility, quality and improved responsiveness towards patient needs (Tynkkynen, Keskimäki & Lehto, 2013, p.221). This model takes many forms; in this case, a service office operated as the purchaser, and home care services were among the providers (Briseid, 2016).

The home care district in the large municipality consisted of three teams comprising approximately 60 full-time equivalents (FTE). About 420 people received help from the home service. Of these, around 45 people had mental health problems (Skatvedt, Andvig, & Baklien, 2015). The secondary data, consisting of three interviews with care partners of older people with mental health problems, are from this municipality.

The home care district in the small municipality consisted of two departments comprising approximately 25 FTEs. Each department had one department manager and two team leaders. The four team leaders were all nurses, and had the same responsibilities towards the patient group as the rest of the staff. Additionally, they were in charge of administrative tasks related to all patients in their team in which their team members also

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<sup>12</sup> • Small municipalities: Municipalities with 0 to 4,999 inhabitants.  
• Medium-sized municipalities: Municipalities with 5,000 to 19,999 inhabitants.  
• Large municipalities: Municipalities with at least 20,000 inhabitants (Langørgen & Aaberge, 2011).

contributed. In this district, the department managers performed the care provision decision making, and were partly responsible for planning the daily care provision for the patients. They were also responsible for the municipality's electronic communication channel with the local hospital during daytime. During evenings, nights and weekends, this was the nurse's responsibility.

The distance to the administration of the municipality was short, and it was common for the health sector Alderman to visit to receive updates on the provision of services. About 200 people received help from this home care district; however, no statistics were available showing the number of patients with mental health problems. The remaining participants came from this municipality: three care partners, three leaders and eight home care staff members.

The significant difference between the two home care districts thus concerned how they organised care provision decision making, in addition to the size of the municipalities where they were located. The latter implies a disparity in the distance between the operational core and the administration. The large municipality was organised according to a purchaser-provider model, a 'true child of New Public Management' (Nyseter, 2015, p. 225), whereas in the other district, the leaders performed the care provision decision making. All employees in the two home care districts, including the service office in the large municipality, were women. Both municipalities were also characterized by constant cutbacks and a focus on improving the efficiency of the services.

## **4.4 Data collection and analysis**

The data collection and analysis processes are described in detail in the three studies (I, II, III). In this section, I summarise the methods and provide a closer look at factors not thoroughly addressed in the individual studies.

### **4.4.1 Study I**

In Study I, the systematic review, systematic searches were conducted using the CINAHL Medline, PsycInfo, Embase, SCOPUS, Age Line, Cochrane and SveMed databases. The Joanna Briggs Institute (JBI) (2014) critical appraisal instruments were used for the quality

assessment of the studies. Finally, the qualitative findings were analysed and synthesised using a content analysis supported by Graneheim and Lundman (2004). For more information, see Study I, pp. e1312–e1313. The Prisma 2009 check list can be seen in the appendix.

#### 4.4.2 Study II

In Study II, semi-structured interviews were conducted with six care partners. Gadamer's (1998/1960) hermeneutics were used to analyse the data. Secondary data were included, as described in the study (p. 5–6), and earlier in this chapter. The questions asked during the interviews in the two municipalities were not exactly the same. The interviews included in the secondary data had a more open-ended approach, but covered the same areas as the interview guide for the primary data. It can be argued that in hermeneutic studies, the analysis begins in the interview setting; in the current case, important information may have been lost because I was not present for the secondary interviews. Considering that the communication process consists of both verbal and nonverbal expressions (Eide & Eide, 2017), this is likely. However, I obtained good information about the context of the secondary data, and the transcribed interviews included details such as laughter and breaks in the conversation. What emerged in these interviews was also recognisable in the primary interview data. More details on the data collection and analysis process can be found in Study II, pp. 4–6.

#### 4.4.3 Study III

This study involved eight health care professionals in two focus groups and in-depth interviews with three leaders in home care services. A framework analysis was used to analyse the data, as explained in detail in Study III (pp. 3–6). The data collection methods are mentioned briefly in the paper, but are explained more in detail here. First, a closer investigation of the concept of focus group interviews is needed. This project is based on Malterud's (2012) open approach to group interviewing. Her method is based on Morgan and Bottorff (2010), who assert, 'There is no single right way to do focus groups. Instead, there are many different options, and for each research project investigators need to select a way of using focus groups that matches the goals of the project' (p. 579). This technique is

used to stimulate discussion and—through the group dynamic—bring out stories and angles that differ from those that emerge in a one-on-one interview. In advance, the participants were encouraged to talk, ask each other questions and comment on each other's statements (Malterud, 2012), which they did to a great extent. It seemed as though the setting and sound recorder prompted inhibitions during the first few minutes, but they were soon forgotten, and an authentic conversation about the theme arose.

It is often recommended that focus groups be led by two people: a moderator and secretary or observer. Because the groups in this case were relatively small (four participants each), I chose to lead them alone. I believed including another person could hinder the discussion, and thought I would be able to moderate, observe and take notes during the interviews. However, taking notes proved difficult and was mostly completed after the interviews. Otherwise, I had good experiences with both focus groups, and relevant, rich data were collected. It is possible another person would have caught details I overlooked, but I think it would have had minimal—if any—impact on the data.

Three in-depth interviews were conducted with leaders in the home care district. The leaders were not included in the focus groups due to existing power differentials, both among them and in relation to the home care staff. Pre-existing power and hierarchal relationships between participants could cause participants to experience difficulty in voicing their opinions in the presence of others (Hofmeyer & Scott, 2007). Individual interviews were therefore arranged with the leaders to avoid this issue.

Participants from two levels of the home care organisation were chosen to gain knowledge about the collaboration between care partners of older people with mental health problems and home care services from multiple perspectives.

## **4.5 Reflexivity, preunderstandings and my background**

*Who am I?* Providing an answer is an ambitious undertaking, as it is a complex question. However, preunderstandings and prejudices should be addressed in research to safeguard openness and transparency throughout the research process. Otherwise, the result might merely be a reflection of what is already in our own understanding (Nyström & Dahlberg, 2001). As a person, I bring my own values and beliefs into the research process;

these are influenced by my gender and class, my social context and personal politics (Creswell, 2013). In turn, these affect my research methods, my philosophical assumptions, my choice of perspectives, my research questions and so forth:

My subjectivity is the basis for the story I am able to tell. It is a strength on which I build. It makes me who I am as a person and as a researcher, equipping me with the perspectives and insights that shape all that I do as a researcher, from the selection of topic clear through to the emphases I make in my writing (Glesne & Peshkin, 1992, p. 104).

Sandelowski (1993) argues that “qualitative research is an art or, at least, as much as science” (p.3). While looking with a view toward discerning connection between the two, the differences between art and science appear more as variations of common themes, rather than differences (Sandelowski, 1994 p. 48). People perceive art differently; a painting can be interpreted in different ways depending on who looks at it. Likewise, in qualitative research, the ways in which the findings are interpreted depend on the eye of the beholder. What different researchers look at, look away from and see as part of a whole will differ. What they see in the foreground, and what recedes to the background, will also be different (Gadamer, 1998/1960). The results of qualitative research can thus be said to reflect not only the life world of the participant(s) in a study, but also the researcher’s.

With this viewpoint as a point of departure, the purpose of this chapter is to give the reader insight into the premises on which this work is based. I draw inspiration for this approach from Muncey (2010), Lieshout (2013) and Creswell (2013). Muncey (2010) and Lieshout (2013) both illustrate perfectly how art, creativity, and personal stories can be integrated into research through an autoethnographic approach. Autoethnography can be defined as ‘an artistically constructed piece of prose, poetry, music or piece of art work that attempts to portray an individual experience in a way that evokes the imagination of the reader, viewer or listener’ (Muncey, 2010, p. 2). Muncey (2010) contends that autoethnography is not a method but rather an approach that can be included in the research process in different ways. Creswell (2013), in turn, emphasizes the importance of reflexivity in research. Creswell (2013) suggests that reflexivity consists of two parts; first, letting the reader

know the author's experience with the phenomenon under investigation, which includes earlier experiences through education, family and work, while the second discusses how these factors have influenced the interpretations of the phenomenon (p. 216). Furthermore, Creswell (2013) argues that when considering reflexivity, qualitative researchers need to position themselves in the writing and be conscious of the values, biases and experiences they bring to the study. Using reflexivity as a tool in the research process can contribute to the quality, validity and reliability of the research results.

To integrate these two perspectives in this thesis, I present a short self-portrait, snapshots of my life and the core values I try to live by. The intention is not to be self-indulgent or inward looking, but to give the reader a better understanding of some factors that have contributed to forming me as a person, both personal and professional. This has in turn formed the basis for the preunderstandings and prejudices I bring in to the research process; "We are historical creatures, we are always on the inside of the history that we are striving to understand" (Gadamer, 1998: p. 28). However, what I will reveal here are only tiny, contextual fragments of 42 years of life, and cannot be seen as a comprehensive presentation of the person I am.

#### 4.5.1 My self-portrait

- I am an infant born in 1977 into a family of three. My mother is a stay-at-home mother, and my father works in a grocery shop.
- I am a 7-year-old schoolgirl with a teacher who managed to see each child in our class as a unique person and treated us accordingly.
- I am a 16-year-old teenager with a gun against my head. I survive, the gunman commits suicide a few weeks later.
- I am a 24-year-old young woman, dancing salsa on the highway in the Negev desert of Israel.
- I am a 31-year-old nurse, working in a home care district characterized by person-centeredness, though neither of us working there had ever heard about this approach to nursing.
- I am a 40-year-old PhD student participating in a national research contest, scared to death to walk out on the stage to meet the audience, judges and film cameras. I take a deep breath and walk out on the stage.
- I am a 42-year-old assistant professor, PhD student, mother, wife, friend, daughter, sister, neighbour and colleague trying to maintain a balance between different roles, responsibilities and expectations, as well as being true to what I believe in.

It may be questioned how important it is for the reader to know for instance that I once danced salsa in a desert. The answer may be that it is not relevant at all. On the other hand, it demonstrates that I, the researcher, am a person who is part of the social world I am studying, a person with my own unique life story. Muncey (2005) describes the capturing of episodes of life “like stills in a film, they convey the skeleton of a life without the flesh and the consciousness of the being (p. 84). In this next section I will share some core values that are important to me, and have guided my research process:

- I value *courage*. For me, courage is about standing up for what I believe in and persisting in the face of challenges— but also to walk away if it is not worth the struggle.
- I value *respect*. This includes being respectful toward myself and the people around me, appreciating the uniqueness of every person and recognising that people act based on their own understandings of reality—an understanding not necessarily the same as my own.
- I value *authenticity*, the ability to be real and genuine. I aim for congruence between my words and actions. I want my footprints in my personal life and professional career to be a reflection of my inner voice and own ideals, not only an echo of external expectations.
- I value *happiness* and aim at creating it every day. I believe happiness is determined by my own mind set; the way I approach people or situations will always affect the outcome.
- Finally, I value *integrity*, a core value present in all the values above, as it is a commitment to being honest, reliable, consistent, responsible and doing what is right. It concerns my own identity, who I want to be as a person, what values are important to me and the way I want to live my life.

