

Adult-Child Caregivers' Motivations when Caring for Home-Dwelling Parents with Dementia

by

Heidi Dombestein

Thesis submitted in fulfilment of
the requirements for the degree of
PHILOSOPHIAE DOCTOR
(PhD)



Faculty of Health Sciences
2021

University of Stavanger
NO-4036 Stavanger
NORWAY
www.uis.no

©2021 Heidi Dombestein

ISBN:978-82-8439-008-6

ISSN:1890-1387

PhD: Thesis UiS No. 590

Research background

The value of taking part in a number of research groups has contributed to my development as a researcher and to the PhD research process. It has been a privilege to have the opportunity to immerse myself in the informal caregiver context and contribute to the knowledge about adult children's motivations as caregivers of persons with dementia.

My master's thesis in health sciences, entitled "Working daughters' perspective on coping and staying power in the caregiver role when parents with dementia live at home", was conducted as part of the Carers Research Group at the University of Stavanger (UiS). The master thesis resulted in the following research article: Norheim, A., & Dombestein, H. (2015). "On the alert" all the time! About the informal caregiver role taken on when family members develop dementia. *Demens & Alderspsykiatri [Dementia & Geriatric Psychiatry]*, 19(4), 22-28.

My work continued when I started as a PhD candidate within caregiver research, where I designed an independent PhD project. As a member of the Carers Research Group, I was part of an interdisciplinary group of researchers with backgrounds in social work, law, and nursing. As part of this research group, I participated in the Sixth International Carers Conference in Sweden (2015) and the Seventh International Carers Conference in Australia (2017).

At a later stage, I became a member of the Health Promotion and Health Challenges (ProHealth) Research Group composed of members with knowledge and experience using motivational theories like self-determination theory (SDT). I participated in several workshops where I presented my work. As part of this research group, I participated in the Conference on Motivation at the University of South-Eastern Norway (2018). When I attended a PhD course on theoretical and innovative approaches to long-term illnesses, I had the opportunity to learn more about SDT, and the theory helped me in structuring my research. In the course paper, I conducted a literature review to see how SDT had been used in dementia caregiver research. As there was little research within the field of dementia, I extended the work to adult caregivers of patients with long-term illnesses.

In 2019, I became a member of, Centre for Resilience in Healthcare (SHARE), in which patient and stakeholder research is a priority. I have presented my work at several research meetings at the SHARE Centre. I have also worked as a coordinator for the Network for Carer Research, organised and financed through SHARE. This work has been highly relevant for the PhD thesis, giving me an overview of the carer research area. At the same time, it has been inspiring and educative to work together with other researchers, healthcare professionals, and caregiver representatives, all with special interests in research areas related to caregiving.

Acknowledgements

Acknowledgement goes to the University of Stavanger represented by the Faculty of Health Sciences for funding and facilitating my doctoral fellowship. This PhD thesis would not have been possible without invaluable assistance and support from many people.

Most importantly, my gratitude and respect go to the informal caregivers who generously spent their time and shared their experiences about having mothers or fathers with dementia. The PhD project relies on their contributions. I also send my thanks to the municipal health department leader who provided access to the research field and the community healthcare services coordinator who recruited the participants.

My warmest and deepest gratitude goes to my main supervisor, Professor Karina Aase, who offered high-quality support and advice. Without her capability in supervision, this thesis would never have reached completion. A special thanks goes to my co-supervisor, Professor Emerita Anne Norheim, for her professional expertise, for ensuring continuity, and for always believing in me throughout the PhD project. I am also grateful to my previous supervisors, Associate Professor Kristin Humerfelt and Professor Bjørg F. Oftedal, for their research competence and guidance. I thank Associate Professor Anne Marie Lunde Husebø for inspiration and for being my co-author on the first article of the thesis. I am also grateful for the valuable feedback from Associate Professor Petter Viksveen on my “90% seminar”. I have learned so much from them all!

I thank all former and current PhD candidates and colleagues of the different research groups I have participated in at UiS for insightful conversations and encouragement through the ups and downs. These past years would not have been the same without them. A big thanks also goes to my family and friends for cheering me on over the years. Last but not least, Helge and our children, Håvard, Hanne, and Henrik, thanks for their support and patience.

Mosterøy/UiS, March 2021

Heidi Dombestein

Summary

Background

It is often seen as demanding to be an informal caregiver of a home-dwelling relative or friend with a long-term illness. Adult-child caregivers are important resources for both their ill parents and their community healthcare services. Dementia is one of the most severe chronic long-term illnesses and represents comprehensive challenges for public health in Norway as in the rest of the world. Research within the caregiver field has generally focused on primary caregivers, the burden of taking on the caregiver role, and interventions to improve health outcomes. Less research has been devoted to understanding how secondary caregivers, such as adult children, remain motivated and how they experience community healthcare services, applying recent theoretical approaches such as self-determination theory and relationship-centred care. Therefore, the overall aim of this thesis was to gain a deeper understanding of adult children's motivations to remain in the caregiver role when parents with dementia live at home.

Methodology

The current PhD project applies a qualitative multi-method design including the following three methods: 1) an integrative literature review of the previous research literature concerning the motivation of caregivers of persons with long-term illnesses, 2) individual face-to-face semi-structured interviews with 21 adult-child caregivers who had home-dwelling parents with dementia, and 3) focus group interviews with 15 of the adult-child caregivers who had been individually interviewed. Analyses were conducted using narrative analysis and systematic text condensation.

Findings

There is consistency between caregivers of persons with long-term illnesses and persons with dementia, describing their quality of motivations and how they experienced being caregivers. High-quality motivation depends on the satisfaction of the caregivers' three basic psychological needs for *competence* (understanding of diagnosis, management of symptoms, problem solving,

communication skills, knowledge of appropriate healthcare services), *autonomy*, (available options, planning, freedom of choice regarding tasks), and *relatedness*, (interacting with parent with dementia and others, being part of the care team, mutual respect, acknowledgement, dialogue, belonging, meaning something to others). Thwarting those psychological needs could lead to amotivation. The main issues thwarting caregivers' motivations include parents being resistant or refusing to receive community healthcare services, challenges in getting access to timely healthcare services, and not being appropriately involved in their services. Still, caregivers of persons with dementia often prioritised their parents' needs over their own. The literature review found the three needs of competence, autonomy, and relatedness to be equally important in predicting the quality of caregivers' motivations and thereby their well-being, as according to the self-determination theory. From the perspective of adult-child caregivers, these basic needs were confirmed as motivational drivers when caring for a home-dwelling parent with dementia. Yet, they reported relatedness as their main motivational driver, including relations with their parents with dementia, with persons in their social network, and with their parents' community healthcare services. Caregivers wanted to be acknowledged as competent partners in the care team who utilise significant efforts to improve the home-dwelling period for their parents. These findings imply that healthcare professionals should value the importance of relatedness when interacting with caregivers of persons with dementia.

Conclusion

By applying self-determination theory combined with a relationship-centred care approach, this thesis offers a deeper understanding of caregivers' motivations in the long-term illness context and, in particular, in caring for persons with dementia. A caregiver's motivation is described along a continuum representing different qualities of motivation. Addressing caregivers' motivations is necessary, as the quality of their motivations for caregiving has consequences for their health and well-being. Caregivers' motivations to remain in this type of role are closely related to satisfaction or thwarting of their basic needs for competence, autonomy, and relatedness. To remain motivated throughout a parent's trajectory of dementia, support to fulfil the three needs is required. Dyadic improvement efforts addressing both caregivers' and patients' needs are recommended.

Articles included in the thesis

The thesis includes the following articles, which will be referred to in the text by their Roman numerals.

Article I

Dombestein, H., Norheim, A. & Lunde Husebø, A. M. (2019). Understanding informal caregivers' motivation from the perspective of self-determination theory: An integrative review. *Scandinavian Journal of Caring Sciences*. 34(2), 267–279. doi:10.1111/scs.12735

Article II

Dombestein, H., Norheim, A. & Aase, K. (2020). Caring for home-dwelling parents with dementia: A qualitative study of adult-child caregivers' motivation. *Nursing Open*. 7(6), 1954–1965. doi:10.1002/nop2.587

Article III

Dombestein, H., Norheim, A. & Aase, K. (2021). How to stay motivated: A focus group study of Norwegian caregivers' experiences with community healthcare services to their parents with dementia. *Health and Social Care in the Community*. 00(0), 1–9. doi:10.1111/hsc.13396

Contents

Research background.....	i
Acknowledgements.....	iii
Summary.....	v
Articles included in the thesis.....	vii
Contents.....	ix
Part I.....	xiii
1 Introduction.....	1
1.1 Informal caregiving.....	1
1.2 Dementia and dementia care.....	2
1.3 Adult-child caregivers vs. spouse caregivers.....	4
1.4 Caregiver burden.....	5
1.5 Caregiver support.....	5
1.6 Motivation to provide care.....	6
1.7 Aim, objectives, and research questions.....	7
2 Contextual background.....	9
2.1 Dementia in the Norwegian context.....	9
2.1.1 Dementia – the illness.....	9
2.1.2 Prevalence of dementia.....	11
2.2 Informal caregiving in Norway.....	12
2.3 National guidelines and legislation.....	13
2.4 Community healthcare services.....	14
3 Theoretical background.....	17
3.1 Current literature within the caregiver context.....	17
3.2 Motivation.....	18
3.3 Self-determination theory.....	20
3.3.1 A motivational continuum.....	21
3.3.2 Caregivers’ basic psychological needs.....	23
3.4 Relationship-centred care.....	24
3.4.1 The relationship-centred care framework in research and practice.....	26

4	Methodology	29
4.1	Philosophical considerations.....	29
4.2	Research design	30
4.3	Use of theory.....	33
4.4	Methods	34
4.4.1	Literature review (Sub-Study 1).....	34
4.4.2	Individual interviews (Sub-Study 2).....	35
4.4.3	Focus group interviews (Sub-Study 3)	36
4.4.4	Multi-method approach (Thesis)	36
4.5	Data collection Sub-Study 1.....	37
4.5.1	Literature search.....	37
4.5.2	Eligibility criteria	38
4.5.3	Study selection	39
4.5.4	Data evaluation.....	40
4.6	Data collection Sub-Studies 2 and 3	41
4.6.1	Setting and sampling strategy.....	41
4.6.2	Sample characteristics	41
4.6.3	Participant selection and recruitment.....	43
4.6.4	Development and use of interview guides.....	45
4.6.5	Conducting the interviews	46
4.7	Data analysis	49
4.7.1	Narrative analysis	49
4.7.2	Systematic text condensation	50
4.7.3	Synthesis of findings across sub-studies.....	52
4.8	Research quality	53
4.8.1	Trustworthiness	53
4.8.2	Reflexivity.....	58
4.9	Ethical considerations	60
5	Findings.....	63
5.1	A literature review of caregivers' motivations.....	63
5.2	Adult children's motivational drivers for dementia caregiving	65
5.3	Community healthcare services and motivational caregiver support	66
5.4	Synthesis of findings across Sub-Studies 1-3.....	68
5.4.1	Caregivers' motivations influence how they perceive caregiving	69
5.4.2	Relationships are vital to caregivers' motivations	70
5.4.3	Competent caregivers stay motivated.....	72

5.4.4	Caregivers prioritise the parents' needs over their own.....	73
6	Discussion.....	75
6.1	Quality of caregivers' motivations.....	75
6.2	The role of relatedness.....	77
6.3	Caregivers as competent partners.....	80
6.4	Priority of needs.....	82
6.5	Methodological considerations.....	84
7	Conclusions.....	87
7.1	Implications for practice.....	88
7.2	Implications for future research.....	89
	References.....	91
	Part II.....	111
	List of articles.....	113
	Article I.....	115
	Article II.....	131
	Article III.....	145
	Appendices.....	157
	Appendix A Participant information letter and consent form.....	159
	Appendix B Interview guide, individual interviews.....	165
	Appendix C Interview guide, focus group interviews.....	169
	Appendix D Western Regional Ethics Committee, response letters.....	173
	Appendix E Norwegian Centre for Research Data, response letters.....	179

List of Tables

Table 1 Motivational continuum.....	21
Table 2 Overview of the three sub-studies in the PhD project.....	37
Table 3 List of paired inclusion and exclusion criteria in Sub-Study 1	39
Table 4 Characteristics of caregiver participants (N=21) in Sub-Study 2.....	42
Table 5 Characteristics of caregiver participants (N=15) in Sub-Study 3.....	43
Table 6 Overview of themes across Sub-Studies 1-3.....	68
Table 7 Excerpts of findings across sub-studies, Theme 1	69
Table 8 Excerpts of findings across sub-studies, Theme 2	70
Table 9 Excerpts of findings across sub-studies, Theme 3	72
Table 10 Excerpts of findings across sub-studies, Theme 4	73
Table 11 Caregivers' motivations	76

List of Figures

Figure 1 Overview of the PhD multi-method study design	32
Figure 2 The PRISMA diagram for Sub-Study 1.....	40

Part I

1 Introduction

This thesis focuses on motivation in the informal caregiver role. It is often considered demanding to be the daughter or son of a home-dwelling parent with a long-term illness. Adult-child caregivers are important resources for both parents and community healthcare services. This also applies to dementia, which is a common long-term illness. Therefore, as the parent's illness progresses, it is vital to understand motivation as it pertains to the caregiver role.