To make visible and to share the core values that guide me as a person, both privately and in the researcher role serve two purposes. First, it serves to shed light on the contextual factors for the research process. Secondly, together with the rest of this chapter, it might be considered a pre-requisite for person-centred research. According to Titchen, Cardiff and Biong (2017), ‘A reflexive researcher should be able to articulate and reflect on their personal values, beliefs and needs (being and becoming) and from this act with a moral intention of doing *good*’ (p. 42), and they see this as an integral part of a person-centred research process.

Finally, I will share a short recap of my professional background. I began my Bachelor of Nursing at the University College of Østfold in 1999. While studying, I worked in a facility for people with special needs and in the orthopaedic ward of a hospital. After graduating, I



continued to work in the hospital until 2006, when I started to work in a home care district. I began a master's in management that the same year and soon became interested in theories of emotions in organisations. In my master's thesis, I wrote about nurses' experiences of emotional labour in hospital wards, and learned a lot about the way in which emotions are controlled and displayed according to expected, established standards (Anker-Hansen, 2011).

Halfway into my master's degree, I began work as a department leader at a nursing home. There, I learned valuable lessons—the importance of an organisation based on person-centred principles, the significance of psychological safety at work and the need to pay attention to power relations. After a short period in this position, I became the project manager for the establishment of a *Helsehus*, a local hospital like institution launched by the Coordination Reform (Ministry of Health and Care Services, 2009). A few years later, I was back in home care services again, this time as a department leader. Having been away from this field for a few years, I could clearly see how the pace had increased and how the Coordination Reform had led to more complex tasks and administrative work for the staff. However, the biggest challenge I experienced as a manager was the dominant focus on hierarchical positions, streamlining and low level of autonomy for the staff.

#### 4.5.2 Being a researcher in my own field

My background as a nurse with work experience in home care services has both advantages and disadvantages. I quickly gained access to this field when starting the current research, and I felt that because of my professional background, I earned the confidence of the participants; I was an 'insider', not a 'stranger in a strange land' (Lincoln & Guba, 1985, p. 302). Gair (2012) characterises the insider/outsider status as 'the degree to which a researcher is located either within or outside a group being researched, because of her or his common lived experience or status as a member of that group' (p. 137). The fact that I could relate to the participants' worlds and 'understand' them may have made it easier for them to open up and talk about personal topics. It was evident during the interviews with the home care staff that they acknowledged that I was one of them, with statements such as "yeah, you know how they can act" and "as you know...". Furthermore, the in-depth knowledge I have about the field has led to deeper insights and an improved understanding of crucial issues I might not otherwise have discovered. On the other hand, it was difficult to maintain a critical

distance from the participants because of my preunderstandings. Sometimes it was for instance a bit challenging to avoid getting into discussion about some of the topics brought up when the participants addressed me for comments. However, I had clarified with the participants up front of the interviews that it was their voice and opinions that were of interest, and that I would try to keep out of the discussions.

#### 4.5.3 My pre-understandings

The concept of pre-understanding is central in Gadamer's philosophy, in what he called prejudices or presuppositions (Gadamer 1996/1960). Moules (2002) holds that 'these prejudices allow us to hear something we would not have heard otherwise, they limit what we can recognise, and thus provide our access to the world' (p.12). Gadamer did not see the pre-understandings to be negative, but rather as something that allows the researcher to understand something in a certain way (Moules, 2002).

According to Creswell (2013), after presenting one's 'experiences with the phenomenon under exploration, it is important to discuss how these factors have shaped the interpretation of the researcher' (p. 216). As described earlier in this chapter, my professional pre-understanding is grounded in nursing science, professional practice in nursing and management. As a former nurse in the home care setting, I am familiar with how the staff work on a day-to-day basis, and I easily identify with the complex challenges they regularly face. I also sympathise with leaders in such organisations, as I understand they are not necessarily in a position to make significant changes. However, I believe that rigid, hierarchical organizations characterized by top-down approaches have little ability to stimulate a culture where employees feel seen, heard and valued. My pre-understanding regarding the care partners concerned different aspects as discussed in study II. I believed that the care partners did not experience good collaboration with home care services and that they, as other care partner groups, had many unmet needs. This understanding came from my own experience, where most care partners were little involved in the care or decision-making processes, and seldom were seen as partners in care. In addition, there was a lack of focus on the needs of care partners, whereby discussions about what services home care could offer the care partners, or how to make the care role easier for them, hardly ever happened. When the care

partners were a topic of discussion it was often due to a care partner being seen as 'demanding' on behalf of their family member. The care partner groups who did receive good follow-up though, were care partners of patients in palliative care, and to some extent; care partners of people with dementia.

To try to counter these pre-understandings and to become further aware of the beliefs and attitudes I had regarding care partners of older people with mental health problems in home care services, I documented personal reflections before the data collection. I also reflected on what findings I could come across, and my reasons for these assumptions. Furthermore, these pre-understandings were discussed with my supervisors. In the analysis processes, I was aware of these prejudices and tried to look past them when interpreting the data. Dahlager and Fredslund (2007) highlight the importance of reading a text with an open mind; "When we read a text that we cannot understand - or will not understand because we disagree - it is important to be open to understanding why the other may think differently from ourselves. This is a first and very important step in understanding what [is] different" (p.170). During the analysis processes, I consciously searched for opinions and experiences in the material that did not confirm my pre-understandings. However, I did come across results that were in line with my presumptions several times. I then questioned the results further and tried to see it from different angles in order to get past these pre-understandings and challenge my own thoughts on the subject. However, it is inevitable that my pre-understandings did shape the way I conducted the interviews, analysed the data and discussed the findings in the three studies (Miles, Huberman, & Saldaña, 2014).

## **4.6 Ethical considerations**

The project was reported to the Norwegian Centre for Research Data (NSD). A request was also sent to the Regional Ethical Committee to determine whether approval was needed; it was not (Appendix). Permission to conduct the study was provided by the heads of the home care services, and the remainder of the consent process was guided by the principles of the Helsinki Declaration (World Medical Association, 1964/2002). Information about the project was provided in both oral and written form, including information about participant anonymity and confidentiality, as well as the participants' right to withdraw from the study at any time for any reason. All participants gave their written consent.

The data were treated according to NSD's recommended procedures to ensure anonymity (Norwegian Centre for Research Data, n. d). In the transcribed material, the participants are consistently referred to by profession and number; for example, Carer 1 and Care Partner 1. A list of the codes identifying the participants was kept locked and separated from the audio files. Other information that may have revealed the identity of the participants or home care district, such as the names of places and organisations, was removed from the transcribed material. Only the author and main supervisor had access to the transcribed interviews. No information that could lead to the identification of persons or places was used in the field notes or reflection notes. The transcribed interviews, field notes and reflection notes were kept in a secured area.

#### 4.6.1 Doing person-centred research

Following general ethical guidelines does not guarantee researchers will place the participants at the centre of their research thinking. McCormack (2003) contends that during the research process, '[T]he closest many researchers get to being person-centred is completing the ethical approval form and hoping that it will get through the process without too many hold-ups' (p. 182). He argues that to embrace person-centredness, researchers need to reconsider the principles underlying their research practices. Person-centred research means the entire research process is informed by person-centred values. It can be argued that this approach to research does not differ significantly from standard ethical research guidelines. However, I think the person-centred approach adds a holistic perspective; the participant is the primary focus and consideration for that person is the priority. Applying these principles can change the way the researcher engages with the participants; collects, illuminates and interprets the data; and translates it into practice (Reid, 2013). In line with the person-centred approach of this current thesis, I use a person-centred research framework developed by McCormack (2003) as guiding principles. Below, I outline the conditions I applied to my research process and how I translated them into practice.

*Adopt a long-term commitment to acting on results*

It is a long-standing joke in academia that when PhD students enter their academic careers, many believe they will revolutionise their fields of study with ground-breaking research, but in reality, their dissertations end up in drawers after being read only by the supervisors and professors in the dissertation committee. However, today article-based projects are more common, and these often reach a wider audience. Yet McCormack's (2003) point regarding the ethical aspect of obtaining knowledge about how practices can be improved for service users without implementing the results remains timely. One element of person-centred research is planning projects with the goal of creating changes in practice. Because this particular project had a strict time frame, implementing change was not possible in this case. To temper expectations, I informed the participants of this during our first meeting. Nevertheless, the long-term vision for this strand of research is to develop projects that can act upon the findings of the current study.

*Inclusion of staff members/preparation of the environment*

It is essential to involve all employees in the studied environment in a person-centred research process. This includes those who are not active participants, because they have the right to know what kind of research occurs in their work place. In the early stages of the current study, all employees in the included home care district received written information about the project and were invited to preliminary meetings. Several members of the staff attended one of the two meetings held. Spending time with the staff in their environment allowed me to gain a deeper understanding of the research context. It also gave them the opportunity to ask questions about the project, and several people showed an interest in participating.

*Represent views authentically*

In research reports, the voice of the participants is often presented in natural form, whereas the voice of the researcher adopts an academic tone. This contributes to a power imbalance between the researcher and participants (McCormack, 2003). McCormack (2003) suggests different ways of resolving this issue, including presenting the voice of both parties in the same manner; asking the participants how they want their voices portrayed and

coming to an agreement; and avoiding ad hoc quotes without considering participants' reactions to seeing their voices represented in this way. I discussed this matter with the participants, and all but one said that the way the material was presented was not important to them. One person was concerned about being identified through the use of quotes, but approved the use of all data in any form after reading the transcribed material.

*Avoid the 'hit and run' approach to research participants*

The 'hit and run' approach refers to situations where the participants are used as objects to further the researcher's goals. McCormack (2003) proposes ways to 'pay back' participants, such as 'clinical supervision sessions, seminars, supporting action from preliminary findings, speaking at public meetings of voluntary groups and collaborative writing with participants' (p. 185). Several participants were invited to participate in collaborative writing in Study III. All were grateful for the opportunity, but did not have the time to participate. Before starting the data collection process, I spoke about person-centred health care to home care staff in one district because this was an unknown theoretical approach they wanted to learn more about. I also agreed to return to this home care district to share the studies' findings after completing the project.

*Practice sympathetic presence and mutuality*

In meetings with the participants, I tried to create a comfortable setting. I interacted with each person in a respectful manner and showed my gratitude for their time and effort. I conversed with care partners both before and after the interviews so I could get to know them better. During these moments, I felt a connectedness far beyond what occurred during the interviews. I took notes after all the interviews to capture the private feelings and concerns shared during these times. These notes helped expand my understanding of what was said during the interviews, but were not directly included in the analysis.