1.1 Informal caregiving

Informal caregiving consists of the ongoing activities and experiences involved in offering unpaid help to relatives or friends who are unable to take care of themselves (Nolan et al., 2003; Roth et al., 2015). This help is given by family members or other informal caregivers, either instead of or in addition to professional caregivers offering public or paid healthcare services (Zigante, 2018). The caregiver's approach to caregiving depends on the patient's type of illness or condition (Sullivan & Miller, 2015), the caregiver's resources (Wennerberg et al., 2016), volition in caregiving (Al-Janabi et al., 2018), and family relations (Hanssen & Sommerseth, 2015). In this thesis, *caregiver* will be used as the main concept, encompassing other common terms in the literature, such as next of kin, carer, relatives, and family.

Long-term serious illnesses, such as cancer, Parkinson's disease, multiple sclerosis, and dementia, are demanding conditions that affect both the care recipients themselves and their informal caregivers on several levels (Adelman et al., 2014; Fu et al., 2017; Sullivan & Miller, 2015). As the illness progresses, the need for care and assistance increases for the person living with a long-term condition. Across the EU, family caregivers account for more than 80% of all care (Hoffmann & Rodrigues, 2010; Zigante, 2018) while in Norway, informal caregivers provide almost 50% of all care (Meld. St. 15, 2017-2018).

Caregiving is not a new role for family members, as people have always provided emotional, physical, and financial support to those with whom they have close relationships. Still, on a general basis, there are some characteristics

and functions that are specific for the long-term illness caregiver role (Schulz et al., 2020). Throughout the trajectory of the patient's illness, the caregiver moves along a continuum from fewer contributions to often substantial contributions (Bøckmann & Kjellevoid, 2015; Nolan et al., 2003). A caregiver can have the role of a receiver of general information if the patient has not consented to healthcare professionals giving out personal information. On the other end of the continuum, a caregiver can provide assistance with daily activities and direct care to the patient. Along the continuum, the caregiver can also have the role of a source of information and provide knowledge about the patient's situation, act as an assistant or collaborator to the healthcare professionals, or represent the patient in making decisions if the patient is not capable of making them on his or her own (Bøckmann & Kjellevoid, 2015).

Dementia is one of the most severe chronic long-term illnesses that has a substantial impact on people receiving the diagnosis and their caregivers. On average, the illness can last about eight years before the patient dies. Therefore, one must be prepared for the need to be an informal caregiver for many years. As a result, it is especially important to focus on caregivers of people with dementia (Alzheimer's Disease International, 2018).

1.2 Dementia and dementia care

Dementia is a collective term for a chronic condition characterised by reduced memory, language, problem solving, and other cognitive capacities that affect a person's ability to perform everyday tasks (WHO, 2020). As dementia symptoms develop, it also affects the family, friends, neighbours, and others interacting with the ill person (Garcia-Ptacek et al., 2019). They often assume the role of caregiver, taking responsibility for the daily care of the person with dementia and meeting basic and instrumental life needs (Chiao et al., 2015).

Many informal caregivers are affected because dementia afflicts approximately 50 million people worldwide. This is a chronic long-term condition that increases the most in prevalence, and thereby constitutes a considerable global health challenge (WHO, 2020). In low-income countries, there might not be systems for official dementia care, and in some countries, dementia is still not considered a diagnosis. These are the same countries that will experience the largest increase in new cases of dementia. While the numbers are estimated to

increase by 78% in Europe by 2050, it will increase by 349% in Latin America. This is due to the fact that the elderly population around the world is sharply increasing (Alzheimer's Disease International, 2018). In line with current ageing policies, older persons with dementia live for as long as possible in their own homes. As the majority of people with dementia live in the community and not in residential care settings, the quality of informal care is crucial for managing the behavioural and psychological symptoms of illness, as well as enhancing the quality of life for both persons with dementia and the caregivers themselves (OECD, 2018). The provision and financing of measures to meet their long-term care needs, including support for their family carers, will inevitably become increasingly urgent political priorities (Prince et al., 2013).

Neuroscience research aiming to improve prevention, diagnosis, and treatment of diseases of the brain are highly prioritised, but still far from finding a treatment for dementia. In anticipation of a cure, society should do its utmost to ensure the best quality of life possible for people with dementia and their caregivers (OECD, 2018). Therefore, it is important to study how people with dementia and their caregivers not only experience their situation, but also how society can better facilitate their everyday lives. There are also large gaps in our knowledge concerning how community healthcare services should be designed and staffed to provide optimal services to people with dementia living at home, including their caregivers (Ministry of Health and Care Services, 2015).

Over the last two decades, western healthcare systems have been striving to provide person-centred care for individuals with dementia described by for example Kitwood (1999) as ideal care (Fazio et al., 2018). Nolan et al. (2003; 2002) advocated that person-centred care does not include caregivers as partners in collaboration with healthcare professionals and persons with dementia. Therefore, they suggested relationship-centred care as a theoretical approach to healthcare services delivered to patients with dementia and their families. Within relationship-centred care, patients, professionals, and family members acknowledge the importance of their relationships with one another to provide high-quality care (Beach et al., 2006). This partnership perspective is in line with the WHO's resolution on primary healthcare emphasising the need to deliver more integrated and people-centred care to everyone. Co-production of health services should be developed and implemented in partnership with individuals and their families (WHO, 2016).

In the dementia context, new research claims that most family caregiving theories are individually focused rather than family-centred and lack consideration of the realities of multigenerational caregiving. As such, researchers have limited guidance to study the complexities within the context and trajectory of dementia caregiving (Gallagher-Thompson et al., 2020). At the same time, person-centred approaches to caregiving have been reviewed lately, including, to a greater extent, caregivers. It is argued that healthcare services need to be designed as person-centred so that caregivers and recipients are engaged and motivated to persevere through challenges during the course of dementia (Connor et al., 2015). Additionally, it has been suggested that perspectives encompassing relations should be valued because it is difficult to separate caregivers from the patients receiving care (Bernild, 2016).

1.3 *Adult-child caregivers vs. spouse caregivers*

More varied family structures and cultural backgrounds will require more alternative thinking about sustainable caregiving plans (Connor et al., 2015). The literature in the field has focused on primary caregivers, almost to the exclusion of other family members (Gallagher-Thompson et al., 2020). The use of informal care is particularly high among co-residents, while caregivers who do not live together with the person who has dementia spend fewer hours providing care (Ydstebø et al., 2020). Other family members and network around the person with dementia are important for how caregivers experience the collaborative climate within the family (Bjørge et al., 2016). In other words, adult children play an important role even if they are not primary caregivers.

A lot of research has treated family caregivers as a homogenous group, with few studies comparing spouse-caregivers with adult-child caregivers (Pinquart & Sörensen, 2011; Tatangelo et al., 2018). Adult children are likely to juggle caregiving with work and other family responsibilities, whereas spouse caregivers are more likely to undertake a full-time caregiving role (Conde-Sala et al., 2010). Therefore, caregivers should not be considered a homogeneous group. A review article of Lloyd et al. (2016) advocates for further research with specific sub-groups comprised of caregivers, such as adult children, for persons with dementia.

1.4 Caregiver burden

The caregiver is often the patient's most important support and, in most cases, wants to be a resource for the patient. This individual knows the patient well and has experience knowing what may be of help in different situations. Dementia caregiving may generate positive aspects with respect to caregiver self-esteem, a feeling of satisfaction with the work carried out, the ability to overcome certain difficulties, and the strengthening of the bond with the person receiving care (Lloyd et al., 2016; Ribeiro et al., 2020; Yu et al., 2018). Nevertheless, it is a highly demanding responsibility, and it provokes caregiver burden and stress (Chiao et al., 2015; van der Lee et al., 2014).

Previous research has focused on potentially negative consequences for caregivers and their considerable burdens of care. The challenges caregivers experience is well known. They undertake the essential care of people with dementia while simultaneously striving to sustain meaningful and mutually satisfying relationships. As behavioural and psychological symptoms of dementia become increasingly difficult to manage with illness progression, caregivers can become cognitively, emotionally, and physically overwhelmed. This often leads to depression and decreased physical health (Pearlin et al., 1990; Schoenmakers et al., 2010), lower quality of life (de Oliveira et al., 2015), and earlier retirement and loss of income (Ugreninov, 2013). This may have a negative effect to people with dementia, caregivers, and society (Chiao et al., 2015). In their systematic review, Beinart et al. (2012) found that a caregiver's demographic and psychosocial attributes can predict greater burden, including factors like older age, lower socioeconomic status, female gender, type of coping strategy, and poor access to social support.

1.5 Caregiver support

Support is pivotal for adult children who are caregivers of a mother or father, as they might be overwhelmed by the burden and uncertainties of being caregivers (Frias et al., 2020). Informal caregivers need support when caring for a person with dementia to prevent burn-out (Holt Clemmensen et al., 2020). Over the past decades, accepted theories guided research in the caregiver context, such as Bandura's self-efficacy model (1977) or interventional research based on Lazarus and Folkman's (1984) original stress and coping

model, modified to a dementia context by Pearlin et al. (1990). These theories have been used with the goal of improving caregivers' mental and physical health outcomes and thereby supporting their well-being (Gallagher-Thompson et al., 2020). Adequate formal support may provide help and relief to family caregivers and reduce the negative consequences of caregiving (Laparidou et al., 2018), but it is still necessary to find better ways to support caregivers to ameliorate the burden (Häikiö et al., 2020). Several interventions have been tested, including information, support groups, and respite care, intended to provide support for caregivers of persons suffering from dementia (Frias et al., 2020). Respite care is understood as any intervention designed to give rest or relief to caregivers (Maayan et al., 2014). Previous research focused has on the drawbacks of caregiving, testing interventions aimed at preventing burden and stress, but only demonstrating small and short-lasting effects (Moniz Cook et al., 2012; Maayan et al., 2014; Reilly et al., 2015).

Other studies focus on the importance of a more balanced view when developing caregiver support services. A shift from “reducing stress” to “optimising positive experience” in the caregiver role is endorsed (Lloyd et al., 2016; Ribeiro et al., 2020). Still, studies that have tried to explain the more rewarding aspects of caregiving are at a relatively early stage, and the topic deserves greater attention (Lloyd et al., 2016; Yu et al., 2018). Factors relating to the positive aspects of caregiving and the association between these positive aspects and well-being are under-researched (Crellin et al., 2014). In order to find better ways to support caregivers of persons with dementia, more research is warranted to focus on how their motivation changes over time (Quinn et al., 2012).

1.6 Motivation to provide care

Given the challenging nature of caregiving, it is important to understand what motivates people to become caregivers. More research should aim to understand why they continue in caregiver roles, despite the growing needs of care recipients (Greenwood & Smith, 2019). Informal caregivers' motives for taking care of family members with dementia have been found to include emotional ties and cultural, spiritual, and religious responsibilities (Zahed et al., 2019). The motivation to provide care is also a significant predictor of the

positive aspects of being a family caregiver of a person with dementia (Quinn et al., 2010; Quinn et al., 2012; Yu et al., 2018) and plays an important role in the development and maintenance of caregiving (Quinn et al., 2015). Quinn et al. (2012) recommended more studies conceptualising motivation within a theoretical perspective. Utilising appropriate conceptual frameworks can further illuminate how motivation can influence caregiving outcomes.

To understand the motivational drivers behind human action, self-determination theory (SDT) has been applied in several research domains, such as education, work, sports, religion, psychotherapy, behaviour change, and healthcare (Milyavskaya & Koestner, 2011; Ng et al., 2012; Rigby & Ryan, 2018; Weinstein & Ryan, 2010). Within these contexts, this theory has been used to identify, understand, predict, promote, and support individual motivation (Ng et al., 2012; Williams et al., 2014). SDT is a broad framework that conceptualises the study of human motivation. It identifies three innate psychological needs as key drivers of motivation that influence well-being and thriving, including competence, autonomy, and relatedness (Ryan & Deci, 2017). This theory is widely used in health research (Ng et al., 2012; Ntoumanis et al., 2020), but is relatively new in the field of caregiving (Barry et al., 2020). Preliminary evidence shows that caregiving based on intrinsic motivation tends to affect the well-being and health of caregivers. Thus, further exploration of the role of SDT in understanding caregiving motivation is recommended (Ryan & Deci, 2017). In this PhD project the term motivation is understood to be the energy in people that drives their action or inaction (Deci & Ryan, 2014; Ryan & Deci, 2017).

1.7 Aim, objectives, and research questions

So far, research within the caregiver field has focused on primary caregivers, the burden of taking on the caregiver role, and interventional research rooted in traditional psychological models to improve health outcomes. Less research has been devoted to understanding how secondary caregivers, such as adult children, remain motivated and how they experience support and healthcare services in the community, using more recent theoretical approaches like SDT and relationship-centred care applied to the long-term illness and dementia context.

Introduction

The overall aim of this thesis is, therefore, *to gain a deeper understanding of adult children's motivations to remain in the caregiver role when parents with dementia live at home*. To address this aim, three objectives with belonging research questions guided the three sub-studies included in the PhD thesis.

Sub-Study 1

- To describe and explore empirical studies of caregivers' motivations from the perspective of self-determination theory.
 - How can an adult informal caregiver's motivation for taking care of a friend or relative with a long-term illness be understood from the perspective of self-determination theory?

Sub-Study 2

- To explore adult children's motivations in caregiving for their home-dwelling parents with dementia.
 - How can adult children's motivational drivers for caregiving be described using self-determination theory?

Sub-Study 3

- To describe and explore adult children's experiences with community healthcare services for their home-dwelling parents with dementia and how these influence their caregiver motivations.
 - How do adult-child caregivers describe their experiences with their parents' community healthcare services?
 - How do these experiences influence their motivations to remain in the caregiver role?

2 Contextual background

As the empirical data in the PhD project was collected in a Norwegian setting, it is appropriate to account for the dementia caregiver context, including national guidelines, legislation, and community healthcare services.