## 5. Presentation and Results of the Studies

I walk to the horizon  
And there I find another  
It all seems so surprising  
And then I find that I know

- 'Anywhere is', Enya

This chapter presents the studies and their results. In the last section of the chapter, I highlight a significant issue underlying the findings of the three studies, which is discussed in the next chapter.

### 5.1 Study I

The purpose of Study I, a systematic review, is to identify and synthesise the needs of the care partners of older people living at home who are aided by home care services. The focus in this study is their expressed needs. Study I centres on the research question, 'What do the care partners of older people living at home need from home care services?' The study also seeks to identify possible approaches to address the expressed needs of the care partners and to recognise gaps in the current knowledge in this area. The systematic review was guided by the Joanna Briggs Institute (2014) methodology, and the qualitative findings were analysed and synthesised using a content analysis supported by Graneheim and Lundman (2004).

The analysis reveals the target group sought to be seen and treated as a person with own needs. Three interrelated categories comprise this latent theme: 1) the need for quality interaction, 2) the need for a shared approach to care and 3) the need to feel empowered. The three categories all represent the care partners' need to be seen, respected and treated as persons with their own needs in the triad of home care services—care receiver—care partner.



The results in the first category, *the need for quality interaction*, highlight the importance of quality interactions between care partners/patients and home care services. The findings can be further subdivided into two groups: 1) the need for a trustworthy, predictable and flexible service and 2) the need for information and education. The included studies revealed the need for services characterised by trust, flexibility and continuity. Furthermore, the care partners expressed their desire for additional knowledge about both the care receivers' diseases and their own situations as the primary care partners. They also wanted more information from the home care staff and more help navigating the municipal health care services.

In the second category, *the need for a shared approach to care*, the included studies reported that care partners felt weighed down by their responsibilities as primary care partners and expressed an urgent need for respite, a social life and someone with whom to share responsibilities. This category can also be broken down further: 1) the need for personal space and 2) the need to share responsibility. The category highlighted the care partners' need for personal time and space. The request for relief was also a recurring theme. Many of the care partners wanted to share the responsibility for care with home care services. Additionally, the importance of collaboration among the different stakeholders in home care services was addressed, along with how care partners' own needs must be identified.

The last category, *the need to feel empowered*, demonstrates the care partners' need for support and emotional connection. The need for support at different levels was reflected on in several studies, and the subcategories are designated as follows: 1) the need for a supportive space and 2) the need for an emotional connection. This category shows that care partners wanted to be seen, respected and acknowledged, and that they wished for more support hours. More home care support for the people they cared for could be considered as help for the care partners. Finally, they expressed their need for emotional support.

Study I identify the needs of care partners of older people who receive home care services. The study demonstrates care partners have several, continuously unmet needs. The discussion considers the benefits of using the person-centred practice framework as a tool for better fulfilling care partners' needs. However, the development of a person-centred

organisational culture is a complex matter, which must be rooted at all levels, from the micro to macro. The findings carry both policy and organisational implications, and highlight the importance of supportive policies and strategic directions as a prerequisite in order to avoid inconsistencies in service provision, and move from NPM strategies toward a more person-centred organisation structure. The review suggests a model for systematic collaboration between care partners and home care services should be developed based on the principles of person-centred health care. Finally, Study I reveals a knowledge gap regarding the needs of the care partners of older people with mental health problems.

## 5.2 Study II

The goal of Study II is to explore the lived experiences of care partners of older people with mental health problems living at home who receive assistance from home care services. The study aims to answer the following research questions: 1) Do the care partners of older people with mental health problems experience collaboration with home care services? 2) What do the care partners of older people with mental health problems need from home care services to cope with their responsibilities? In-depth interviews were conducted with six care partners; the data were analysed using Gadamer's hermeneutics (Gadamer 1998/1960).

The three identified themes are: 1) invisible cornerstones, 2) dimensions of collaboration and 3) unwanted roles. For the category *invisible cornerstones*, the primary findings outline how care partners function as invisible cornerstones. In general, care partners silently accepted their situation, although many experienced severe burdens in their caregiving; they needed to push to get the help they were entitled to, and many went without help for years but still expressed satisfaction with the home care service. Different *dimensions of collaboration* are described in the next category, which spanned a contrasting continuum. Common experiences included a lack of structure and flexibility in the service delivery. In the last category, *unwanted roles*, it was found that the care partners took on unwanted roles, and emotional work was a common experience in the care partner role.

Few or no routines for collaboration exists between the care partners and home care staff, and the care partners seem to have little knowledge of their legal rights. They desired more information, spare time and the opportunity to remain in their original family roles.

However, their main concern is for the patient to receive the necessary help from home care. Because home care services are designed as effective, task-oriented organisations, staff have few resources to meet these needs and, like the care partners, experienced a sense of powerlessness and lack of influence over their own situation. The study demonstrates a need for a fundamental shift in policy, as person-centred principles disappear when the emphasis is on utility and cost effectiveness. Finally, the study shows that in order for home care services to meet care partners' needs, a connection must be established between what is communicated at the system level and its realisation in practice.

### 5.3 Study III

This study explores whether a focus on personhood can help explain the relationship between home care staff and care partners, from the perspective of home care staff. It aims to answer the research question, 'Does a focus on personhood help to make sense of the nature of the collaborative relationship between home care staff, leaders and care partners?' Study III uses a qualitative design involving eight health professionals in two focus groups and in-depth interviews with three leaders in one home care organisation. The data were analysed using a thematic framework analysis built on previous research on personhood (McCormack, 2004).

The results of Study III illustrate the complexity of the collaborative relationship among home care staff, leaders and care partners. The analysis reveals four themes: 1) non-negotiated relationships, 2) contradictory agendas, 3) weak paternalism and 4) moral compromise. The results in the first category, *non-negotiated relationships*, indicate the involved persons' roles and the overall agenda were not negotiated upfront, and unspoken expectations and undeclared roles seemed to dominate the collaboration between the home care services and care partners. The challenges originated from non-negotiated relationships, which can dominate systems that lack a coherent means of establishing and promoting collaborative relationships. The next category suggests *contradictory agendas* existed among the staff, the leaders and the organisation. The staff frequently mentioned that care partners *should* be included in the care process, but it seemed organisational factors limited interactions. Additionally, the leaders had a responsibility to safeguard organisational interests while still paying attention to the interests of the staff, the service

users and the care partners. *Weak paternalism* encompasses the leaders' mediator role and how staff were treated. The staff signalled through their attitudes in certain situations that they were superior care partners and had the overall responsibility in decision making processes. The last category, *moral compromise*, exposes contradictions between the espoused and lived values within the organisation. The staff often found themselves in situations where they had to put their own professional evaluations aside because of limited opportunities to execute tasks in accordance with their own moral values and the purported values of the organisation.

Study III indicates that, throughout all levels of the home care organisation, collaborative relationships are rarely facilitated. The interactions between care partners and home care staff appear to frequently produce low or negative levels of emotional energy, and situations occur where the personhood of neither party was respected. The study suggests that paying attention to the four modes of being (McCormack, 2004) through a person-centred approach increases the likelihood of creating stronger partnerships in these care relationships. In turn, this can lay the foundation for the interactions between home care leaders, home care staff, care partners and patients to generate positive emotional energy. Finally, Study III cautions against imposing additional responsibilities on home care services, because these organisations already are under tremendous pressure to meet their statutory duties.

## 5.4 Summary

This thesis illuminates the poor correlation between Norway's health care policy and the conditions in which the home care staff can provide moral, responsible care for care partners of older people with mental health problems. It demonstrates a discrepancy between the espoused and lived values of the home care organisation in which it is difficult for the staff to work according to expected moral standards and to establish collaborative relationships with care partners. Together, the studies indicated that the collaboration between home care staff and the care partners of older people with mental health problems often did not function satisfactorily. In general, it seemed like the staff wanted to include the care partners in the care process, collaborate and take care of their needs, but organisational factors limited interactions. However, attitudes of the care partners being to

demanding and 'in the way' was also seen. The findings of Study I and II are coincidental, the care partners have many, continuous unmet needs. What they ask for is more information, respite and to be enabled to remain in their original family role. However, support for their family member was more important than support for themselves. Collaborative relationships were rarely facilitated, and the interactions between care partners and home care staff appear to frequently produce low or negative levels of emotional energy. Unspoken expectations and undeclared roles seemed to dominate the relationship between the home care services and care partners, indicating the involved persons' roles and the overall agenda were not negotiated upfront.

It can be summarized that what characterized the relationship between home care services and the care partners was a lack of communication and clarification of roles and responsibilities. Home care staff had many good intentions, but the service was characterized by inadequate funding, which was visible through the continuous shortage of time. In addition, there were challenges regarding the attitude of some staff members towards the care partners. The care partners on their side wanted quality collaboration, but were cautious about promoting claims on their own behalf. The hierarchical organizational framework of home care services largely laid the premises for what was the agenda for the staff, and traces of powerlessness could be seen in both staff and care partners.

The findings of the studies carry both policy and organisational implications, and highlight the importance of supportive policies and strategic directions in order to avoid inconsistencies in service provision. Further, the studies demonstrate a need for a shift in policy, where a move from NPM principles toward a more person-centred organisation structure could be beneficial. However, cautions must be made regarding imposing additional responsibilities on home care services, because these organisations already are under tremendous pressure to meet their statutory duties.

The issues revealed in these three studies can be placed in the wider context of gaps and weaknesses identified in health care systems across the globe. Examples of these are negligence of psychosocial factors, communication and relational skills, overly biomedical-oriented health systems, and mediocre health care financing mechanisms leading to inadequate case management and the discontinuity of care (WHO, 2007, p. 6). Several challenges identified in this thesis align with previous research involving other care partner

groups, or the collaboration between care partners and home care services (NOU, 2011; Ott, Sanders, & Kelber, 2007; Sklenarova et al., 2015; Tatangelo, McCabe, Macleod, & You, 2018; Tønnessen, 2011; Tuomola, Soon, Fisher, & Yap, 2016; Ward-Griffin & McKeever, 2000). The literature reveals a great deal about what care partners in general need, and that these needs often are not met (Keeling, 2014; Landmark, Aasgaard, & Fagerström, 2013; Silva, Teixeira, Teixeira, & Freitas, 2013; Stoltz, Udén, & Willman, 2004). The research is ongoing, and the Norwegian government maintains its focus through reports, reforms and white papers (Ministry of Health and Care Services, 2009, 2013, 2018; NOU, 2011, p. 17). Yet despite this rich knowledge base, one question still remains: Why do care partners experience the same challenges, and why is it difficult to achieve a well-functioning collaborative relationship between care partners and home care services? The three studies demonstrate that the situation today for the home care staff is that they are somehow unable to fully meet the needs of care partners, nor to facilitate functional collaborative relationships. Home care staff appear to experience a sense of powerlessness, in which they are not in a position to influence the conditions in which they work. The research questions in this thesis are considered as illuminated through the three studies (I, II & III), and the next chapter considers which factors limit the opportunities for home care services to help create well-functioning collaborative relationships with care partners and meet their needs. This will be explored through a lens of person-centredness. Finally, it will be considered how a commitment to the ongoing development of more person-centered practices can make a positive contribution regarding these issues.