2.1 *Dementia in the Norwegian context*

It is necessary to describe the dementia illness to illuminate the trajectory of dementia caregiving to understand the caregiver role (Ulstein, 2007).

2.1.1 *Dementia – the illness*

The Norwegian Directorate of Health (2019) refers to the WHO's definition of dementia:

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain (WHO, 2019, ICD-10).

Thus, dementia is not a disease in itself, but it is a syndrome that results from various diseases or damage to the brain, and it is entirely attributable to normal ageing. The different types of dementia are usually divided according to cause. The three primary pathologies of dementia are degenerative brain diseases, vascular dementia, and secondary dementia diseases. Degenerative brain diseases include Alzheimer's as the most common but also frontotemporal dementia, Lewy body, and Parkinson's disease (Engedal & Haugen, 2009; WHO, 2020). Most commonly, dementia is caused by the consequences that occur when brain cells are destroyed and die.

Different forms of dementia have various symptoms in the early stages, depending on which part of the brain is attacked first. Therefore, the challenges and stressors faced by caregivers vary (Svendsboe et al., 2016; Terum et al., 2019). As the disease spreads to larger parts of the brain, typical dementia symptoms become more prominent irrespective of the type of origin (Engedal & Haugen, 2009). Therefore, it is useful to get a diagnosis early to receive the right services at the right time and be able to plan for the future together with caregivers (Ministry of Health and Care Services [MHCH], 2020). Still, not all dementia patients are given a specific diagnosis, but are underdiagnosed or just categorised under a broad “dementia” diagnosis (Skogli et al., 2020a; Vossius et al., 2015).

Usually, dementia is an insidious disease, and as the brain injury spreads, the lack of cognitive ability becomes severe enough to interfere with activities of daily living. Many experience cognitive symptoms like impaired concentration, being more easily distracted, falling out of conversations, weakened short-term memory, and gradual loss of language. The capability of reasoning and thinking abstractly is reduced, and dealing with time or handling money can be difficult. The ability for physical orientation can deteriorate and make it difficult to drive a car or find the way home. Eventually, one may have problems performing practical tasks like using the stove and preparing meals. Despite these cognitive challenges, many persons with dementia can preserve resources to manage a lot of activities in daily life, even with illness (Norwegian Directorate of Health, 2018; WHO, 2020).

It is challenging for caregivers to deal with cognitive impairment and changes that occur in a person with dementia (Bruvik, 2014; Nordtug, 2011; Ulstein, 2007). Typically, the biggest challenge facing a caregiver involves neuropsychiatric symptoms that develop in over 90% of people with dementia. This can be divided into the following four categories of symptoms: 1) behavioural symptoms, such as aggression, agitation, lack of inhibition, irritability, and repetitive behaviour; 2) psychotic symptoms, (e.g., hallucinations, delusions); 3) affective symptoms, such as depression, anxiety, euphoria, and apathy; 4) vegetative symptoms, such as sleep disturbances and changes in appetite. People who develop dementia can also experience motor symptoms, such as problems with muscle management, coordination of

movements, and incontinence. As the condition progresses to severe dementia, many patients experience a greater degree of physical symptoms, eventually becoming bedridden and totally dependent on care from others (Norwegian Directorate of Health, 2018).

Currently, dementia does not have a cure, and no one survives it. However, there are medical treatments available that may improve some symptoms for a period. If the person with dementia does not die from other causes, dementia will have a fatal outcome (WHO, 2020). A Norwegian survey found that a dementia course lasts an average of 8.1 years, but this varies depending on the point of time of diagnosis, the type of dementia, and the person's age at the time of onset (Vossius et al., 2015). Either way, dementia is characterised as a long-term illness, and thus caregivers remain in their roles over a prolonged period.

2.1.2 Prevalence of dementia

Until recently, prevalence figures in Norway have been inaccurate based on studies from other countries carried out in the 1990s (Skogli et al., 2020a), which estimated that approximately 77,000 people with dementia lived in Norway in 2013 (Alzheimer Europe, 2013; Prince et al., 2013). A new survey found that the prevalence of dementia in Norway is higher than previously estimated. In 2020, the total number of people with dementia in Norway was estimated to be 101,000. This constitutes 14.6% of the population over 70 years. The most common type of dementia in Norway is Alzheimer's disease (57%), followed by vascular dementia (10%), mixed dementia (9%), dementia with Lewy bodies (4%), and frontotemporal dementia (2%) (Gjøra et al., 2020).

Dementia illnesses are strongly linked to advanced age. Statistically, women live longer than men. Therefore, more women develop dementia. As the population gets older, we can expect the numbers to increase (WHO, 2020). It is estimated that the number of people with dementia will increase to 235,000 in the year 2050 and to 380,000 in the year 2100 (Gjøra et al., 2020). The recent figures provide a more accurate estimate to help the government plan the right scope of services for people with dementia and their caregivers (MHCH, 2020).

2.2 Informal caregiving in Norway

In 2020, it is estimated that more than 400,000 close relatives or friends are caregivers to people with dementia (Norwegian Health Association, 2020). The home-dwelling period for a person with dementia lasts for approximately six years, and during this period, over 90% receive informal help from relatives or friends. Even after the dementia diagnosis, an average of 60 to 80 hours of informal caregiver support a month is provided. Prior to moving to a nursing home, this increased to around 160 hours of help the last month living at home, equivalent to a full-time position (Skogli et al., 2020b; Vossius et al., 2015). During the subsequent nursing home stay, a caregiver provides on average 6.7 hours of help per month, indicating that the nursing home staff take over most of the care for the patient (Vossius et al., 2015). During the home-dwelling period, the amount of time and effort caregivers spend depends on whether they live together with the person with dementia, if they share the caregiver tasks with someone else, access to healthcare services (Ydstebø et al., 2020), and how relationships and collaboration are handled within the family (Bjørge et al., 2017).

The care provided by adult children includes things like assistance with practical tasks, transportation, support for personal care, and medical treatment. However, it mostly involves emotional support, including spending time talking with the parent and visiting or calling to ensure that the parent is safe. Compared to caregivers who are not cohabitants, spouses, partners, and others living together with the person who has dementia spend more hours providing care and might also assist with activities like preparing meals, personal hygiene practices, and toilet visits (Norwegian Directorate of Health, 2018). Adult children are important care providers in their parents' final years of life, independent of diagnosis. The contribution of adult children often depends on whether they live in close proximity to their parents (Daatland et al., 2010).

About half of the caregivers of people with dementia engage in income-generating work. Of them, between 20% and 50% report losing working hours due to the parent, but less than 1% of them stop working (Vossius et al., 2015). Adult-child caregivers who combine full-time work with caring for elderly parents are more prone to report poor health with a higher probability of sick leave absence (Ugreninov, 2013). Caring for older parents has a negative

impact on the child's labour market participation, more so for daughters than sons (Gautun & Bratt, 2017; Vangen, 2020).

2.3 National guidelines and legislation

Expecting an increase in the number of persons with dementia, the Norwegian Ministry of Health and Care Services published, as one of the first countries in the world, a national dementia plan in 2007 to better meet the needs of patients and their caregivers. The dementia plan was updated in 2015 and in 2020 (MHCH, 2020). In 2020, the government also published the first Caregiver Strategy, to be seen in conjunction with the Dementia Plan 2025 (Ministries, 2020). One of the main goals of the current plan is to enhance support for family caregivers and create a more dementia-friendly society that takes care of and integrates people with dementia in the community so they can live longer in their own homes (Meld. St. 15, 2017-2018; MHCH, 2020).

A new calculation estimates that informal care in Norway amounts to about 136,000 man-labour years (MHCH, 2020). This is almost at the same level as the community healthcare service, which amounts to about 142,000 man-labour years. As family caregiving is recognised as the backbone of dementia care, viewing caregivers as resources is regarded as a high priority. National guidelines and the Norwegian political framework point to the importance of making caregivers' efforts visible and appreciated. The goal is to keep the efforts of caregivers at the current level. One of the objectives of the "Programme for an active, future-oriented informal care policy" (Meld. St. 29, 2012-2013) is to improve the interaction between public and informal care. The need for more knowledge concerning motivating and burdensome aspects of the caregiver role has been emphasised together with the development of measures to improve collaboration between healthcare professionals, patients, and caregivers.

The Norwegian national guidelines for dementia care (2018) provide an overview of legislation regarding caregivers' rights and duties. It is the healthcare services that provide healthcare to patients that should offer information and follow-up for caregivers of persons with dementia. Adult children do not have a legal duty to take care of their parents, but they still may feel that they have to participate due to moral commitments (Bøckmann &

Kjellevold, 2015). If the parent has defined the adult-child as their next of kin, the adult child has the right to take part in decisions together with or on behalf of the parent (The Patient and User Rights Act, 1999). Healthcare professionals have a duty to provide information, training, and support for caregivers (The Health Personnel Act, 1999). Municipalities are committed to offer respite-care and economic compensations to caregivers with especially onerous caregiver tasks (The Municipal Health Services Act, 2011). The national guidelines for caregivers in the healthcare sector provide recommendations on how healthcare services can involve and support caregivers (Norwegian Directorate of Health, 2019).

Compared to other countries, Norway has an advanced position in terms of national plans, guides, policies, and legislation to safeguard the caregivers of persons with dementia (Norwegian Directorate of Health, 2018; Skogli et al., 2020b). Nevertheless, empirical research suggests that professionals do not adequately involve the family as partners in daily care. Families experience inadequate communication, are not acquainted with the staff, and are unfamiliar with the way homecare services are organised. They experience a lack of mutual information exchange and clarification of roles and responsibilities (Henriksen et al., 2020; Moholt et al., 2020; Aasgaard et al., 2014).

2.4 Community healthcare services

In Norway, public healthcare services provide the majority of care, rendered free of charge to patients (Meld. St. 29, 2012-2013). The public welfare model is constructed for taking care of persons with dementia, supplemented by support from informal caregivers, and the healthcare services of people with dementia should be person-centred (MHCH, 2020). Specialist care is provided by regional health authorities and consists of hospitals and specialised units, such as memory clinics and geriatric hospital wards.

Primarily, 356 Norwegian municipalities offer formal care for people with dementia (MHCH, 2020). General practitioners (GPs) are responsible for the diagnosis. Nearly 80% of Norwegian municipalities have dementia teams or coordinators that consist of nurses and occupational therapists. Persons with dementia and their caregivers have the right to support and follow-up once dementia is diagnosed (Norwegian Directorate of Health, 2018). About 60% of

all people with dementia live in their own home (Gjøra et al., 2020). In the home-dwelling period, homecare services are common. Initially, the services are limited, but they increase with the progression of dementia. The type of healthcare services the person with dementia receives is dependent upon the severity of symptoms and the family situation, and at the end of the disease, moving the parent into a nursing home is often unavoidable (Norwegian Directorate of Health, 2018). Home-based nursing can be perceived as insufficient by caregivers and not individually adapted, especially for those in the later stages of dementia (Tretteteig et al., 2019). Research has highlighted the challenges and barriers to coordination in dementia care in Norwegian municipalities (Haugen, 2020; Larsen, 2017; Øydgard, 2018) and the caregivers' need for support (Moholt, 2019).

Even if the municipalities are obliged to provide assistance to the caregivers, only 74% of them report having routines for surveying caregivers' support needs, including assessment of their need for information, training, guidance, and respite care. Nevertheless, almost all municipalities (97%) state that they provide relief to caregivers in the form of short-term stays for patients at nursing homes, day-care centres, or in their homes (Norwegian Directorate of Health, 2018). However, there is a lack of data regarding how often or how many caregivers receive these forms of support. Tretteteig et al. (2019) found that caregivers of persons with dementia perceived day care as a high-quality option that provides positive relief for caregivers, while respite short-term stays in nursing homes need improvement.

Sixty-eight percent of the municipalities in Norway offer caregiver courses, so-called "caregiver schools" (Norwegian Directorate of Health, 2018). The "schools" provide caregivers with opportunities to learn more about dementia. Usually, the participants meet five to eight times. Also, a lecturer is invited to every meeting. The lectures can cover everything from what the disease means to the legal rights of the person with dementia and their caregivers. Among caregivers living in municipalities with such tailored support structures, 36% reported that they had used this type of services (Norwegian Directorate of Health, 2021). A Norwegian study found that participation in family support classes can be experienced differently and does not necessarily suit everyone (Tretteteig et al., 2019). The Dementia Association, Red Cross, and other

Contextual background

voluntary organisations offer peer work and other measures to support caregivers of persons with dementia (Norwegian Health Association, 2020).

3 Theoretical background

This chapter first presents the current literature within the caregiver context, then the research field of motivation, including the self-determination theory, and finally an overview of a relationship-centred approach to care.

3.1 *Current literature within the caregiver context*

The main body of research considered within the caregiver context has traditionally centred on negative aspects with a focus on stress, burden, and consequences. However, the positive aspects of caregiving have gained increasing attention in the research literature, including the experiences, emotions, appraisals, resources, and strengths the caregivers have in managing their roles (Lloyd et al., 2016; Zarit, 2012). Examples of the positive aspects include a caregiver's feeling of uplifts, gratification, acceptance, reciprocity, reward, mastery, growth, and improved relationship quality. Also, being useful and important to others makes caregivers feel satisfaction (Lloyd et al., 2016; Nolan et al., 1996). Yu et al. (2018) reviewed conditions predicting the emergence of positive aspects of being a caregiver of a person with dementia, where finding meaning and motivation in this role were considered essential.