## 6. Discussion

The thing that is important is the thing that is not seen

Antoine de Saint-Exupéry, *The Little Prince*

This chapter builds on the findings from the three studies outlined in the previous chapter. In this chapter, factors that influence the challenges of care partners and home care services will be highlighted and the limitations of the welfare ambition will be discussed. Finally, how a more person-centred practice can help strengthen the collaborative relationship between caregivers and home care services and address the needs of care partners will be considered, through the use of a person-centred practice framework.

### 6.1 Factors hindering the establishment of well-functioning collaborative relationships: An exploration through the lens of person-centredness

The previous chapter, together with the three studies (I, II & III), demonstrate that there are several challenges faced by care partners and home care staff. From the findings it is evident that care partners' needs are not always being met and that the collaborative relationship between care partners and home care staff does not work satisfactorily. These issues can be understood by exploring them through a lens of person-centredness. The Macro context level of the PCP framework—specifically *health and social care policy* and *strategic frameworks* (Figure 1; McCormack & McCance, 2017)—provide some political context to these issues and challenges. Although the Norwegian state promotes ambitious welfare initiatives, it could be argued that sufficient resources to implement those initiatives are not always

available. The national health policy thus becomes difficult to realise in practice at the local level in the country's municipalities (Briseid, 2017; Vike et al., 2002).

*Decentralisation: Responsibility without power*

The most recent example is the *Living All Life* quality reform (Ministry of Health and Care Services, 2018). The goals of the reform are for older people get help when needed, care partners to get sufficient support, and employees to be able to use their expertise in the provision of health care services. The reform does not involve an increase in funding from the state to municipalities and thus must be implemented within existing budgets. Christiansen and Bjørk (2016) claim that municipalities barely have the resources needed to care for sick and older people within the existing budget, and there are generally very limited resources for statutory services (Kassah, Tønnessen, & Tingvoll, 2014). Thus, it is likely that tasks that are desirable, but not statutory, such as more support for care partners, will still not be prioritised. The new legal rights of care partners (The Municipal Health Services Act, 2011, §3-6) and the new mental health strategy (The Ministries, 2017) present the same problem: increased funding does not follow the initiatives.

The challenge of this issue was evident in both Studies I and II, in which the shortcomings regarding taking care of the needs of care partners was evident. The patterns that emerge here are corresponding: the municipalities' responsibilities have increased, but the funding has not. They are expected to take on more responsibility within the same financial framework, which is already stretched to the limit (Kroken, 2006; Tønnessen, 2011). Consequently, the implementation and operationalisation of new reforms, directives, and legislation become the responsibility of street-level bureaucrats<sup>13</sup>—in this case, the home care staff. The staff must therefore find strategies to bridge the gap between what people are entitled to and what the staff are actually able to provide (Vike, Debesay, & Haukelien, 2016). Failing to find such strategies results in a dissonance between the services that citizens are

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<sup>13</sup> Street-level bureaucrats are defined as 'frontline workers in bureaucracies, e.g. nurses, who regularly interact directly with citizens in discharging their policy implementation duties and who have some discretion over which services are offered, how services are offered, and the benefits and sanctions allocated to citizens' (Erasmus, 2014, p. iii70).



entitled to and the services they actually receive, as discussed in Studies I and II. This is what Vike et al. (2002) described as the decentralisation of dilemmas—how power in the welfare state seems to be about the ability to decentralise dilemmas and responsibilities, such as the contradiction between performance requirements and performance ability. Through the bureaucratisation of home care services, the staff are managed in less detail; they instead have set standards and measurements to meet, and the staff themselves must figure out how to achieve these. This means that homecare staff are in an operational dilemma in which they have more room to manoeuvre in terms of how the tasks are performed, but they have simultaneously greater responsibility for ensuring that the delegated objectives are met. In this way, the dilemma ultimately ends up as a concrete challenge for the staff in home care services (Vike et al., 2002). According to Vike et al. (2002), the exercise of power in the neoliberal welfare state is largely to achieve such decentralisation.

Decentralisation of dilemmas can also be seen in the way the care partners in Study II struggled to get home care services for their family members until they developed a somatic illness. One striking finding in this thesis is thus that the dilemmas of responsibility and care tasks, which Vike et al. (2002) claimed are drifting down the systems to the frontline workers, are, at times, pushed even further down the system onto the care partners of older people with mental health problems. This finding suggests that care partners must sometimes take responsibility for care, because the welfare state does not have enough available resources. The case managers thus act as gatekeepers, and refusing services to older people with mental health problems can be seen as one of the strategies that home care services use to manage the flood of responsibilities.

Other studies have also shown that the staff in home care create strategies that allow them to juggle their tasks when there is insufficient time or space to carry out required work (Kirchhoff, 2010; Tønnessen, 2011, 2016; Vike, 2002). Examples of such strategies include working faster, spending less time with patients, reducing or stopping services for certain patients, lowering quality, and providing help during their spare time, such as lunch breaks or after work (Kirchhoff, 2010; Sæterstrand, Holm, & Brinchmann, 2015; Vike, 2002). It has also been shown that staff delegate care tasks to care partners (Tønnessen, 2016; Ward-Griffin & McKeever, 2000). To disregard the needs of care partners, as seen in Study II and III can also be considered as another strategy in this regard.

*Mandatory volunteering: State dependence on unpaid care partners*

The care partners in this thesis all had a long history in their carer roles and had experienced severe challenges along the way. However, though the care partners contributed a lot to care, the message from the government is that this is simply expected and that future health care perspectives will assume the efforts of care partners. A recent white paper stated that not all care tasks are supposed to be performed by public health care services. The document highlighted that the citizens are responsible for planning for old age and remarked that care partners are invaluable to the health and care services: 'it (sic) is a renewable resource that it is important to take care of' (Ministry of Health and Care Services, 2018, p. 46). This is a clear signal from the authorities that each person ought to take more responsibility for their own ageing and that care partners are expected to contribute; if not, 'the society's provision of care would probably collapse' (Ministry of Health and Care Services, 2018, p. 47).

In light of the findings of this study, it is questionable whether this is a reasonable expectation of care partners of older people with mental health problems. Several care partners were already stretched to the limit and had been taking care of the needs of their family members for years without getting any support. Sending signals that the care partners are 'included in the calculation'—that care provision would collapse without their contributions—can put additional pressure on family members to take on more responsibility than they initially have the resources to handle. If this governmental discourse is internalised, it can cause care partners to judge their own efforts according to these expectations (Jenhaug, 2018). This, in turn, can lead to an increased sense of guilt among those who are unable to contribute and can cause other care partners to be reluctant to ask for help from public services until absolutely necessary, as seen in Study II. As Burr (1995) eloquently noted, 'Discourses are not simply abstract ideas, ways of talking about and representing things that, as it were, float like balloons far above the real world. Discourses are intimately connected to the way that society is organised and run' (p. 54).

In order to safeguard the resource that the care partners represent, it is reasonable to assume that, instead of feeling obligated to contribute to care, they should be encouraged to

seek help at an earlier stage and be offered statutory services—or at a minimum, be informed about the legal rights they have as care partners.

*Management by paperwork: When reporting becomes as important as doing*

Another element that contributes to the squeeze that home care staff often experience is the time needed to meet the documentation and reporting requirements. Both home care districts in this study are partly influenced by NPM principles, which emphasise control, economic efficiency, and documentation systems. When the results of home care services must be visible and measurable, the foundation for a more bureaucratic, inflexible, hierarchical, and controlling system is created (Stamsø, 2005). Home care services are, for example, subject to extensive requirements for reporting, mapping, and documentation. One example of such requirements is the National Individual Care Statistics Register (IPLOS), in which all users of municipal health care services have their details registered. IPLOS is used as a reporting tool in which home care staff must estimate their time spent with each patient. The patients are also scored on variables related to their need for assistance, which must be updated regularly and re-evaluated each time there is a change in the patient's needs (Norwegian Directorate for Health, 2018). The home care districts in this study provided care for more than 600 patients; thus, it is reasonable to assume that IPLOS registration alone generated significant administrative work. In addition to this, staff must also maintain a continuous journal for all patients and fill out a number of forms, such as those pertaining to nutrition, symptoms of dementia, and general risk assessment to name a few.

A Norwegian report from 2012 shows that 9,812 FTEs were used yearly to meet the state and municipal documentation and reporting requirements in the health care sector (Gjertsen, Solvoll, & Gjernes, 2012). The three Studies (I, II & III) made little explicit mention of how the lengthy registration and documentation processes detracted from the provision of direct care or the support of care partners. This may be because no direct questions were asked about this matter—or perhaps because this paperwork has become such an integral part of everyday life for home care staff that no one thought to mention it. However, the staff members spoke often about the limited time available in their daily work schedules, both directly and indirectly. One staff member said that she had to run from patient to patient, and

others talked about things that could not be done due to the lack of time, such as sitting down for a chat with both patients and care partners. This lack of time also had ramifications at the interpersonal level, such as in situations where the personhood of the involved persons was not respected, which was particularly evident in Study III. The paradox of this is that staff must 'run' to complete their care tasks to have sufficient time to report on the care they provided (or failed to provide) and update patient metrics. When the amount of time nurses spend on quantifiable tasks increases, the time spent with patients decreases (Chan, Jones, & Wong, 2013; Kieft, Brouwer, Francke, & Delnoij, 2014), and, as a natural consequence, there is less time to spend with the care partners as well. Jakobsen (2007) claimed that municipalities' care services are threatened by market-oriented principles under which budgetary concerns force a choice between quality and quantity. In other words, the struggle for balanced budgets leads to care being neglected in favour of efficiency, which in turn leads to assigning a low priority to factors that promote person-centred practice, as seen in Studies II and III.

*Doing more with less: Unrealistic expectations and the prioritisation of what is measured over what is needed*

This emphasis on measurement, reporting, and standardised procedures affects the priorities of the health care staff members by orienting them towards prioritising what is being measured and controlled (Kleiven, Kyte, & Kvigne, 2016), which contradicts the core values of the health care professions and person-centred practice (Hobbs, 2009; McCormack & McCance, 2010). This was in particular evident in Study III, where it was discussed how the staff had to make moral compromises to keep up with the organisation's agenda regarding priorities, and there was a discrepancy between the espoused and lived values. Solbrekke and Heggen (2009) argued that nurses often find themselves at the intersection of their professional moral responsibility towards individuals and communities on the one hand and their technical and financial accounting duties on the other, which may also be the case in this study. The issues of both ageism and the low priority given to mental health problems was discussed in chapter 2.3. The findings in this thesis may indicate discrimination towards older people with mental health problems when it comes to accessing home care services. The findings also suggest that the mental health of older people and the support needs of their

care partners are not prioritised after accessing the services either. The diagnoses of the patients could serve as an explanation for why the care partners experienced receiving insufficient support from home care services. As seen in Study II, the main focus of care partners is on the patient receiving the necessary help from home care. However, it is difficult to measure mental health; the help this patient group needs is often diffuse and unmeasurable (Skatvedt et al., 2015). Perhaps the status of the measurable tasks is a contributing factor to the patients' psychosocial needs not being prioritised. When these needs are downgraded, it also means that care partners do not receive the help they said was most needed; for the patient to receive the necessary help from home care (Study III).