A previous review of the quantitative research literature described motivation for caregiving as "why carers take on the role" (Quinn et al., 2010). They found that a caregiver's relationship to the dementia patient and their cultural background influenced the motivation for caring. Religion and filial responsibilities played a role for some groups more than others. Motivation is not always related to positive aspects of caregiving and can be driven by emotional ties and cultural, spiritual, and religious responsibilities (Zahed et al., 2019). As such, it is useful to consider caregivers' motives as a multidimensional construct when studying their stress and coping mechanisms (Romero-Moreno et al., 2011). In the context of informal caregiving, researchers have studied caregiver motivation as intrinsic (i.e., caregiving as a valued activity) and extrinsic (i.e., caregiving as a duty) (Lyonette & Yardley, 2003; Quinn et al., 2012; Romero-Moreno et al., 2011). Intrinsic motives were related to meaning, caregiver competence, and caregiver satisfaction. Extrinsic motivation was related to caregiver stress, burden, and feeling like a captive in

the role. Quinn et al. (2015) found that caregivers scoring simultaneously low on intrinsic motives and high on extrinsic motives may be at particular risk for negative caregiving outcomes. One study suggested that intrinsic and extrinsic motives for caregiving are not mutually exclusive and may combine to provide a better explanation of the impact caregiving has on their well-being and adaptation (Romero-Moreno et al., 2011).

Greenwood and Smith (2019) synthesised the qualitative research literature on what motivates a person to care for someone with dementia. They understood motivation as a reason for caregiving. However, they were unable to establish whether motivation for starting to provide care for someone with dementia was similar or different to the motivation for continuing in the role. Examples of common reasons were reciprocity, love, duty, commitment, and responsibility. Satisfaction derived from caring was more often highlighted by carers from western countries, while the term filial piety (i.e., a son or daughter's obligation towards a parent) was more frequently reported in studies from Asia and Africa. The authors refer to different understandings of the term motivation across cultures as a limitation of their review (Greenwood & Smith, 2019), while different theoretical approaches to motivation are not included. To better understand the motivation for caregiving, it is necessary to comprehend the theoretical concept of motivation in general.

3.2 Motivation

Motivation is a substantial research field applied by philosophers, psychologists, parents, educators, students, employers, employees, healthcare professionals, and patients (Lillemyr, 2016). Romain et al. (2020) have, for example, conducted a meta-analysis of interventions in healthcare based on different motivational theories and how these interventions can impact a patient's ability to be more physically active. There are an abundance of motivational theories, such as competence motivation theory (White, 1959), expectancy value theory (Vroom, 1964), achievement motivation theory (Atkinson, 1964), goal-setting theory (Locke, 1968), intrinsic motivation (Deci, 1975), self-efficacy-theory (Bandura, 1977), stress and coping (Lazarus & Folkman, 1984), and self-determination theory (Ryan & Deci, 2000).

Reeve (2018) summarised the understanding of motivation from different theoretical perspectives. Currently, motivation is mainly understood as internal processes that give behaviour its energy, direction, and persistence. Mobilisation of *energy* and *direction* implies there are processes that create interest, develop engagement, and desire to invest of oneself for certain activities and actions. *Persistence* implies that behaviour has endurance and sustains itself over time. Original grand theories of motivation were based on human *will*, *instincts*, and *drive*, which were exemplified by Freud's drive theory in 1961. In this theory, he argued that human motivation and drive for behaviour is largely due to unconscious urges or psychological energy rooted in early childhood. As the research field evolved, the early grand theories were found to be less relevant as their scope was seen as too limited or too broad, studies turned into dead ends, and the theories were accused of only naming motivation instead of explaining the phenomena (Reeve, 2018).

Inspired by the grand theories, new motivational theories were developed, giving mainly two types of explanations. One focused on basic biological, social, and psychological *needs*, as in Maslow's theory from 1954 of a hierarchy, and the other focused on *extrinsic reward or punishment* as motivation for behaviour (Reeve, 2018). Consequently, researchers revealed that humans engaged in activities for other reasons, including expressing positive feelings of interest, enjoyment, and satisfaction when conducting certain tasks. The researchers posited new motivational drivers and called it *intrinsic motivation* (Sansone & Harackiewicz, 2000). Today, several theories of motivation acknowledge the requirement for a combination of cognitive and affective aspects. The social perspective should also be prominent as in the self-determination theory (Reeve, 2018).

As mentioned, there are common factors involved in several motivational theories. They deal with why people take certain actions and list internal (e.g., intrinsic) and external (e.g., extrinsic) reasons behind them making these choices. Examples of extrinsically motivated behaviour are when we feel controlled, driven by an external reward, or want to avoid punishment. Examples of intrinsic motives are finding it enjoyable, satisfying, and meaningful to perform certain tasks. The behaviour then comes naturally and spontaneously when we feel free to follow our own interests or values (Sansone & Harackiewicz, 2000). Human behaviour is often composed of both

intrinsically and extrinsically motivated actions. However, if the action is based more on intrinsic than extrinsic motivation, it may have positive consequences, such as thriving and well-being. The distinction between intrinsic and extrinsic motivation has traditionally been controversial and is still involved in an ongoing debate. For example, studies have illustrated the paradox that extrinsic rewards can undermine intrinsic motivation like receiving payment for conducting tasks that initially were satisfying in themselves. Nonetheless, Sansone and Harackiewicz (2000) suggest in light of this debate that researchers in all contexts who wish to understand motivation should base their research not just on studying human struggle, but also looking at the positive and joyful sides of life and learning from them.

3.3 Self-determination theory

Since intrinsic motivation is essential for understanding the motivation for caregiving, a motivational theory that recognises the importance of this is vital (Barry et al., 2020). According to Reeve (2018), SDT is increasingly engaged by the fact that self-determination has a strong impact on human intrinsic motivation and, in recent years, has influenced theory development. The theory includes cognitive, affective, and social dimensions, while intrinsic motivation is best stimulated in contexts where the person receives support for making choices, has a sense of competence, and a sense of belonging. This focus is also timely in the caregiver context.

SDT was developed from empirical motivational research by the psychologists Richard Ryan and Edward Deci. It is an approach to describe and explore human motivation and well-being. SDT has been applied to research in other healthcare-related fields, such as physical activity promotion, medication adherence, dietary change, smoking cessation, and other areas critical to health (Ryan & Deci, 2019), and in a study of the caregiver context (Barry et al., 2020). There is preliminary evidence that goals and actions based on intrinsic motivation, through experiences of competence, relational affiliation, and autonomy, can promote mental health and well-being among caregivers (Ryan & Deci, 2017). Based on what we know about the situation for family caregivers, their mental health is exposed, and there is a risk that providing long-term care will result in poorer health. With this perspective, support that

gives caregivers better motivations in their daily lives will have a positive effect on their health and well-being (Barry et al., 2020; Tretteteig et al., 2017b).

3.3.1 A motivational continuum

SDT has been able to identify several distinct types of motivation, each of which has specific consequences for personal coping, how humans perceive experiences, and for their well-being (Ryan & Deci, 2000). Motivation, according to SDT, is not considered in the form of quantity, but rather by quality. It can be placed on a motivational quality continuum. SDT differentiates types of motivation along such a continuum from non-self-determined to self-determined motivation based on different types of regulatory styles (see Table 1). Barry et al. (2020) link examples from the caregiver context to the specific types of motivation (Table 1).

Table 1 Motivational continuum based on Ryan and Deci (2000) and Barry et al. (2020)

	<div style="display: flex; justify-content: space-between; align-items: center;"> Non-self-determined Self-determined </div> <div style="text-align: center; margin-top: 5px;"> </div>					
Type of motivation	Amotivation	Extrinsic Motivation				Intrinsic Motivation
Regulatory styles	Non-Regulation	External Regulation	Introjected Regulation	Identified Regulation	Integrated Regulation	Intrinsic Regulation
Source of motivation	Impersonal	External	Somewhat External	Somewhat Internal	Internal	Internal
Examples of motivational regulators in the caregiver context	Passivity and lack of intentionality for caregiving	External rewards like payment or threats like punishment from family members	Avoid feeling ashamed if not giving care	Caregiving seen as important and valuable to the patient	Caregiving seen as inherent to the caregiver's identity	Feeling pleasure or interest when caring for the patient

Types of motivation that are non-self-determined, also named controlled motivation, include amotivation, external, and introjected regulated motivation. At the left of the self-determination continuum is *amotivation*, labelled *non-regulation*, the state of lacking the intention to act where people either do not act at all or act without intent by just performing the tasks while going through the motions (Ryan & Deci, 2000, 2017). Barry et al. (2020) suggest that an amotivated caregiver might have fallen into the caregiving role unintentionally, or may feel a lack of motivation despite continuing to engage in the behaviour. The caregivers may feel that the support they provide is not effective or they do not connect it with personal meaning or interest. Regarding amotivation, caregivers experience increased role limitations due to physical problems, decreased social functioning, increased pain over time, and thereby experience a decrease in their well-being (Barry et al., 2020). *External* regulation characterises behaviour that people engage in to satisfy an external demand, such as avoiding punishment or receiving rewards. Caregivers who possess an external source of motivation may provide care because they receive payment for caregiving or other family members would be angry with them if they do not take care of the patient. *Introjected* regulation refers to behaviour a person engages in to avoid bad feelings like guilt or anxiety or to attain ego enhancements, such as demonstrating ability or avoiding failure. An example of introjected motivation would be caregivers who provide care because they would otherwise be ashamed.

In contrast to non-self-determined motivation for behaviours is self-determined motivation. This is also named autonomous motivation, referring to the experience of freely choosing to engage in a certain behaviour. Types of more autonomous regulatory styles include identified, integrated, and intrinsic regulation. *Identified* regulation refers to consciously valuing and engaging in a behaviour because you feel it is important (Ryan & Deci, 2000, 2017). An example within caregiving would be to provide care because it is important and valuable to the recipient. *Integrated* regulation refers to engaging in a behaviour because you have evaluated and brought it into congruence with your other values and needs. An example would be a caregiver who provides care because it is inherent to their identity. The most autonomous and self-determinant type of motivation at the right end of the continuum is *intrinsically* regulated, referring to behaviour that people are engaged in because it is enjoyable,

satisfying, or interesting. People who are intrinsically motivated to engage in caregiving do so because they feel pleasure or interest when caring for their patients. Barry et al. (2020) found that high energy levels were positively associated with intrinsic motivation and thereby emotional well-being in the caregiver role.

3.3.2 Caregivers' basic psychological needs

SDT provides a framework for understanding the factors that promote motivation and well-being. The framework addresses how social-contextual factors thwart or support people's thriving through the satisfaction of their basic psychological needs for competence, autonomy, and relatedness. These universal and innate psychological needs are understood as an energising state that, if satisfied, conduces to health and well-being but, if not satisfied, contributes to pathology and ill-being (Ryan & Deci, 2017). For informal caregivers, satisfaction of these needs is necessary for optimal motivation, physical health, psychological well-being, and social integration. In addition, caregivers' motivations will help them to sustain their persistence and performance of caregiving tasks over time (Barry et al., 2020; Kim et al., 2008; Kindt et al., 2016). SDT argues that all three needs are equally essential, as thwarting any of those needs will lead to distinct functional costs (Ryan & Deci, 2017).

Having a sense of *competence* is described as the first basic psychological need, as this is a well-researched issue building on the competence motivation theory (White, 1959). The need for competence is essential in all humans, and it refers to experiencing capability, mastery, and perceptions of performing tasks with confidence (Ryan & Deci, 2017). Strelakova (2016) addressed a caregiver's need for competence by efforts to seek information, to understand the patient's diagnosis, and to find out how to locate professional help. Another example is from an SDT-informed intervention study within the field of cancer care. It aimed to support a caregiver's competence by standardised, tailored manuals on self-care, stress and coping, symptoms management, problem solving, and skills in maintaining and enhancing relationships. Caregivers with stronger competence and the ability to master their roles will more likely invest greater

effort compared to those who consider themselves to be incompetent in conducting caregiver similar tasks (Badr et al., 2015).

The need for *autonomy* refers to volition as having a sense of choice and ownership over one's actions. The association between people's values, interests, attitudes, priorities, and actions is essential (Ryan & Deci, 2017). When caregivers are autonomous, their actions are characterised by feelings of freedom and their ability to make choices because they can set goals based on personal preferences and experiences. It is important to make efforts to achieve autonomy e.g., allow caregivers to make their own decisions, and to have the choice regarding the capacity to help the patient (Kindt et al., 2015), and to be able to autonomously plan for the future (Strekalova, 2016).

The need for *relatedness* concerns the universal desire to feel belonging, connection, and meaningfully related to others. This also includes the feeling of being personally accepted by others as someone they trust and consider to have importance. Likewise, finding satisfaction in supporting and caring for others, is essential (Ryan & Deci, 2017). Strekalova (2016) found that caregivers satisfied their needs for relatedness through contact and support from other families in a similar situation. The quality of the caregivers' existing relationships with their patients strongly influences the degree to which they experience relatedness and thereby endorse their support roles. Relatedness in the caregiver context seems to be particularly important for caregivers' motivations (Kim et al., 2008; Kindt et al., 2015). Improving caregivers' relationships, specifically with patients and healthcare providers, can positively impact their motivations to provide care and their well-being (Barry et al., 2020). Since relatedness seems especially important in the caregiver context, it is useful to explore a theoretical approach that addresses the relationships among patients, caregivers, and healthcare professionals.

3.4 Relationship-centred care

Many terms have been used within the health and caring sciences to emphasise an individual approach to care, such as client-centred care, patient-centred care, and person-centred care. More recently, a family-centred approach has been supported that includes not just the patient and the primary caregiver but embodies the family as a whole (Connor et al., 2015). Nolan et al. (2006; 2004;

2003; 2002) advocated that a relationship-centred approach to care might be more appropriate. Within relationships in healthcare, information is exchanged, appointments are made, and training, support, and help are given or received. Relationships provide the context for activities and functions, as none of the examples mentioned involve solely one party. The qualities of the relationships link patients, caregivers, and healthcare professionals together (Beach et al., 2006; Nolan et al., 2003). Relationship-centred care can be defined as “care in which all participants appreciate the importance of their relationships with one another” (Beach et al., 2006). Within relationship-centred care, triadic relationships are based on mutual appreciation of each other’s knowledge, recognition of each other’s equal worth, and enhancing and facilitating joint understanding (Nolan et al., 2002). The term “partnership” is also used to emphasise the dynamic interactions among those involved in caring, including the patient, family caregivers, and healthcare professionals. The purpose of such a partnership is to promote processes to reduce stress and burden and create balance for everyone involved in the care team (Beach et al., 2006; Nolan et al., 2003).

Based on the perspectives from relationship-centred care, Nolan et al. (2001; 2003) developed a framework underpinned by a belief that all parties involved in caring should experience relationships that promote senses of *significance*, *belonging*, *achievement*, *security*, *continuity*, and *purpose*. These senses provided a means of highlighting important, but often taken-for-granted, aspects of care. The framework considers how positive relationships can be created and sustained. The focus is on the sources of satisfaction for family carers with regard to their caring relationship as opposed to focusing on sources of stress and burden. The six senses and what they hold from the perspective of older people, for staff, and for family carers are described in Nolan et al. (2003). Most relevant for this PhD thesis are the senses seen from a caregiver perspective, and therefore this part of the framework is outlined in the following.

The framework claims the importance of a caregiver’s feeling of *significance*. This feeling implies that they are recognised and listened to as people, to feel that their actions and existence are important, that they matter, and that their caring efforts are valued and appreciated. The sense of *belonging* entails that they feel like an active and equal partner in caregiving, able to maintain

relationships, confide in trusted individuals, and don't feel alone. The sense of *achievement* is described as "to feel you're getting somewhere". It is important to meet challenges successfully, develop new skills, and meet competing demands successfully to know they have done their best. The sense of *security* implies that caregivers feel confident and able to provide good care without the loss of personal well-being. It is also essential to have adequate support networks, timely help when required, and the ability to relinquish care when appropriate. The sense of *continuity* represents a caregiver's ability to maintain shared pleasures and pursuits with the care recipient while maintaining involvement in caregiving across environments. To provide competent and consistent standards of care, whether they are delivered by caregivers themselves or by others, is important for sustaining a sense of continuity in caregiving. The sense of *purpose* relates to caregivers having goals to aim for, to feel that they are able to make a difference. The purpose is to ensure that the patient receives the best possible care while safeguarding their dignity and individuality. The purpose also includes being able to achieve a balance between caregiving and other important parts of life (Nolan et al., 2001; Nolan et al., 2003).

The relationship-centred care approach expands the psychological need for relatedness referred to in the SDT framework in the way that it takes a more social and contextual view. Williams et al. have studied relationship-centred care integrated with SDT concepts from a patient outcome perspective, a patient-family perspective (2000), and later from a patient-practitioner perspective (2014). Findings point toward the positive effects of relationship-centred care on motivation, pinpointing both psychological and social factors. So far, no research has been identified on the interface between relationship-centred care and SDT, including from the caregiver perspective.

3.4.1 The relationship-centred care framework in research and practice

The Nolan et al. (2001; 2003) relationship-centred care framework has been developed through research and is empirically tested in close collaboration with older people, family carers, and practitioners, mostly within nursing homes. Later, the framework was used to guide the development and evaluation of

Theoretical background

responsive information and communication technology support services for older people living at home and their caregivers (Magnusson & Hanson, 2004). Other research projects have used the framework to identify strategies that promoted relationship-centred care in acute hospital settings for older people and their caregivers (Dewar & Nolan, 2013), or studied migrant caregivers' relationships to frail older people living at home (Teshuva et al., 2019).

The framework offers educational and practical tools that have been used to achieve better quality relationship-centred care, including a dementia context. Studies found that the framework provided practical guidance for supporting relationship-centred care until the end of life for people with advanced dementia (Watson, 2016). The use of the framework empowered caregivers and patients, but also enhanced the job satisfaction of professional dementia carers (Brown Wilson et al., 2013). De Witt and Fortune (2019) found support for the six senses to be vital aspects of positive dementia care experiences in community settings for all involved. The focus was on ensuring continuity in care so that time could be spent on relationships during home visits through consistent healthcare professionals paired with patients and their caregivers.

To emphasise the positive sides of care for all involved, the relationship-centred approach presents practical applications for healthcare services (Nolan et al., 2001; Nolan et al., 2003). Therefore, the approach was introduced in the PhD project (Sub-Study 3) to address the need for understanding how adult-child caregivers could stay motivated in the caregiver role by applying the operationalised set of senses described by Nolan et al. (2003).

4 Methodology

This chapter presents the methodological approach used to study adult children's motivations to remain in the caregiver role when parents with dementia live at home. A brief introduction to the philosophical underpinning of the PhD project is included, together with research design, data collection, sample, data analysis, research quality, and ethical considerations. The strengths and limitations of the PhD project are included in the discussion chapter.

4.1 *Philosophical considerations*

Guided by the overall aim of this PhD project, to gain a deeper understanding of caregivers' motivations, a qualitative approach was required (Hesse-Biber et al., 2015). Such approach has the common assumption that social reality is constructed and that subjective meaning is a critical component of knowledge building. Within the constructivist paradigm, one assumes that social reality is subjective, consisting of narratives or meanings constructed and co-constructed by individuals within a specific social context. The aim is to gain a deeper understanding based on the participants' experiences (Lincoln & Guba, 2003). This was also the case in this PhD project where a literature review explored a deeper understanding of motivation in the long-term illness caregiver role. In the empirical sub-studies, the participants' experiences formed the basis for describing their ideas, thoughts, meanings, and perceptions of motivation in the caregiver role within the context of caring for a home-dwelling parent with dementia.

In this PhD project, I have combined different qualitative methods within the constructivist paradigm (Hesse-Biber & Johnson, 2015). I have chosen to lean on pragmatic philosophy, as this view of science is often applied when using multiple methods in combination (Cherryholmes, 1992; Frost & Shaw, 2015; Polit & Beck, 2018).

Pragmatism holds that reality is multiple, complex, constructed, and stratified, and considers truth as "what works". Therefore, it is the research question that should drive the design of the study (Biesta, 2010; Polit & Beck, 2018). The

PhD project is in line with this way of thinking since the overall aim has guided the selection of applied methods for data collection and analysis. Within pragmatism, participants' experiences and the consequences of these experiences and actions are central, as experience emerges in a continual interaction between people and their environments (Frost & Shaw, 2015; Lincoln & Guba, 2003). It is advocated that the researcher's position, interests, and values in making decisions affecting the research process must be transparent (Cherryholmes, 1992). Pragmatism also seeks to link theory and practice, and there is a strong belief in transparency where researchers should be reflexive about how theory has been used in the research process (Frost & Shaw, 2015).

During the initial empirical data collection, the PhD project was inspired by phenomenological thinking. More specifically, the project utilised interpretative phenomenological thinking in the exploration of everyday practical knowledge, where the phenomena and its context outlined the interpretative process of understanding the lived experiences of adult-child participants (Benner, 1994). As the PhD project was further developed, including several methods, pragmatism was seen to better frame the overall aim of the PhD project.

4.2 Research design

Guided by the aim, the design of this PhD project was a qualitative sequential multi-method design (Hesse-Biber et al., 2015; Hunter & Brewer, 2015) including an integrative literature review, semi-structured individual interviews, and focus group interviews. Multi-method design is, according to Creswell and Plano Clark (2011) combining multiple types of qualitative or quantitative methods, while mixed-methods design traditionally combines at least one qualitative and one quantitative method. Overall, multi-method designs are particularly suitable when exploring areas that have not yet received much attention (Hesse-Biber et al., 2015). As there has been limited focus on exploring the motivations of caregivers of parents with dementia, and the self-determination theory has not been applied to this context, the outlined multi-method design was seen as appropriate.

The core component when designing the PhD project was qualitative interviews used to gain a deeper understanding into the motivations of caregivers of persons with dementia (Hesse-Biber & Johnson, 2015). After conducting preliminary analyses based on extrinsic and intrinsic motivation, I realised that the data material called for a broader perspective on motivation and chose to re-analyse the data and redesign the PhD project using elements from the SDT. This also included adding a literature review to the design of the PhD project.

According to Morse and Niehaus (2009) it is possible to redesign a research study by adding a supplementary component, in this case an integrative literature review, to gain a deeper understanding of how SDT had been used in a caregiver context. Through the literature review, a broader perspective of motivation (competence, autonomy, relatedness) based on SDT became evident and provided me with nuances to enrich the analysis of the empirical data material.

When redesigning a research study, pacing is essential because it is understood as the mode in which the core and complementary components are synchronised (Morse, 2017; Morse & Niehaus, 2009). The design of the PhD project can thus be defined as a sequentially paced design (Morse & Niehaus, 2009) as the core component (interviews) was completed before the supplementary component (literature review) commenced. As each component was equally weighted, they resulted in separate articles, followed by synthesising the sub-studies in this thesis. Figure 1 provides an overview of the PhD study design.

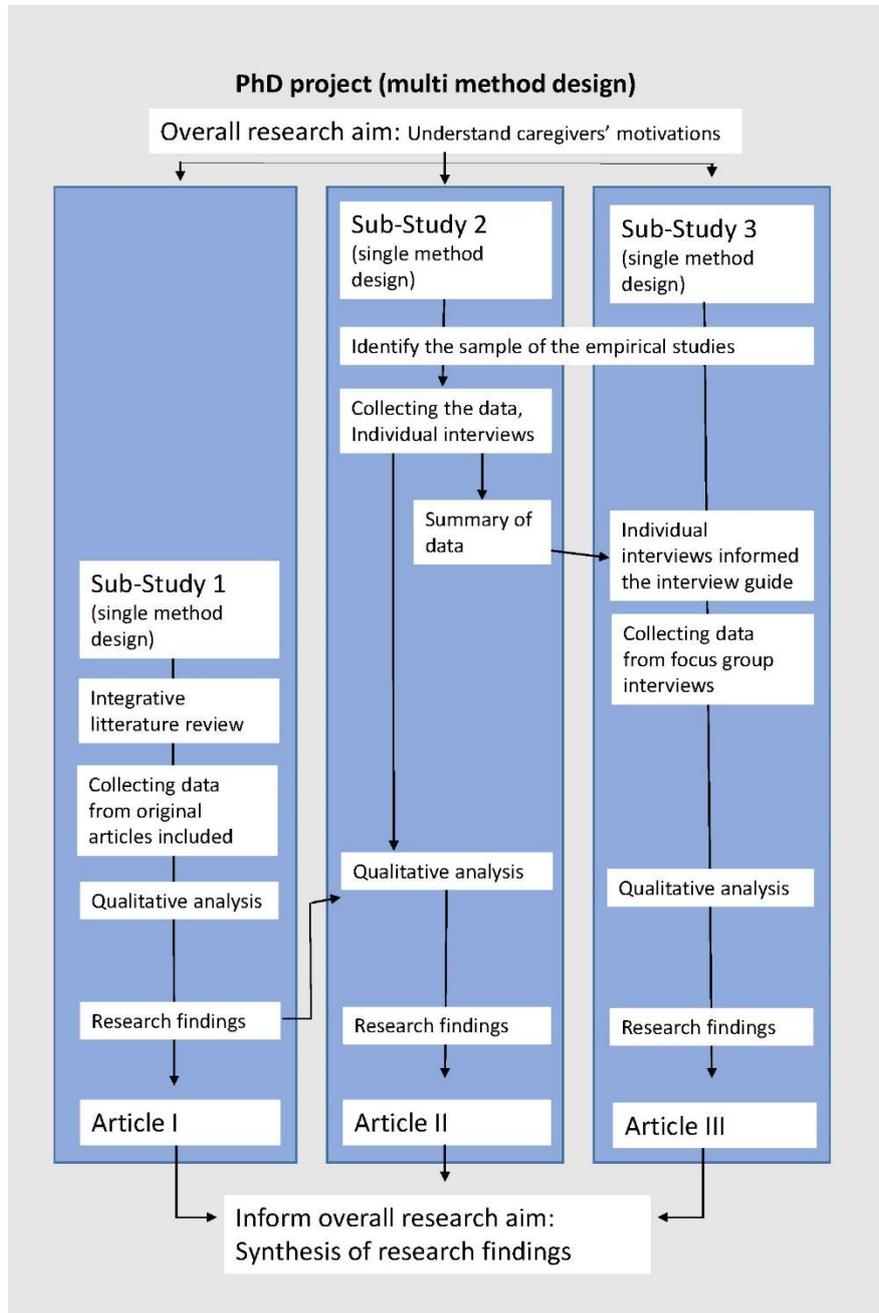


Figure 1 Overview of the PhD multi-method study design inspired by Morse and Niehaus (2009). The timeline of the sub-studies is illustrated by vertical positioning.

4.3 Use of theory

Qualitative research questions are not neutral, but they provide the researcher with a theoretical lens through which data are viewed (Morse, 2015, 2017). Transparency in the use of theory throughout the research process is important, as it influences the findings of the PhD project. Therefore, I have described the use of theory in different steps of the research process.