The disparity between the ideals and reality is evident in the expectations of staff members, such as requiring them to fulfil all tasks according to high quality and ethical standards while knowing that this standard is, in part, impossible to meet. Doty (2009) explained such an unhealthy compromise as 'the feeling that you are breaking a commitment to yourself or someone else, failing to protect or live up to a responsibility' (p. 19). It is important to determine the effects on home care staff of continuously being asked to do more with less; although staff members do not have the capacity to adequately care for either their patients or the care partners, they must still attempt to meet their organisations' requirement to constantly provide more services (Vike et al., 2002). This implies a constant evaluation of the relevance of needs against each other and can lead to a compromise of their personal values. These conditions create a workplace in which it is difficult for the staff to work according to person-centred principles, which can affect their approaches towards each other, patients, and care partners. Finally, the inability of staff to assume moral responsibility also indicates a small degree of professional autonomy and a larger degree of organisational control. Autonomy is weakened when work is managed according to goals to be achieved but there is little room left for professional judgement. This was reflected in the attitudes of the leaders in Study III. The hierarchical model in home care services was evident, showing that it was the leaders who had authority and decided the agenda of the service, down to details such as when and where the care partners should be offered respite from their family members.

*Professional distrust: Ranking and rating*

When a home care organisation's focus is directed towards measurable indicators, bureaucracy swells while confidence in the staff is reduced (Nyseter, 2015). It could be said that this approach assesses the degree to which the home care staff are trustworthy and accountable. O'Neill (2002) argued that systems constructed to safeguard accountability and trustworthiness actually distract professionals from doing their jobs:

Across the last few decades, we've tried to construct systems of accountability for all sorts of institutions and professionals and officials and so on that will make it easier for us to judge their trustworthiness. And all over our public life, our institutional life, we find that problem, that the system of accountability that is meant to secure trustworthiness and evidence of trustworthiness is actually doing the opposite. It is distracting people who have to do difficult tasks, like midwives, from doing them by requiring them to tick the boxes, as we say (p. 3).

Traditionally, professional norms have dictated how work is to be managed and have influenced employee assessments (Solbrekke & Heggen, 2009). Research shows that NPM principles challenge the perceptions and practices of professional accountability (Noordegraaf, 2007) and weaken the autonomy of the health profession. This is expressed in all three studies, with a sense of powerlessness as a recurring theme, and can also be seen as a sign of low employee involvement and ability to exercise professional judgement.

## **6.2 Person-centred practice as a potential alternative to the current practice in home care services**

This thesis reveals the limitations of current home care services in terms of establishing well-functioning collaborative relationships with the care partners of older people with mental health problems, as well as in meeting their needs. An approach based on person-centred principles could be beneficial in addressing these limitations. The Person-centred Practice

Framework (Figure 1, McCormack & McCance, 2017) provides a potential solution as a framework to inform ways in which a person-centred culture could be fostered in the home care organisation, which would in turn enable the development of person-centred collaborative relationships with care partners. This section explores key elements of the framework and the ways in which these elements can shape the person-centred experiences of all involved in the interactions between home care services and care partners. Figure 2 uses the PCP framework of McCormack and McCance (2017) to illustrate the characteristics of a person-centred home care service. The elements have been selected from the framework in relation to their relevance towards the data material.

### *The macro context of municipal health care services*

One criticism of the earlier version of the person-centred nursing framework developed by McCormack and McCance (2010) was the absence of the macro level (Glasby, 2017). Indeed, this thesis shows that many of the mechanisms that control the provision of home care services are found at the macro level. However, in the revised edition of the Person-centred Practice Framework (McCormack & McCance, 2017), this omission was acknowledged, and the Macro context level was added to the outside circle of the model. At this level, the strategic and policy context of healthcare need to embrace the principles of person-centredness in order to ensure that home care services are enabled to transfer strategic priorities and policies into meaningful practices. Glasby (2017) states that 'you can't integrate a square peg into a round hole' (p. 70), referring to what clinical staff are often asked to do in terms of joining up services that are not designed with integration in mind. It is therefore crucial that the responsibility for setting priorities is assumed at the macro level and that clear guidelines are set regarding what services should be provided and what should be prioritised. Further, emphasis should also be placed on acknowledging the mental health problems of older people, as well as the role of their care partners.

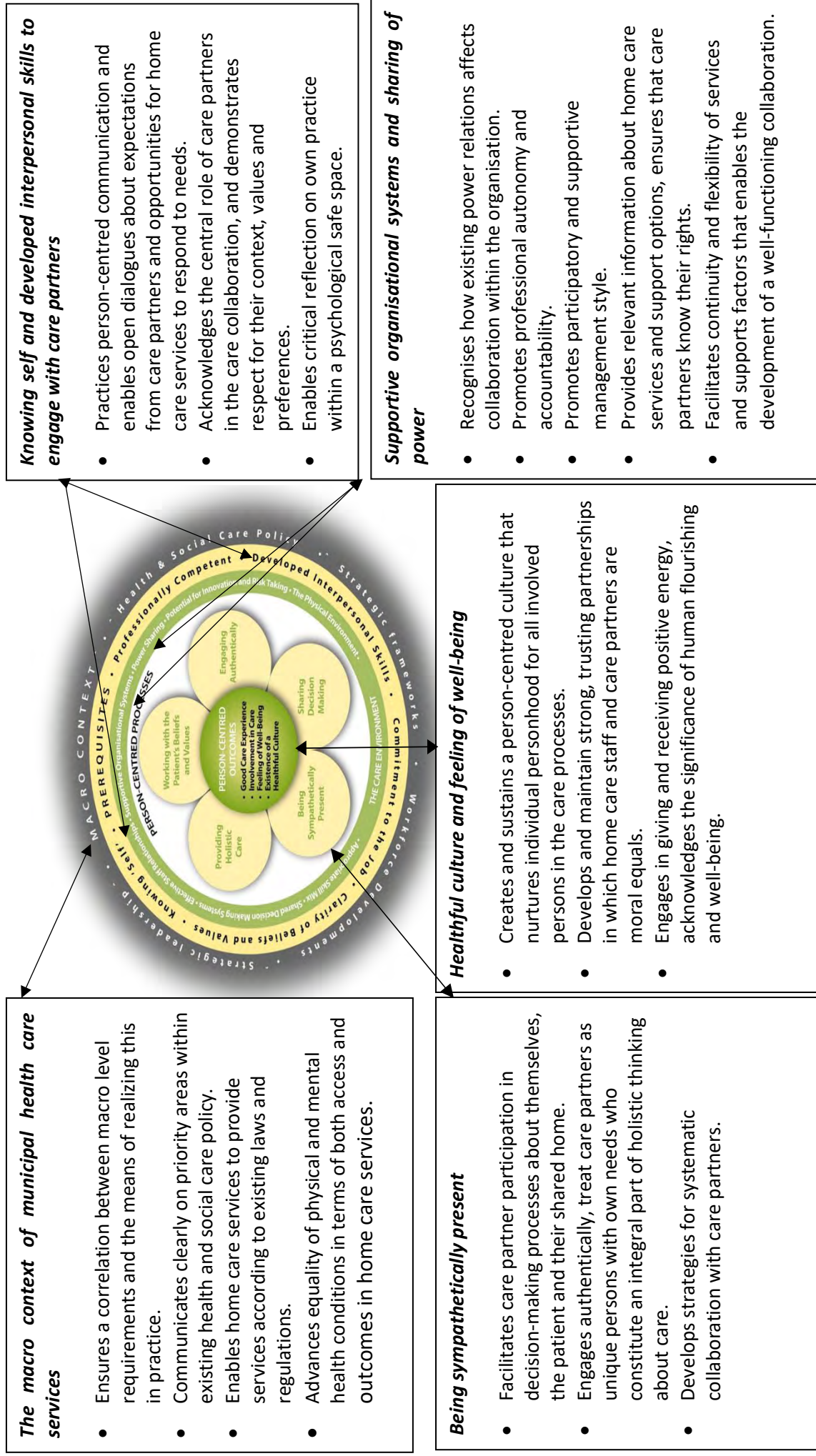


Figure 2. Visual translation of the PCP Framework into a home care service practice/care partner context based on Studies I, II & III.



*'Knowing self' and 'developed interpersonal skills' to engage with care partners*

Person-centred communication emphasises listening actively to other people and recognising the value of working with their feelings and ideas (Eide & Eide, 2017). In this context, it is important to explore the care partner's expectations and to clarify how the home care staff can contribute towards meeting the needs of both the care partner and the patient, as well as towards further care planning. As previously mentioned, getting adequate help to meet the needs of the patient is a need that ranks high for the care partners of older people with mental health problems.

Bolton and Delderfield (2018) argue that reflection and reflexivity are crucial for responsible and ethical practice. Neither of the home care districts had formal, professional reflection groups in which reflection on practice was facilitated. However, it could appear that there was a conscious awareness regarding attitudes, such as when a leader emphasized the importance of talking about attitudes towards care partners. Other staff members expressed a less reflective attitude though, and thought for example that the care partners demanded too much. Through participation in regular, formal reflection groups, home care staff could be given the opportunity to reflect on their own attitudes and strengthen their ability to recognise ethical dilemmas (Weidema, Molewijk, Kamsted & Widdershoven, 2013). McCormack and McCance (2017) claim that without systematically reflecting on actual practice, no amount of tools or processes will create more person-centredness. Critical reflection on own practice can thus be seen as a prerequisite for establishing person-centred cultures.

*'Supportive organisational systems' and 'sharing of power'*

According to Edmondson (2012, p. 131), people are socialised to be sensitive to power structures and hierarchies, and are typically aware of their own position within the workplace hierarchy. Study III showed the clear hierarchical divisions in the organisation, which was recognised by both the managers and the staff. Edmondson (2012) claims that this hierarchical structure affects the staff's willingness to take

interpersonal risks at work. An interpersonal risk in this context might be the staff speaking up about the moral compromises they have to make, the lack of time they have to provide the expected services and how all this affects them. Furthermore, person-centred practice cannot be developed in a paternalistic, hierarchical organisation in which employees are deprived of their professional discretion and autonomy. Person-centred cultures must be built on person-centred principles, such that the horizontal integration of the organisation's values is as important as the vertical integration (McCormack et al., 2017). Thus, a participatory and supportive management style is not only desirable, but also crucial in the development of a person-centred culture. Additionally, a proper balance of control, needs and autonomy must be sought, enabling professionals to trust their judgment and engage in building collaborative relationships with the care partners of older people with mental health problems.

Sharing power is another important factor to address in promoting a collaborative relationship between care partners and home care services. For a well-functioning relationship to be established, some fundamental elements must be in place. The care partners must have extensive knowledge of the home care services that are available, and they must be aware of the options for support. They should also be informed of their rights as care partners, as well as the rights of their family members as the recipients/applicants of services from home care. Finally, the care partners must be seen as equal partners in the collaboration. This entails a recognition from the home care services that the care partners' knowledge, wishes and goals are as important as their own perspectives.

The last point in the framework under this heading concerns the continuity and flexibility of the services. Several care partners in this thesis (Studies I & II) mentioned that there were many staff members from home care that took care of their family member. This practice had negative consequences for the patient especially, but also for the care partners, such as unpredictability and little knowledge of the individual staff member. In order to build collaborative, quality relationships and facilitate continuity of care, providing help with as few carers as possible is thus desirable.

*'Being sympathetically present'*

Since the amount of time for interaction is scarce, being present in the moment is of uttermost importance. Thorne, Hislop, Stajduhar and Oglov (2009) demonstrate that it is possible for health care providers to create a compassionate space with a sense of 'presence' in the interaction, despite time pressures. Another type of presence can be created by establishing systematic collaboration, such as through scheduled meetings, or phone calls, as a care partner requested in Study II. However, whatever the chosen mechanisms, based on the results of this study, it seems that some form of systematic approach to collaboration is preferable.

McCormack and McCance define *being sympathetically present* as 'An engagement that recognises the uniqueness and value of the individual, by appropriately responding to cues that maximize coping resources through the recognition of important agendas in their life' (p. 57). This statement reflects some of the elements that the care partners in this study felt were missing, such as being seen and treated as unique persons with their own needs. Therefore, focusing on what is important to the care partners is also an important prerequisite for a well-functioning collaboration. A starting point for this must be the recognition of home care staff and care partners as moral equals. Finally, effective collaboration requires the inclusion of care partners in decision-making processes that concern them, and in appropriate cases, decisions involving the patient.

*'Feeling of well-being' and 'a healthful culture'*

The outcomes of person-centred practice include the *feeling of well-being* and a *healthful culture*, within the context of care partners and home care services. This relates to the feeling of being valued, which is of importance to both parties. McCormack and McCance (2010, 2017) argue that, in order for the staff to be able to deliver person-centred care, a person-centred culture that embraces persons involved in all levels of the system must be established. The staff cannot be expected to work in person-centred

ways unless they themselves are treated and respected according to person-centred values.

Together, the elements of the PCP Framework (McCormack & McCance, 2017) create the foundation for a healthful culture. From the perspective of the staff, this culture is one that supports them, and enables them to experience person-centredness and work in a person-centred way that is in line with their values (McCormack and McCance, 2017). This person-centredness creates the foundation for human flourishing, which is eloquently described by McCormack and Titchen (2014):

Human flourishing occurs when we bound and frame naturally co-existing energies, when we embrace the known and yet to be known, when we embody contrasts and when we achieve stillness and harmony. When we flourish we give and receive loving kindness (p. 19).

Developing a person-centred practice in home care services cannot be seen as a project, which after having introduced the essential elements, is considered done. It must rather be considered as a 'way of being', which must constantly be challenged, evaluated and further developed. McCormack (2004) recognises that this can be difficult to execute in hectic, everyday life and thus contends, '[W]e shouldn't chase after an ideal of person-centredness, but instead strive for a constant state of "becoming more person-centred" in our practice' (p. 37).

This application of the PCP Framework (McCormack & McCance, 2017) into a home care practice/care partner context has been made with the care partners of older people with mental health problems in focus. However, much of this framework can be said to also concern the actual patients, and its key principles are most likely relevant for other care partner groups as well. Another consideration is that while five elements from the framework have been chosen to highlight the key issues in this specific context, it is necessary to point out that all the elements of the framework are equally important in developing a person-centred culture.

*Objections and challenges regarding person-centeredness*

The PCP Framework (Figure 1, McCormack & McCance, 2017) has been presented as a potential solution as a framework to inform ways in which a person-centred culture could be fostered in the home care organisation, which could in turn enable the development of person-centred collaborative relationships with care partners. It is easy to agree that the elements described both in the framework and how they link with home care services and care partners can lead to positive changes. An integration of all the elements has the potential to both address the support needs of care partners in their caring roles and contribute to well-functioning collaborative relationships between care partners and home care staff. However, implementation of the person-centred practice can be considered complex and difficult (Glasby (2017). Organisations need to empower and enable practitioners in doing this, but evidence suggests that organisational factors hinder implementation from happening (Tadd, Hillman, Calnan, Bayer & Read, 2011). Further, there is a lack of understanding and knowledge of person-centeredness. Research shows for example that nurses mistakenly believe they have a person-centered approach to care, while in reality they have a task-focused approach (Clissett, Porock, Harwood, & Gladman, 2013). Further, it can be argued that a person-centred approach *per se* is just another version of the 'emperor's new clothes', meaning it is not new within nursing but reflects the way nurses have been caring throughout modern history. Such attitudes can lead to a lack of commitment in the process of implementing a person-centred practice. Indeed, many of the underlying values of person-centred thinking have been fronted by leading figures in the development of nursing as an independent profession. However, traditional nursing theories, along with conceptual approaches to person-centeredness, do not emphasise a person-centred approach where everyone involved in the care process has their personhood respected (Henderson, 1966/1998; Martinsen, 2005; Røsvik, Kirkevold, Engedal, Brooker, & Kirkevold, 2011). Further, the emphasis on how a person-centred practice is enabled by the development of person-centred cultures can also be considered as unique to this particular approach.

### 6.3 Methodological considerations

Kierkegaard (1848/1996) famously said, '[L]ife can only be understood backwards but it must be lived forwards' (p.164). This is illustrative of the research process; when it comes to an end, one arrives at the understanding one wished to have from the beginning. This includes the knowledge of what might have been done differently for the results to be better, more reliable and more trustworthy. Several limitations have been raised in the three studies (I, II & III) and this introductory chapter. In this section, I highlight elements that have not been described, and elaborate on limitations briefly mentioned earlier.

As outlined in Chapter 4, this thesis is placed within a social constructionist, interpretive paradigm. This implies that there is no correct answer or truth, but only meaningful constructions, located in one specific reality:

[O]utcomes are not descriptions of the 'way things really are' or 'really work', or of some 'true' state of affairs, but instead represent meaningful constructions that individual actors or groups of actors form to 'make sense' of the situations in which they find themselves (Guba & Lincoln, 1989, p. 8).

Thus, the goal of this thesis has not been to draw strict conclusions, but rather develop knowledge based on the experiences of care partners and staff and leaders in home care services. The thesis' primary strength is that it is able to fill certain knowledge gaps within this field of research. Although much of the literature pays little attention to the care partners of older people with mental health problems, this study sheds light on their needs. Home care staff play a major role in this work, and it demonstrates that the responsibility for ensuring the staff and this particular care partner group work optimally together lies at the macro level, with executive authorities.

In retrospect, one weakness of this study is that the two types of interviews— in-depth interviews with leaders and focus group interviews with staff members— created certain challenges. The leaders were not included in the focus group interviews, as the asymmetric power relationship could have inhibited group

discussions. For the same reason, I chose not to conduct focus group interviews with the leadership team, as it consisted of several management levels. While this likely did not significantly affect the results, it made the presentation of the findings more complex, and possibly more difficult for the reader to grasp, considering the overall results were presented in the same study (Study III). However, in terms of power relations as described in Chapter 4, alternative ways of conducting interviews with the leaders could have created other problems. The best solution may have been to conduct in-depth interviews with all the home care staff. That said, the focus groups contributed to rich, complementary interviews, in which participants had conversations that flowed easily between them. This would have been lost with individual interviews.

The number of participants, 17, could also be considered a limitation. It is reasonable to assume that more participants would have provided more information. The participants, however, contributed valuable stories about their experiences and preferences regarding their care roles, which led to new insights and further development of knowledge. Furthermore, according to a hermeneutic approach, a low number of participants does not represent a flaw in the study, as the hermeneutic inquiry is not validated by numbers, but the way in which the topic under investigation has been examined thoroughly and in depth, and created a raised understanding of the experience (Sandelowski, 1995; Smith, 1991).

In Study II, it was difficult to involve care partners for two reasons: they were too exhausted or too busy for an interview. It is likely those who chose to participate were not those who assumed the most demanding care roles. The results may have differed had other care partners been able to participate. They would perhaps have been more critical of the help they received from home care services, or described other types of needs both on their own behalf and regarding their relationship with home care staff. Thus, it is important to keep in mind that other care partners may have different experiences than those described by the participants.

As pointed out in Study II, another weakness of the study is that the care partners are considered a homogeneous group, although the participants are three spouses and three sons. However, the findings indicate there are no significant

differences in needs between the two groups, whether related to their own situation or to their collaboration with home care services. Finally, it may have been preferable to have included care partners of different genders. On the other hand, it can be seen as a strength and a contribution to knowledge that this project has generated insights about male care partners, as their voice is underrepresented in this research field (Greenwood & Smith, 2015).

The setting and background of the interviews have been described thoroughly, but can it be trusted that what is said during the interviews matches reality? Glasø (2006) uses the phrase 'social desirability' to describe the participants' desire to present themselves and their own response patterns in a better light. This may have occurred in this study, but my impression is that all the participants were open and honest. What they shared sometimes did not favour them, and they expressed both positive and negative emotions.

## **6.4 Implications for policy and practice**

This thesis has the potential to help decision makers and service organisations understand how care partners of older people with mental health problems can be supported in their roles. In order to reach the proclaimed political goal of closer collaboration between health care services and care partners, their interests must be addressed. It is not enough to grant care partners new rights; a framework must be provided enabling home care staff to fulfil these rights. Furthermore, it must be made a priority for care partners to be informed about the rights they are entitled to, and ensure that the rights are fulfilled. Leaders and policy makers should note that increased demands and responsibilities imposed on home care staff can lead to moral compromises and inadequate care. Thus, it is necessary to equip home care workers to meet care partners' needs and ensure they have the means to realise what is communicated at the system level. Home care staff cannot take on more responsibilities within the current management model and financial framework. There are clear indications that moving toward organisations based on person-centred principles would be advantageous in many ways, both from an organisational perspective and for the persons involved in the care process. However, the concept of



person-centredness must be used with caution. In order to avoid it being just another buzzword within health care services, it must be clarified and agreed on what is meant by the concept, what it means to be person-centered and how this should be implemented and operationalized at the organizational level, in the Norwegian context. Only then can person-centredness become a watchword for good practice.