SDT (Ryan & Deci, 2000, 2017) has influenced the PhD project consistently and in several ways, while relationship-centred care (Nolan et al., 2001; Nolan et al., 2003) played a complementary role toward the end of the PhD project in Sub-Study 3 and in the thesis synthesis. The abstract term motivation was a main component of the phenomena under study, and it was necessary to present a definition and an operationalisation of the phenomenon, leaning on motivational theory. There are many existing motivational theories, and the choice fell on SDT since this has been widely used in research in various health contexts and presents a broad perspective to motivation encompassing several elements (autonomy, competence, relatedness). The theory is relatively new and could therefore add to the dementia caregiver context.

Since the aim of Sub-Study 1 was to gain a deeper understanding of caregivers' motivations from the perspective of SDT, it was selected as an inclusion criterion for the articles included in the literature review. Even though the narrative analysis was data driven, SDT had already automatically influenced the findings, as application of the theory was an inclusion criterion for the sample of articles. In Sub-Study 2, the interview guide was inspired by intrinsic and extrinsic motivation, also elements in SDT. The first steps in the analysis were inductive, reading the transcripts with an open mind, coding, and forming sub-groups close to the data. The last step was deductive using core components from SDT (i.e., competence, autonomy, relatedness) to structure the sub-groups into categories. In Sub-Study 3, SDT was used to define and operationalise the concept of motivation. The analysis of the interviews was done in an inductive way close to the data. The findings of Sub-Study 3 were then discussed in light of relationship-centred care (Nolan et al., 2001; Nolan et al., 2003) framing the motivations of caregivers of persons with dementia in a relational perspective with healthcare professionals interacting with them. Throughout the research

process, I moved between different theoretical perspectives, followed by a move between inductive and deductive approaches (Polit & Beck, 2018).

If the researcher overemphasises theory, this might result in blinding him or her to the contextual aspects of the phenomenon (Hesse-Biber et al., 2015). On the other hand, pre-existing theories can also help identify aspects that would otherwise go unnoticed. Both the research questions and the theory used in the sub-studies guided my attention towards caregivers' motivations throughout the research process.

4.4 Methods

4.4.1 Literature review (Sub-Study 1)

The starting point for conducting the literature review was to explore how SDT has been used in current dementia caregiver research. This was based on the fact that Ryan and Deci (2017) previously referred to only one SDT study in the dementia context (Pierce et al., 2001), including few details on caregiver motivation. In the current test searches, I found no studies combining dementia caregiving and SDT. As demonstrated by previous research, there are similarities regarding caregivers of persons with long-term illnesses, such as dementia, cancer, Parkinson's disease, multiple sclerosis, and stroke (Adelman et al., 2014; Sullivan & Miller, 2015). As a result, the literature search was extended to apply to long-term illnesses in general. A preliminary search revealed a limited research area that consisted of studies using diverse methodologies. An integrative literature review was then suitable, as the topic had not yet been extensively researched (Doolen, 2017; Whittemore et al., 2014). The integrative review method by Whittemore and Knafl (2005) was considered appropriate, as the research topic could be investigated using theoretical, quantitative, or qualitative methods.

Traditionally, integrative reviews have been descriptive, lacking a theoretical perspective to focus the review within a broad sampling frame (Whittemore & Knafl, 2005). SDT was therefore chosen as a theoretical perspective and formed one of the inclusion criteria. The review method was used to understand

caregivers' motivations and provide a more solid evidence base with the potential for contributing to development of the SDT.

Even though the integrative literature review consisted of qualitative and quantitative original articles, the analysis and presentation of findings should be considered qualitative. This is due to the exploratory research question of understanding informal caregivers' motivations. Written narratives of the findings in each article were used as units of analysis. This is in line with Gough et al. (2012) differentiating review methods as either aggregative or configurative. Reviews that are exploratory and seek to understand the variation and complexity of a phenomenon are based on a configuring logic with results presented as narrative text. Therefore, Sub-Study 1 is embedded in a qualitative research approach along with Sub-Studies 2 and 3, based on interviews.

4.4.2 Individual interviews (Sub-Study 2)

Individual retrospective face-to-face semi-structured interviews were used in Sub-Study 2 to explore the caregivers' motivations at the time that their parents with dementia lived at home and thereby their motivational drivers to serve in the caregiver role. This method was chosen as individual, semi-structured interviews fit the purpose of gaining a deeper understanding and revealing the meaning of the participants' actions and thoughts (Polit & Beck, 2018). The method also holds the potential to facilitate trust between participant and interviewer, which was warranted in this PhD project, so that data on participants' feelings and experiences could be collected (Kvale & Brinkmann, 2009).

Seeking the caregivers' personal experiences could produce memories leading to emotional reactions. The potential for revealing issues of a sensitive nature made individual interviews the preferred method over focus groups (Kvale & Brinkmann, 2009). Observations would also present challenges. It would be difficult to gain insight into the participants' experiences, thoughts, and descriptions (Robson, 2002) of their motivations as caregivers based on observed actions.

4.4.3 Focus group interviews (Sub-Study 3)

Focus group interviews were used in Sub-Study 3 to describe and explore adult children's experiences with the community healthcare services for their home-dwelling parents with dementia. Their experiences are embedded in and formed by their social contexts (Creswell & Creswell, 2018) and focus group interviews were appropriate to discuss experiences that all participants have in common (i.e., community healthcare services) and that occur in a social context (Krueger & Casey, 2015). The interaction among the participants provided new insight, opened up new perspectives, and identified aspects of motivation. This was reinforced when they exchanged experiences, complemented each other, but also by disagreeing and bringing different viewpoints to the table (Morgan, 1997). The focus for the group interviews was not considered sensitive for the participants, but suitable for exchange of experiences and engaged discussions.

Focus group interviews were chosen because the collective interaction and dynamics among participants might have brought forth reflections and ideas that would not have been captured through individual interviews (Kvale & Brinkmann, 2009).

4.4.4 Multi-method approach (Thesis)

The goal of using multiple methods, various data sources, and two theoretical approaches was to inform the overall aim of the PhD project from different perspectives (Hesse-Biber et al., 2015). According to current mixed-methods literature, a supplementary component cannot stand alone and be published as an independent publication (Morse, 2017). This is assessed differently in a multi-method design, where each sub-study might be published, and a final publication may integrate the different study components (Green, 2015). In this PhD project the three sub-studies resulted in three separate articles, and the thesis serves to integrate and synthesise the sub-studies. Table 2 summarises the multi-method approach with empirical settings, data collection, data material, timing, and analysis of each sub-study.

Table 2 Overview of the three sub-studies in the PhD project

	Sub-Study 1	Sub-Study 2	Sub-Study 3
Empirical setting	Adult caregivers of persons with long-term illness	Adult-child caregivers of home-dwelling parents with dementia	
Data collection methods	Integrative literature review	Individual interviews	Focus group interviews
Participants/material	10 peer reviewed articles	21 caregivers	15 caregivers
Timing of data collection	Dec. 2018	Dec. 2016 – May 2017	May – June 2017
Analysis methods	Narrative analysis	Systematic text condensation	
Timing of finalising analysis and writing the articles*	Jan. - April 2019	April – Nov 2019	Nov. 2019 – July 2020
Articles	Article I	Article II	Article III

*The analysis processes of data from Sub-Studies 2 and 3 started immediately after the interviews but were finalised in the periods prior to writing Articles II and III.

4.5 Data collection Sub-Study 1

The integrative review method outlined by Whittemore and Knafl (2005) guided the literature review process of Sub-Study 1. After defining the research area of caregivers’ motivations, the research question was formulated applying self-determination as a theoretical lens.

4.5.1 Literature search

The literature search in databases used combinations of the following search terms: “caregiver”, “family care”, “next of kin”, “informal care”, and “self-determination theory”. Relevant MeSH and thesaurus terms were applied when

possible. When not possible, the search terms using asterisk (*) or quotation mark were searched for in article title, abstract, and keywords. The search strategy began with the union (“OR”) of terms to capture articles related to the main concept “caregiver”, and then the intersection (“AND”) of the term “self-determination theory” to identify the full range of articles that combined the two main concepts. In databases that allowed limitations, peer-reviewed articles were preferred, and no limitations were placed on publication year or language.

The search strategy was comprehensive, comprising two searches (initial and follow-up). The initial systematic literature search of the bibliographic databases MEDLINE, Scopus, PsychInfo, PsycNET, Cinahl, and Cochrane Library was conducted in May 2018, resulting in 105 titles. An updated and extended follow-up search was performed in December 2018, including the search terms “spouse”, “filial”, and “relatives”, and by adding the EMBASE database. The updated search identified 54 new titles. In sum, literature searches in the multidisciplinary databases Scopus and EMBASE, using the term *caregiv** in combination with self-determination theory, gave the most relevant records.

4.5.2 Eligibility criteria

After defining the research question and establishing the search terms and applicable databases, eligibility criteria (Whittemore & Knafl, 2005) were decided, guiding the process of selecting articles for further analysis. The a priori inclusion and exclusion criteria are displayed in Table 3.

Table 3 List of paired inclusion and exclusion criteria for the literature review

Inclusion	Exclusion
Health context	Not health context
Adult informal caregivers	Children under 18 years as caregivers
Patient/person cared for must have a long-term illness	Caregiving in an acute illness setting
Informal caregiver perspective	Formal/professional caregiver perspective only
Reporting informal caregiver outcome	Studies reporting patient outcomes only
Specified use of self-determination theory	Not specified use of self-determination theory
Peer-reviewed articles	Books, book chapters, protocols, reviews, study protocols, conference, and poster abstracts

4.5.3 Study selection

Eligible studies were identified from database searches, a manual search of reference lists, and an additional record (Pierce et al., 2001) identified through Ryan and Deci (2017) as an expert source. A total of 159 titles were identified. After removal of duplicate items (N=100), none of the remaining records (N=59) were excluded after scanning the titles. Guided by the eligibility criteria, the remaining abstracts were independently evaluated by three researchers. The reasons for excluding certain abstracts were mostly because those studies reported only patients' outcomes (N=19) and studies not reporting from a health context (N=15). Of the reviewed abstracts, 14 articles were selected for full-text reading. After screening the full-text records identified in the database searches, eight articles were included in the review. Manual searches were performed in the reference lists of included studies, and two additional studies were included, adding a total of 10 articles in the review. The PRISMA diagram (Moher et al., 2009) was utilised for the review process (see Figure 2).

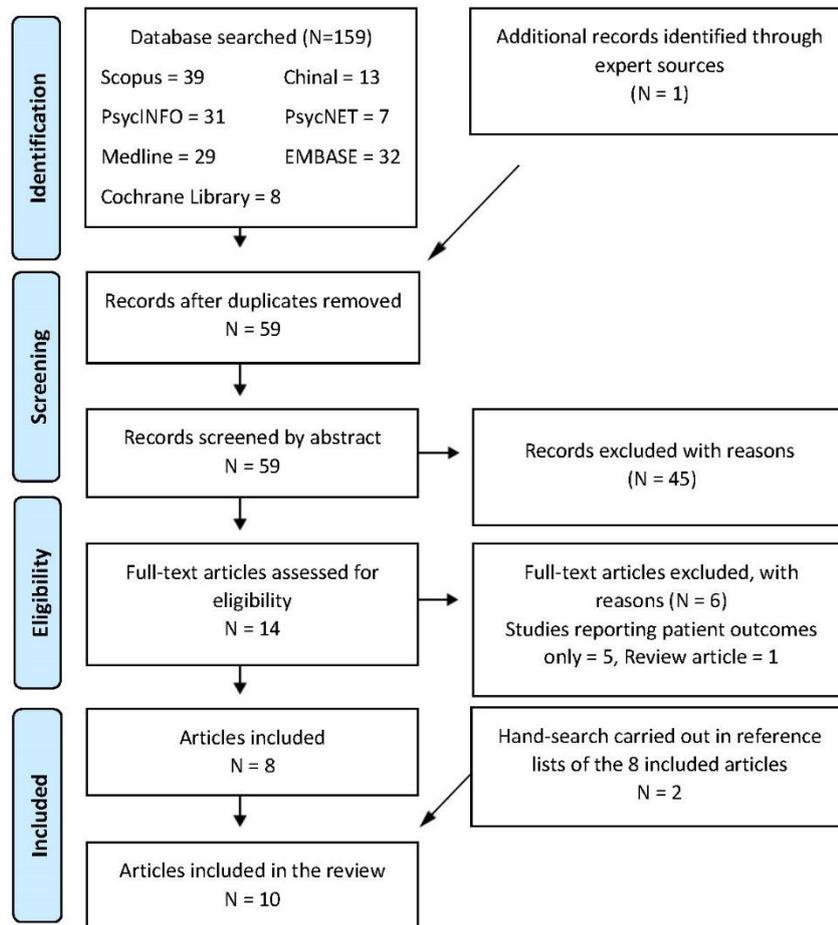


Figure 2 The PRISMA diagram (Moher et al., 2009) illustrating the workflow of identification, screening, eligibility, and inclusion of studies in the literature review (Dombestein et al., 2019).

4.5.4 Data evaluation

To enhance the rigour of an integrative review, it is crucial to conduct a data evaluation to assess the quality of the included studies (Whittemore & Knaf, 2005). The Mixed Methods Appraisal Tool (MMAT), version 2018 (Hong et al., 2018), was used to evaluate the methodological quality of the included

articles. The MMAT is designed for methodological quality appraisal when performing complex systematic reviews and assesses the quality of qualitative, quantitative, and/or mixed-methods studies (Pluye et al., 2009). Data evaluation was performed by three researchers who independently rated the articles, followed by a discussion to achieve consensus. The quality of the included studies was above moderate, with MMAT remarks on four of them. No articles were excluded based on the quality assessment.