## **6.5 Future perspectives**

The findings outlined here should not be seen as the ‘the final truth’ on these issues. Instead, they might be viewed as one piece of a puzzle, which together with a hundred other elements forms one composite image of a reality that exists in a given context. Building on this metaphor, certain other elements would add further knowledge to the overall picture. As the care partners consisted of men only, it would be helpful to learn more about female care partners of older people with mental health problems. The patient’s perspective on the collaboration between their care partner and home care services, and what kind of support they prefer from whom, would also be interesting to examine. Another angle that remains unexplored is the macro level. How do politicians view the care partners of older people with mental health problems? Do they recognise the dilemmas outlined in this thesis, and do they reflect on the challenges? Similarly, it would be beneficial to examine politicians’ and health care leaders’ opinions about adopting new management and organisational models. Further, it would be of significant interest to pilot a person-centered practice approach within the Norwegian health care context. Person-centredness is a complex concept however, with several definitions and approaches. There would be merit in developing a Norwegian understanding of person-centredness that makes clear how it differs from other concepts, such as ‘person-oriented’, so that an inclusive and consistent approach to person-centred practice with home care services could be developed and evaluated.

## 7. Conclusion

We are not going in circles; we are going upwards.  
The path is a spiral; we have already climbed many steps.

Hermann Hesse, Siddhartha

I approached this thesis with the understanding that there exists limited knowledge about the needs of care partners of older people with mental health problems and their collaborative relationship with home care services. The aims were to develop knowledge about the needs of this care partner group and to explore their collaborative relationship with home care services. The findings indicate that care partners have several, continuously unmet needs, few or no routines for collaboration exist between the care partners of older people with mental health problems and home care, and that the care partners seem to have little knowledge of their legal rights. Care partners of older people with mental health problems and home care staff do not form satisfactory collaborative relationships, and all levels of the home care organisation seem to lack the resources to facilitate such collaboration. The interactions between the care partners and home care staff sometimes have negative outcomes, and situations occur where the personhood of both parties is not respected. Furthermore, the findings may indicate discrimination towards older people with mental health problems in accessing home care services, which can increase the burden on their care partners.

The discussion focuses on factors that influence the challenges of care partners and home care services and the limitations of the welfare ambition. It was shown how the efficacy norm and elements of NPM negatively affect staff members' autonomy and ability to perform moral, coherent care, and limits the practice of person-centredness. Taken together with today's financial framework, home care staff have little or no opportunity to provide care or services to care partners. I argue that it is necessary to reconsider how to fill the gap between expected areas of responsibility

for home care services and what can be accomplished within the current service framework. Through linking the findings of the studies to the PCP framework, it is demonstrated how a person-centred practice can help strengthen the collaborative relationship between caregivers and home care services, and help address the support needs of care partners.

The issues raised in this thesis are complex, but they centre on the ability to offer care at all levels. Home care staff need to be enabled to do their job according to the laws and regulations and should not be expected to provide increasingly more services without adequate funding. However, the challenges does not only concern economic resources, but must also be seen in the context of attitudes and priorities within home care services. The way in which home care services is organised must change in order for a more trusting, morally coherent practice to emerge. As such, it is time to move from metrics to trust. We need to establish person-centred organisations, with person-centred cultures, where the personhood of everyone involved in the care process is respected.

## Closure

At the very end, the title of this thesis calls for some clarification. When reading the studies (I, II &), observant readers will quickly pick up the common thread between the first two. The care partners are referred to as invisible in different ways, such as ‘the third person in the room’ or ‘invisible cornerstones’. In addition, the thesis was early on given the title, ‘On Making the Invisible Visible’, which originally referred to my attempt at making this care partner group more noticeable. However, during my midterm evaluation, I was asked about this ‘invisible label’ I (and others) had put on care partners, which gave me something to think about. As I wrote earlier about the term care partner, words have power. With this in mind, I started to problematize this way of labelling care partners. Was the issue centred around them really being invisible in the care landscape or was it that they were being treated *as if* they were invisible? Today, I no longer believe they are invisible, but rather that those who should see them, choose to look away.

So why did I choose to retain this title? In my opinion, several aspects this work focuses on (such as the systemic issues and the pressure on home care staff) remain invisible, and I believe the core issue is about the mechanisms that force people who should see care partners—people who most probably *want* to see care partners—to look away. Those mechanisms are truly invisible for many people. These mechanisms, the reasons why home care staff fail to prioritise certain people and tasks, which in turn can cause them not see care partners, make it easy to blame the home care staff. This is why it is essential to make the invisible visible. When home care staff are treated as objects rather than persons, this needs to be made visible. And when the government disseminates discourse that creates high expectations of what it means to be a ‘good’ care partner, but the message between the lines is really about prompting care partners to contribute more without having much influence on the process or benefiting from it, this must be made visible.

In these final lines, I will return to the opening quote by Kitwood (1997a):

Behind the mask of confidence and competence, behind the proud ideology of individualism and self-determination, perhaps every human being yearns to be truly cared for and to care (p. 3).

I believe this quote captures the essence in both this thesis and the person-centred perspective. People want to be seen as who they are and be treated accordingly in authentic ways, regardless of whether the person is a care partner, a nurse in home care or a five-year-old boy with a broken arm.

*I can't go back to yesterday because I was a different person then.*

Lewis Carroll, *Alice in Wonderland*

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## **Study 1**

Anker-Hansen, C., Skovdahl, K., McCormack, B., & Tønnessen, S. (2017). The third person in the room: The needs of care partners of older people in home care services. A systematic review from a person-centred perspective. *Journal of Clinical Nursing*, 27, e1309-e1326.

Papers omitted from online edition due to publisher's restrictions

## Study 2

Anker-Hansen, C., Skovdahl, K., McCormack, B., & Tønnessen, S. (2018). Invisible cornerstones. A hermeneutic study of the experience of care partners of older people with mental health problems in home care services. *International Journal of Older People Nursing*, *14*(1), e12214. doi:10.1111/opn.12214

Papers omitted from online edition due to publisher's restrictions

### **Study 3**

Anker-Hansen, C., Skovdahl, K., McCormack, B., & Tønnessen, S. (2019). Collaboration between home care staff, leaders and care partners of older people with mental health problems: A focus on personhood. *Scandinavian Journal of Caring Science*. ISSN 0283-9318. doi: 10.1111/scs.12714

Papers omitted from online edition due to publisher's restrictions

## Appendix

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<b>Region:</b>	<b>Saksbehandler:</b>	<b>Telefon:</b>	<b>Vår dato:</b>	<b>Vår referanse:</b>
REK sør-øst	Mariann Glenna Davidsen	22845526	15.03.2016	2016/53 REK sør-øst B
			<b>Deres dato:</b>	<b>Deres referanse:</b>
			12.01.2016	

Vår referanse må oppgis ved alle henvendelser

Camilla Anker-Hansen  
Høgskolen i Buskerud og Vestfold

## **2016/53 Pårørendes rolle og ansvar i den norske velferdsstaten – erfaringer fra å være omsorgsperson for eldre hjemmeboende ektefelle/samboer med psykiske helseutfordringer**

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 17.02.2016. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

**Forskningsansvarlig:** Høgskolen i Buskerud og Vestfold  
**Prosjektleder:** Camilla Anker-Hansen

### **Prosjektleders prosjektbeskrivelse**

*Formålet med undersøkelsen er å utvikle kunnskap om pårørendes rolle og ansvar og få frem deres erfaringer med å være omsorgsperson for hjemmeboende eldre ektefelle/samboer med psykiske helseproblemer. Fokuset er rettet mot samarbeidet mellom pårørende og hj.spl, hvilke støttetiltak pårørende selv uttrykker behov for og hvordan samarbeidet kan kvalitetssikres. Forskningsspørsmål: •Hvordan opplever pårørende samarbeidet med hj.spl? •Hvilke roller og hvilket ansvar opplever pårørende å ha i samarbeidet med hj.spl? •Hvilke støttetiltak opplever pårørende at de har behov for og hvilke tilthvilte tiltak ønsker de at hj.spl skal bidra med? •Hvordan opplever lederne og sykepleierne samarbeidet med pårørende? \* Basert på en felles forståelse av pårørende, , hjemmesykepleiere og ledere, hva er de viktigste prinsippene som ligger til grunn for en samarbeidsmodell? Dette er en kvalitativ undersøkelse, hvor data vil innhentes gjennom intervju med pårørende, sykepleiere og ledere.*

### **Komiteens vurdering**

Formålet med prosjektet synes å være en kartlegging av pårørendes rolle, ansvar og erfaringer, som omsorgsperson for sin hjemmeboende eldre ektefelle med psykiske helseproblemer. Fokuset i prosjektet vil også være samarbeidet mellom helsepersonell og pårørende, og kvalitetssikring av et godt samarbeid mellom disse partene. Helseforskningsloven gjelder for medisinsk og helsefaglig forskning, det vil si «virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom», jf. helseforskningsloven § 2, jf. § 4. Komiteen anser dermed at prosjektet ikke omfattes av helseforskningslovens virkeområde. Det kreves ingen forhåndsgodkjenning fra REK for å gjennomføre prosjektet.

### **Vedtak**

Etter søknaden fremstår prosjektet ikke som medisinsk eller helsefaglig forskning, og det faller derfor utenfor helseforskningslovens virkeområde, jf. § 2.

*Klageadgang*

Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst B. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst B, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Komiteens avgjørelse var enstemmig.

Med vennlig hilsen

Grete Dyb  
førsteamanuensis dr. med.  
leder REK sør-øst B

Mariann Glenna Davidsen  
rådgiver

**Kopi til:**

- *Høgskolen i Sørøst-Norge ved øverste administrative ledelse*
- *Førsteamanuensis Siri Tønnessen, Høgskolen i Buskerud og Vestfold*



Siri Tønnessen

Institutt for sykepleievitenskap (Vestfold) Høgskolen i Buskerud og Vestfold

Raveien

3184 BORRE

Vår dato: 26.10.2015

Vår ref: 44722 / 3 / MHM

Deres dato:

Deres ref:

## TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 17.09.2015. Meldingen gjelder prosjektet:

44722	<i>Pårørendes rolle og ansvar i den norske velferdsstaten – erfaringer fra å være omsorgsperson for hjemmeboende ektefelle/samboer</i>
<i>Behandlingsansvarlig</i>	<i>Høgskolen i Buskerud og Vestfold, ved institusjonens øverste leder</i>
<i>Daglig ansvarlig</i>	<i>Siri Tønnessen</i>

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, <http://www.nsd.uib.no/personvern/meldeplikt/skjema.html>. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, <http://pvo.nsd.no/prosjekt>.

Personvernombudet vil ved prosjektets avslutning, 31.03.2018, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Katrine Utaaker Segadal

Marianne Høgetveit Myhren

Kontaktperson: Marianne Høgetveit Myhren tlf: 55 58 25 29

Vedlegg: Prosjektvurdering

*Dokumentet er elektronisk produsert og godkjent ved NSDs rutiner for elektronisk godkjenning.*

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## Prosjektvurdering - Kommentar

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Prosjektnr: 44722

Formålet med prosjektet er å få kunnskap om pårørendes rolle og ansvar, og å få frem deres erfaringer med å være omsorgsperson for hjemmeboende ektefelle/samboer. Fokuset er rettet mot samarbeidet mellom pårørende og pleiepersonell, hvilke støttetiltak pårørende selv uttrykker behov for og hvordan samarbeidet kan kvalitetssikres.