4.6 Data collection Sub-Studies 2 and 3

Data collection in Sub-Studies 2 and 3 included information on adult-child caregivers' motivations for caring for home-dwelling mothers or fathers with dementia and their experiences with the community healthcare services the parents received.

4.6.1 Setting and sampling strategy

The data collection was carried out in different parts of a large municipality in Western Norway containing urban areas and rural districts. The municipality offered healthcare services to persons with dementia, including general practitioners, homecare, day-care centres, and nursing homes. Information and support to caregivers was partially included in these services.

Purposive sampling (Polit & Beck, 2018) was used and involved selecting participants who shared particular characteristics and had the potential to provide rich, relevant, and diverse data pertinent to the overall research aim of gaining a deeper understanding of adult-child caregivers' motivations. A total of 21 adult-child caregivers were continuously recruited and participated in individual interviews in Sub-Study 2. Of those, 15 agreed to continue participating in the project by taking part in the focus group interviews in Sub-Study 3.

4.6.2 Sample characteristics

The participants in Sub-Studies 2 and 3 were daughters and sons. Biological, adoptive and foster children were given equal status. At the time of interest when parents with dementia were living at home, none of the participants had

Methodology

been sharing a household with them. In addition to being informal caregivers, all participants were between 40 and 69 years old and had paying jobs.

Sample in Sub-Study 2

In Sub-Study 2 the sample consisted of 21 participants and 12 of them had parents living alone, while for nine of them, the parent with dementia was living with her or his spouse. Table 4 shows the variation in caregivers' ages, genders, education, job statuses, and the parents' household statuses.

Table 4 Characteristics of caregiver participants (N=21) in Sub-Study 2

Characteristics		N=21
Gender, N (%):	Female	12 (57)
	Male	9 (43)
Age group, years, N (%):	40 – 49	5 (24)
	50 – 59	11 (52)
	60 – 69	5 (24)
Education, N (%):	Public school	2 (10)
	High school	5 (24)
	University	14 (66)
Job status, N (%):	Full-time	19 (90)
	Part-time	2 (10)
Parents' household statuses, N (%):	Mothers living alone	7 (33)
	Mothers living with spouse	5 (24)
	Fathers living alone	5 (24)
	Fathers living with spouse	4 (19)

Sample in Sub-Study 3

The sample in Sub-Study 3 was a sub-set of the sample in Sub-Study 2, meaning that the participants (N=15) contributed to both the individual interviews and the focus groups. In Sub-Study 3, the sample consisted of 15 participants and eight of them had parents living alone, while seven of them had parents with

dementia living with their spouses. All of the adult children had been in contact with healthcare professionals in their municipalities and had experiences interacting with these professionals related to their parents' healthcare services. Table 5 contains information about the variation in participants' ages, genders, education, job statuses, and the parents' household statuses.

Table 5 Characteristics of caregiver participants (N=15) in Sub-Study 3

Characteristics	N=15	
Gender, N (%):	Female	10 (67)
	Male	5 (33)
Age group, years, N (%):	40 – 49	3 (20)
	50 – 59	8 (53)
	60 – 69	4 (27)
Education, N (%):	Public school	1 (7)
	High school	3 (20)
	University	11(73)
Job status, N (%):	Full-time	13 (87)
	Part-time	2 (13)
Parents' household statuses, N (%):	Mothers living alone	6 (40)
	Mothers living with spouse	5 (33)
	Fathers living alone	2 (13)
	Fathers living with spouse	2 (13)

4.6.3 Participant selection and recruitment

To be included in Sub-Study 2 and 3, a participant had to be over 18 years old and registered as a primary or secondary caregiver of a parent who was diagnosed with dementia and receiving healthcare services in the municipality. In addition, the parent should have moved to a nursing home in the period between 2 and 12 months prior to the interview. The reason for conducting retrospective interviews (Morse, 2011) was that the last home-dwelling period, waiting for a place in the nursing home for the parent, could be especially stressful for both parents and caregivers. Consequently, a caregiver might then

find it difficult to express the positive elements of the caregiver role. Thus, by interviewing a caregiver at least 2 or more months after the parent had moved to a nursing home, the caregiver would have had time to create some distance from the parent's home-dwelling period and be better able to reflect on the situation, add meaning to this experience, and articulate it. The upper limit (12 months) was set so that each participant would be able to recall the caregiver experience.

Recruitment Sub-Study 2

Adult daughters and sons who met the inclusion criteria were identified and recruited by a project nurse who worked as a coordinator in the municipality. She was instructed to recruit both male and female caregivers. She telephoned 31 people. Five declined to participate, claiming that they did not have the time, energy, or capacity to do so. I then sent a letter with information (see Appendix A) about the PhD project to the 26 participants who had agreed to be contacted by the researcher. After one week, I called them and asked if they were still interested in participating in individual interviews. Interview appointments were made with the 21 people who agreed to participate. In sum, 10 people declined to participate in the study, and 21 people consented to be interviewed.

The recruitment process for Sub-Study 2 lasted for 5 months, and the interviews started as soon as the first participants were recruited. Recruitment thus took place in parallel with the interviews. In interview numbers 20 and 21, no new relevant information was generated, and the interviews confirmed the revelations of previous participants. Therefore, the number of participants was discussed within the research group (Polit & Beck, 2018). It was agreed that continued interviews were unlikely to provide any further information. This was also in accordance with the Malterud et al. (2016) model of information power and sample size in qualitative studies.

Recruitment Sub-Study 3

When the participants from Sub-Study 2 received the letter with information about the PhD project (Appendix A), it also contained information about the focus group interviews in Sub-Study 3. The participants could choose whether they would take part in only the individual interviews or in both Sub-Studies 2 and 3. Toward the end of each individual interview, the participants and I talked

about important relevant themes to discuss in the focus groups, and the participants were asked if they wanted to proceed to Sub-Study 3. In this way, I functioned as a gatekeeper and had to be conscious that I did not manipulate, pressure, or discourage the participants to continue participation in the project. According to Malterud (2012a), gatekeepers benefit from having established trust among the participants, and I believe that the participants in Sub-Study 2 felt free to decide whether they wanted to take part in Sub-Study 3. Of the 21 participants in Sub-Study 2, 15 participants volunteered to take part in the focus group interviews in Sub-Study 3. Five declined to participate and said they did not have the time or were not comfortable talking about the topic in a group of “strangers”.

After conducting three focus group interviews with the 15 participants, the research group discussed the number of participants. Following the Malterud et al. (2016) pragmatic model for appraisal of sample size in qualitative interview studies, the sample size was determined to have acceptable information power, as the focus groups had provided rich data and in-depth knowledge based on their experiences. Hence, the number of interviews and participants was considered to be sufficient.

4.6.4 Development and use of interview guides

Two semi-structured interview guides were sequentially developed and reviewed by the research group, and the interview guide used in Sub-Study 2 was pilot tested.

Interview guide for individual interviews

For Sub-Study 2 a semi-structured interview guide with open-ended questions (Kvale & Brinkmann, 2009; Polit & Beck, 2018) was informed by motivational theory and discussions within the research group. The purpose was to explore a caregiver’s motivation at an individual level. Therefore, aspects elaborating on intrinsic and extrinsic motivation informed the interview guide, as it was necessary to operationalise motivation. The interview guide was tested on a daughter who met the inclusion criteria. She found it hard to answer the question about why she had put so much effort into helping her father. She recommended breaking the question into smaller themes to encourage

participants to start talking about their motivations. She requested more precise questions about her relationship with her father before and after the dementia diagnosis, her knowledge about dementia and of her father's symptoms, and the importance of being able to decide for herself what she should and should not do as a caregiver. Her feedback led to a more detailed and expanded interview guide (see Appendix B). In all subsequent interviews in Sub-Study 2, the same revised interview guide was used. However, the pilot interview guide was sufficiently like the final interviews contributed with relevant and rich data. The interview was therefore included in the analysis.

Interview guide for focus group interviews

Toward the end of each individual interview in Sub-Study 2, participants were asked to describe important support structures that influenced their motivations to continue caring for their parents. Their responses were summarised and formed the basis for the contents of the interview guide for Sub-Study 3 to ensure relevant discussions in the focus group. A semi-structured interview guide (Krueger & Casey, 2015; Malterud, 2012a) with open-ended questions was then developed with the following three main themes: 1) experiences with caregiver support and parents' healthcare services, 2) acknowledgement of adult children's efforts as caregivers, and 3) prioritising support to sustain caregivers' motivations (see Appendix C). All focus group interviews used the same interview guide.

4.6.5 Conducting the interviews

Before conducting the interviews, all participants were informed that I was a PhD student writing my thesis on the topic of caregiver motivation. They were also informed that I am an experienced nurse trained in interviewing and consulting older patients and their caregivers.

Individual interviews

The data was obtained from individual face-to-face semi-structured interviews (Kvale & Brinkmann, 2009; Polit & Beck, 2018) conducted by me in 2017. The interviews took place at times and places that were convenient for the participants, such as their workplaces, their homes, or a meeting room at the

university. All participants were interviewed once, and each interview lasted from about one to two hours (median 71 min, range 56 to 107 min). In each interview session, only the participant and the interviewer were present.

Each participant's subjective narrative was essential (Kvale & Brinkmann, 2009), and in that respect, the interviews started by encouraging the participant to talk about his or her experience in the caregiver role when their parent with dementia lived at home. Most of the participants had never been asked about this and were therefore happy to share their caregiver stories in great detail. In some interviews, I had to be aware of the conversation not turning into a therapeutic interview. For example, if the participant started to cry, I asked him or her whether they wanted to take a break or return to the current question later. I was also cautious about giving advice or guidance to participants who made the requests. Instead, I encouraged them to contact their parents' nursing homes for information. After the interviews, some participants said that it felt good to tell their stories. In some instances, I could sense this and therefore did not stop the participants even though they talked about issues that were perhaps outside the main scope of their interviews. Their stories were typically centred on practical issues, psychological stresses, and lack of support and/or respite services in their everyday care for their parents with dementia. By listening to their stories, I tried to follow up with questions from the semi-structured interview guide whenever appropriate (Kvale & Brinkmann, 2009). In this way, a trusting atmosphere was established in which the participants were able to share their experiences and reflect on the influence on their motivations.

By telling their caregiver stories, the participants shared examples and reflected upon several of the questions in the interview guide, making it unnecessary to ask all interview guide questions. Still, some topics were more difficult for the participants to elaborate on, particularly the question "What made you help your mother/father while she/he lived at home?" The follow-up questions developed to make the topic more specific were then useful (Kvale & Brinkmann, 2009). The semi-structured interview guide also allowed me to spontaneously formulate follow-up questions. This flexibility helped in validating the information from the participants if I was uncertain about the meaning of their responses, and also allowed for elaboration of specific issues.

An issue when conducting retrospective interviews was that some participants could switch from the past to the present time and talk about the parent living in the nursing home. Therefore, there was a risk of obtaining irrelevant information. This was handled in the interview situation by asking the participants to specifically recall examples from the home-dwelling period.

In participants' caregiver stories, information about their parents with dementia was naturally integrated. This raised an ethical issue, as their parents had not consented to the data collection. Therefore, I had to remind the participants to keep the focus on themselves as caregivers and their experiences. Still, it was inevitable that some information on the health status of their parents was included, and therefore I anonymised it when transcribing the material.

The data material was digitally audio-recorded and later transcribed, mainly by me. A professional service was hired to transcribe seven interviews. The transcripts were not returned to participants for comments, as their spontaneous descriptions were considered essential for the aim of the study.

Focus group interviews

Sub-study 3 employed focus group interviews to describe the caregivers' experiences with healthcare services for their parents with dementia, with the aim of gaining a deeper understanding through group interactions and discussions (Morgan, 1997). Participants decided which focus group interview they wanted to attend depending on what time would best suit them. According to their time schedules, five participants were allocated to each of three focus groups. Group 1 consisted of two daughters and three sons, in Group 2, five daughters participated, and Group 3 consisted of three daughters and two sons.

The data collection was conducted over a 2 month period in 2017, and the focus group interviews took place in a meeting room at the university. Each interview was conducted in one session and lasted from 92 to 106 minutes. I moderated all three focus groups, and my co-supervisor acted as co-moderator in two of the groups, while a research fellow co-moderated the third group. I facilitated the group discussions while co-moderators asked for clarifications and took notes on group dynamics, interactions, and nonverbal communication (Krueger & Casey, 2015; Malterud, 2012a). After each interview, the moderators

reviewed the discussion, the atmosphere in the group, and evaluated the notes. The notes were not part of the systematic text condensation analysis but were used to reflect on my interview skills and as project documentation. All three focus group interviews started with the participants seeming a bit nervous, only having met the moderator once before. After a few “warm-ups” questions, the participants discussed their experiences and expressed their opinions. The participants were encouraged to comment on each other’s experiences (Krueger & Casey, 2015). Participants in all groups were engaged, shared, and discussed both positive and negative experiences with their parents’ healthcare services. This reflected that a trusting atmosphere was established in the groups.

To reduce the risk of predetermined responses and increase the chance of an open group discussion, participants were not sent the interview guide before their interviews. The focus group interviews were digitally audio recorded and subsequently transcribed verbatim by me. The transcripts were not returned to participants for comments, as their intuitive experiences were essential to explore the aim of the study.