Utvalget består av pårørende til hjemmeboende ektefelle/samboer som mottar tjenester fra hjemmesykepleien, samt sykepleiere og ledere som jobber i hjemmesykepleien.

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er godt utformet.

Data innhentes gjennom intervju. Personvernombudet tar høyde for at det registreres sensitive personopplysninger om helse.

Personvernombudet legger til grunn at forsker etterfølger Høgskolen i Buskerud og Vestfold sine interne rutiner for datasikkerhet.

Forventet prosjektslutt er 31.03.2018. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:

- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)

# Forespørsel om deltakelse i forskningsprosjektet

## *”Pårørendes rolle og ansvar i den norske velferdsstaten – erfaringer fra å være omsorgsperson for eldre hjemmeboende ektefelle/samboer med psykiske helseutfordringer”*

### **Bakgrunn og hensikt**

Dette er et spørsmål til deg om å delta i en forskningsstudie som ønsker å få frem pårørendes erfaringer med å være omsorgsperson for hjemmeboende eldre ektefelle/samboer med psykiske helseutfordringer. Fokuset for prosjektet er samarbeidet mellom pårørende og hjemmesykepleien, hvilke støttetiltak pårørende selv uttrykker behov for og hvordan samarbeidet kan kvalitetssikres.

Du som deltar vil bli intervjuet om dine erfaringer med samarbeidet mellom hjemmesykepleien og pårørende. På bakgrunn av informasjonen som kommer frem under intervjuene skal personorienterte prinsipper for systematisk pårørendesamarbeid identifiseres.

Dette prosjektet har som målsetning å avklare grenseoppgangene mellom hjemmesykepleiens og pårørendes roller og ansvar, samt å identifisere tiltak som kan gjøre det enklere for pårørende å håndtere omsorgsgiver rollen. Dette er kunnskap som forhåpentligvis kan bidra til å styrke samarbeidet mellom pårørende og hjemmesykepleien, samt bidra til at pårørende får bedre forståelse og hjelp i møte med hjemmesykepleien.

Prosjektet drives i regi av Høgskolen i Sørøst-Norge, Fakultet for helsevitenskap, Institutt for sykepleievitenskap. Forskningsprosjektet vil gjennomføres av doktorgradsstipendiat Camilla Anker-Hansen. Førsteamanuensis Siri Tønnessen er hoved veileder.

### **Hva innebærer studien?**

I prosjektet vil både pårørende, ledere og sykepleiere bli intervjuet. Du vil bli bedt om samtykke om delta i intervjuet som er haket av i ruten ved siden av beskrivelsen:

- Pårørende. Deltakelse i studien innebærer et intervju som tar omkring en til to timer. Tid og sted for intervjuene avtales etter at du eventuelt har takket ja til være med i studien.
- Lederne. Deltakelse i studien innebærer et intervju som tar omkring en time. Tid og sted for intervjuene avtales etter at du eventuelt har takket ja til være med i studien.
- Sykepleiere. Deltakelse i studien innebærer et fokusgruppeintervju, hvor du vil bli intervjuet sammen med tre til fem andre sykepleiere. Undertegnede vil styre prosessen, og du vil bli bedt om å dele egne refleksjoner og kunnskaper i gruppen. Dette intervjuet tar omtrent to timer.

### **Mulige fordeler og ulemper**

Som deltaker vil du ikke få noen spesielle fordeler av å delta i studien, men resultatene fra denne studien kan bidra til ytterligere kunnskap om samarbeidet mellom pårørende og hjemmesykepleien. Mange vil oppleve det som meningsfullt å bidra til forskning som kan forbedre dagens praksis.

Ulempen med undersøkelsen kan være den tiden undersøkelsene krever.

### **Hva skjer med informasjonen om deg?**

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. Det vil ikke bli oppbevart lister med personopplysninger som kan kobles direkte til deg. Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. Det vil bli brukt en båndopptaker under intervjuet, og lydfilene vil oppbevares på en passord beskyttet harddisk. Lydfilene, ditt navn og kontaktinformasjon vil bli slettet senest når prosjektet avsluttes, 31. mars 2018.

Så langt det er mulig vil resultatene bli publisert slik at du ikke vil bli identifisert. Dette vil skje gjennom at du blir gitt et fiktivt navn. Dersom det i intervjuene kommer fram opplysninger som kan gjøre deg lett gjenkjennelig, vil disse enten bli omskrevet eller fjernet.

### **Frivillig deltakelse**

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det vil få noen konsekvenser for deg. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte Camilla Anker-Hansen på telefon 466 14 494 eller mail: [ca@hbv.no](mailto:ca@hbv.no), eller Siri Tønnessen på telefon 473 27 454 eller mail: [siri.tonnessen@hbv.no](mailto:siri.tonnessen@hbv.no)

Vennlig hilsen

Camilla Anker-Hansen  
Doktorgradsstipendiat

## Samtykkeerklæring:

Jeg har lest informasjonen ovenfor og samtykker til delta i studien:

***”Pårørendes rolle og ansvar i den norske velferdsstaten – erfaringer fra å være omsorgsperson for hjemmeboende ektefelle/samboer med psykiske helseutfordringer”***

----- (Signert av deltaker, dato)

Kontaktinformasjon deltager:

Telefon:

E-post:

Jeg bekrefter å ha gitt informasjon om studien

-----  
(Signert, rolle i studien, dato)

# Intervjuguide fokusgruppeintervju

## 1. Deltakerne presenterer seg selv

Deltakerne presenterer seg selv med fornavn, når de var ferdig utdannet, hvor lenge de har arbeidet i hjemmesykepleien.

Spørsmål:

- Kan du fortelle hva du heter og litt om hvem du er
- Når var du ferdig utdannet og hvor lenge har du jobbet i hjemmesykepleien?

## 2. Introduksjonsspørsmål

- Hva tenker dere på når dere hører begrepet pårørendesamarbeid?
- Kan dere fortelle om noen opplevelser/erfaringer med pårørende?

## 5. Nøkkelspørsmål

- Hvordan opplever dere samarbeidet med pårørende? Blir pårørende sett på som en samarbeidspartner?
- Delegerer dere oppgaver til pårørende? (f.eks. medisint levering, sårstell) Hvordan følges dette opp? Hvordan gis opplæring? Faste rutiner på dette?
- Hvem har ansvaret for omsorgsoppgavene pårørende utfører?
- På hvilken måte tenker dere at hjemmesykepleien kan gi støtte til pårørende?
- Hvordan følger dere opp de pårørende og de tjenestene de yter som omsorgspersoner?
- Hva slags omsorg gis til pårørende?

## 6. Avslutningsspørsmål

- Kan du oppsummere ditt syn på saken?
- Har vi glemt noe?
- Er det noe annet vi burde tatt opp i diskusjonen?
- Hvordan var det å delta i en slik samtale?

# Intervjuguide for pårørendeintervju

## Del 1 Bakgrunnsopplysninger

### Kjønn

- Kvinne
- Mann

### Alder

- 60-70
- 70-80
- 80-90

### Sivilstatus

- Gift
- Samboer

### Diverse

- Hvor lenge har du hatt omsorgsoppgaver for din ektefelle/samboer
- Hvor lenge har hjemmesykepleien utført omsorgsoppgaver i hjemmet?
- Mottar du omsorgslønn
- Hvor mye tid bruker du i gjennomsnitt til omsorgsoppgavene?

## Del to

1. Kan du beskrive en vanlig dag og hva slags omsorgsoppgaver den inneholder? Ta f. eks utgangspunkt i dagen i går (f. eks stell, utlevering av medisiner, kontakt med fastlege etc.)

2. Hvordan opplever du samarbeidet med hjemmesykepleien?

3. Hvordan opplevde du det første møte med hjemmesykepleien?

4. Opplever du at hjemmesykepleien tar deg med på rådgivning når det er snakk om endringer i omsorgsutøvelsen (omsorg/medisinering/kontakt med lege /sykehusinnleggelse etc.)

5. Kan du fortelle litt om hvordan hjemmesykepleien er organisert?  
-Vet du hvem som er din kontaktperson i hjemmesykepleien dersom du har spørsmål? –Hvor henvender du deg?
7. Hvilke opplysninger etterspør hjemmesykepleien i fra deg?
8. På hvilken måte blir du som pårørende fulgt opp av hjemmesykepleien?
9. Hvilke forbedringspunkter tenker du det finnes i samarbeidet du har med hjemmesykepleien?
10. Hvilke behov har du som pårørende, som hjemmesykepleien kan hjelpe deg med å dekke for å lette din hverdag?
11. Hvilket ansvar tenker du at du har i samarbeidet med hjemmesykepleien?  
-Har dere drøftet hvem som har ansvaret for hva?
12. Hender det at du utfører oppgaver som hjemmesykepleien har bedt deg om å gjøre, f.eks. utlevering av medikamenter/skifte på sår/stell e. l?  
-hvis ja, hvilken opplæring har du fått, og hvordan opplever du den?
13. Hva slags møtepunkter med hjemmesykepleien finnes for å diskutere samarbeidet?
14. Er det noe mer du har lyst til å legge til?

*Eventuelle oppfølgingsspørsmål:*

- *Kan du utdype det*
- *Hva mener du med det?*
- *Hva er det som gjør at du synes...*
- *Hvorfor tror du det har blitt sånn?*

# Intervjuguide for lederne

## Del 1 Bakgrunnsopplysninger

### Kjønn

- Kvinne
- Mann

### Alder

- 20-30 år
- 30-40 år
- 40-50 år
- 50-60 år

### Yrkesaktive år som leder

- 0-5 år
- 5-10 år
- 10 år eller mer

## Del 2

1. Kan du fortelle litt om hvordan pårørende som får hjemmesykepleie ivaretas av deg som leder?  
-Har du som leder noen faste møtepunkter med pårørende?  
-Hvor ofte er du i kontakt med pårørende?
2. Hvilke formelle rutiner for pårørendearbeid har dere?
3. Hva tenker du når du hører begrepet pårørendesamarbeid?
4. Hvordan opplever du samarbeidet med pårørende?
5. Hvilke forbedringspunkter ser du i samarbeidet du har med pårørende?
6. Er det noe du kan tenke deg at kan forbedres i forhold til samarbeidet, eventuelt hva?
7. Er det noe mer du har lyst til å legge til?

### Eventuelle oppfølgingsspørsmål:

- *Kan du utdype det?*
- *Hva mener du med det?*
- *Hva er det som gjør at du synes...*
- *Hvorfor tror du det har blitt sånn?*



Doctoral dissertation no. 57

2020

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ISBN 978-82-7860-414-4 (print)

ISBN 978-82-7860-415-1 (online)

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usn.no