4.7 Data analysis

Leaning on the pragmatic philosophy of science (Cherryholmes, 1992), different types of analyses were used in the PhD project. Systematic text condensation as outlined by Malterud (2012b) was applied in Sub-Studies 2 and 3. Narrative analysis inspired by Whittemore and Knafl (2005) was used in Sub-Study 1 and in synthesising the findings across the sub-studies in the thesis synopsis.

4.7.1 Narrative analysis

The integrative literature review in Sub-Study 1 was conducted using a narrative analysis, according to Whittemore and Knafl (2005). The data analysis comprised four stages, including 1) data reduction, 2) data display, 3) data comparison, and 4) conclusion drawing and verification. The synthesis of evidence was performed as a narrative analysis, allowing for a movement from descriptions of patterns and relationships to higher levels of abstraction from the particular to the general (Whittemore et al., 2014; Whittemore & Knafl, 2005).

The data analysis was carried out during two analysis workshops in which three researchers participated. In the first stage, relevant data from each article was extracted by writing narratives and compiling them into a matrix (data reduction). In the second stage, extracted data was converted into a display to visualise patterns and relationships among the primary sources (data display). The tabulation of quantitative and qualitative findings within a single matrix supported the synthesis of both statistical and narrative data, facilitating a systematic comparison of the primary data sources. The third stage involved coding for each of the included articles. This was followed by a review by my two fellow researchers to identify new themes or data suggesting variance or dissonance within or between the articles (data comparison). In the fourth stage, an interpretive approach was used to describe how caregivers' motivations could be understood from an SDT perspective. The data synthesis was then verified using the findings from the included articles for confirmability and accuracy (conclusion drawing and verification).

4.7.2 Systematic text condensation

The data material from Sub-Studies 2 and 3 was organised with NVivo 12 (QSR International, 2019), including 402 written pages of transcribed data material in Sub-Study 2 and 79 pages in Sub-Study 3. NVivo was used to systematise and identify meaning units related to each of the code groups. Three researchers participated in the analyses of Sub-Studies 2 and 3.

Systematic text condensation, a four-step method for thematic analysis of qualitative data (Malterud, 2012a, 2012b), was adopted to explore the motivation across caregivers. A single designated participant might have illustrated a typical case but not demonstrated variations in caregivers' motivations. Analysis of the data consisted of the following four steps: 1) reading all the data material to obtain an overall impression, identifying preliminary themes; 2) identifying meaning units representing different aspects of themes and describing codes and code groups; 3) condensing the contents into subgroups; and 4) summarising the contents of each subgroup, structuring it into result categories.

Analysis Sub-Study 2

One of the research team members and I read all transcribed interviews, while the third researcher read one-third of them. The three researchers independently listed emerging themes and, through discussions, agreed on preliminary themes. I then identified meaning units and quotes reflecting each theme, followed by descriptions of code groups. Descriptions reflecting each of the code groups were discussed among the research team before reorganising, renaming, and eliminating code groups. I then condensed the contents into subgroups before a new analysis workshop was used to reach consensus on seven subgroups. The first three analysis steps involved an open data-driven approach where coding, condensates, and subgroups were developed to represent the essence of the participants' experiences and reflections (Malterud, 2012b).

In the fourth step, we used the theoretical constructs of SDT to structure subgroups into categories and find meaningful headings for the categories. The seven sub-groups were sorted into three categories representing the motivational drivers of the participants, including competence, autonomy, and relatedness. Consensus was reached after several analysis workshops. The deductive approach used in the fourth step may risk the exclusion of relevant data (Overgaard & Bovin, 2014). This has been handled by summarising and reporting findings, which was not categorised according to the SDT.

Analysis Sub-Study 3

In the same way as in Sub-Study 2, three researchers constituted the research team in analysing the data material in Sub-Study 3 following Malterud's (2012a, 2012b) systematic text condensation. In contrast to Sub-Study 2, all the steps of the analysis were inductive. SDT was only used as a background for defining and operationalising motivation in the interview guide. All three researchers independently read the focus group transcripts. Otherwise, the first three steps of analysis were similar to the process in Sub-Study 2, as described above. In the fourth step, the contents of the subgroup condensates were synthesised into three result categories describing caregivers' experiences with healthcare services for their parents with dementia and how this influenced their motivations. Consensus on the three categories was achieved after several

analysis workshops, where all three researchers participated, summarising the contents of each subgroup and structuring it into result categories.

4.7.3 Synthesis of findings across sub-studies

To inform the overall aim of the PhD project, synthesis of findings across the three sub-studies is warranted (Morse & Niehaus, 2009). According to Malterud (2019), the purpose of synthesising is to reveal new knowledge compared to individual findings from the sub-studies.

Motivation in the caregiver role was studied using three different methods (literature review, individual interviews, and focus groups). The use of different methods calls for individual analysis of each study followed by a synthesis of findings (Hesse-Biber & Johnson, 2015; Morse & Niehaus, 2009). In the PhD project the three analyses and their findings are presented in Articles I-III. Whittemore and Knafl's (2005) method of narrative analysis is suitable when synthesising findings from studies using different research methods to fully understand a research topic (Doolen, 2017). This analysis method was also used in the literature review in Sub-Study 1. The analysis units are the three written articles in the PhD project. In Article I, findings are presented as themes in line with Whittemore and Knafl (2005), while Articles II and III findings are presented as categories according to Malterud's systematic text condensation. As both analysis methods are thematic analyses, they can still be combined in synthesis of research literature (Malterud, 2012b; Vaismoradi et al., 2013).

The narrative data synthesis comprised four stages (Whittemore & Knafl, 2005). First, relevant data from the findings in each of the three articles was extracted and written in the form of narratives, and then the text was coded (data reduction). In the second stage, extracted data from the individual articles was converted into one display to visualise patterns and served as a starting point for interpretation (data display). The third stage involved examining the data display to identify new patterns, themes, or data suggesting variance or dissonance between the articles (data comparison). In the fourth stage, an interpretive approach was used to describe adult children's motivations to remain in the caregiver role when parents with dementia live at home. The data synthesis was then verified by the findings from the three articles for confirmability and accuracy (conclusion drawing and verification). The

interpretive approach in the fourth stage was furthermore complemented with Malterud's qualitative meta-synthesis (2019), providing more detailed descriptions of synthesising.

All three articles were given equal weight in the synthesis, independent of the number of participants and amount of data (Carter et al., 2014). The integration and synthesising of findings from the three sub-studies provided a deeper understanding of caregiver motivation than each study alone (Malterud, 2019). The synthesis of findings is presented in Chapter 5.4 and discussed in Chapter 6.

4.8 Research quality

Several measures were taken throughout the PhD project to ensure the quality of the research. In qualitative research, trustworthiness is used to assess quality and refers to the extent to which one can establish trust in the results and consider them relevant to other settings (Polit & Beck, 2018). Malterud (2002) proposed reflexivity as an overall criterion for the appraisal of quality.

4.8.1 Trustworthiness

Lincoln and Guba (1985, 2003) have developed a widely used framework for evaluating trustworthiness in terms of the following five criteria: credibility, dependability, confirmability, transferability, and authenticity. The framework is outlined in Polit and Beck (2018, p. 297) and the five criteria are used to discuss the strategies utilised to enhance trustworthiness in the PhD project.

Credibility

Credibility refers to confidence in the data, and it involves two aspects, including conducting the study (e.g., selection of setting, participants, data collection approaches) and describing the results so that they are regarded as credible by external readers (Lincoln & Guba, 1985). A predefined project plan and a description of possible deviations with justifications will help to strengthen the credibility. I have tried to provide accurate descriptions of the research process so the reader can take this into consideration when interpreting the findings. In Sub-Study 1, this was complied with using Whittemore and

Knafl's (2005) method for integrative literature reviews. In Sub-Studies 2 and 3, the qualitative approach permitted a number of options. So, to enhance credibility, I used the consolidated criteria for reporting qualitative research (COREQ), a 32-item checklist (Tong et al., 2007) when reporting the two studies in the articles.

The credibility of the PhD project was strengthened by including samples with sufficient information power (Malterud et al., 2016). Sample adequacy, data quality, and the variability of relevant participants were valued as more important than the number of participants. The sample size of 21 participants in Sub-Study 2 with specific experiences related to caregiving for parents with dementia ensured variation and rich data material. The interview guide formed the basis for a specific focus on caregiver motivation. Open-ended questions were asked, and participants were given the opportunity to respond based on their own experiences and using their own words. As the participants were informed about confidentiality, both written and orally prior to the interviews, this presumably contributed to trust and honest responses. This was particularly important in the focus group setting, where a trusting atmosphere contributed to more easily exchanging conflicting and varying views among participants. An open and direct dialogue also indicated sufficient information power in the sample (Malterud et al., 2016).

During the individual interviews, adequate information power was achieved after 21 participants had been interviewed. During the focus group interviews in Sub-Study 3, each interview provided new information as the discussions elaborated on relevant nuances of the study aim. I could have conducted additional group interviews to obtain more information about caregivers' motivations, but also realised that the participants' experiences with their parents' healthcare services was an inexhaustible topic. Therefore, the research team considered the data material sufficient, as three focus groups had given valuable information on the topics in the interview guide.

I have attempted to remain aware of and reflective about my own role as a researcher (see Chapter 4.8.2) to enhance the credibility of the findings and interpretations of the PhD project. Credibility also deals with the analytical process, the selection of meaning units, and how well the categories cover the data (Polit & Beck, 2018). I was a member of a research team in all sub-studies

that contributed to the analysis process through discussions and agreement on how data should be analysed. Such researcher triangulation increases credibility, not just during analysis but throughout the entire research process (Polit & Beck, 2018). The PhD project has a multi-method design using different methods and investigating different caregiver groups. Furthermore, using different perspectives, methods, and researcher triangulation has contributed to the credibility of the PhD project.

Dependability

Dependability in qualitative research refers to the stability of data over time and shifting conditions (Lincoln & Guba, 1985). An example from Sub-Study 3 was the composition of participants in the focus groups representing different conditions, interests, settings, and atmospheres influencing the data collection. A stabilising aspect was that the same interview guide was used in all three focus groups. The individual interviews in Sub-Study 2 took place under different physical conditions, locations, and times, where the interview guide contributed to stability. To ensure solidity in the material, I constantly checked that all topics in the interview guides were covered during all interviews.

Consistency during the research process is a central aspect of dependability (Lincoln & Guba, 1985). In the PhD project I have arranged for consistency by conducting all parts of the project myself and by being directly involved in all phases. This consistency provided stability and continuity in the project. This also made it possible for me to get a clear overview of all phases of the project and to provide detailed descriptions of the research process.

According to Lincoln and Guba (1985), dependability also means whether the study can be replicated under similar conditions by other researchers. This is possible for Sub-Study 1, as the literature review method (Whittemore & Knafl, 2005) provided a stringent approach to the study, represented by its rigorous and systematic review procedure. Even though comprehensive descriptions of the research process are provided in Sub-Studies 2 and 3, trying to duplicate this would probably be possible only to a certain extent, as is often the case for qualitative empirical studies. Still, it is valuable and necessary to describe the entire research process in as much detail as possible, as this illustrates how the

findings depend on the planning and accomplishment of the studies included in the PhD project (Polit & Beck, 2018).

Confirmability

Confirmability refers to objectivity to the extent that it is the participants' and not the researcher's opinion that is documented through the research (Lincoln & Guba, 1985). The major technique for establishing confirmability is an inquiry audit (Polit & Beck, 2018). In the PhD project, this involved the creation of a project journal where I gathered relevant literature, methodological and theoretical orientations, field notes, process notes, reflection notes, and summaries. During analysis in all three sub-studies, I also collected analysis records with tables and data reduction matrixes. If findings can be traced back to data, it can contribute to establishing confirmability. Using NVivo (QSR International, 2019) for management of the data material made it possible to easily trace the process from subgroups to codes to the original text in the transcripts.

During the interviews, I used a technique (Kvale & Brinkmann, 2009) where I summarised the participants' answers, asking them to confirm, disconfirm, or provide a further explanation. This contributes to confirmability in the interview setting, as misunderstandings are prevented (Polit & Beck, 2018). Initially, a workshop with the participants was planned to present the findings from a preliminary analysis in Sub-Study 2. It would have been a strength to test the findings in an analytical stage to confirm them (Lincoln & Guba, 1985). Due to practical constraints and time issues, this was not feasible.

Objective research findings are a central aspect of confirmability, and a criterion is that several researchers agree on the findings (Polit & Beck, 2018). Measures taken in Sub-Study 1 to increase confirmability were that the literature searches were done under the supervision of a specialised librarian. All researchers on the team participated in the article selection, in writing narratives that formed the basis for analysis, and in workshops to reach a consensus on themes representing the findings. In Sub-Studies 2 and 3, all authors participated in several workshops and negotiated preliminary themes, code groups, and categories. This process is referred to as "peer review" or "peer debriefing" by Polit and Beck (2018), which is understood to involve

sessions with peers of the researcher to review and explore various aspects of a qualitative study to strengthen confirmability. As a member of different research groups and environments, I have had presentations and received feedback on my research ideas, empirical interpretation, and theoretical orientation. This feedback contributed with critical input assuring me not to seek confirmation of my preunderstandings.

Transferability

I have attempted to remain aware of and reflective of the potential the qualitative findings have for being applicable in other settings, contexts, or groups (Lincoln & Guba, 1985). It is the researcher's responsibility to report the study in a way that the reader can evaluate for themselves the applicability of the data and findings (Polit & Beck, 2018). To promote transferable findings in Sub-Studies 2 and 3, participants were recruited from a large municipality containing urban areas and rural districts. A purposeful sampling strategy provided a variety in age and gender when recruiting participants, ensuring rich and detailed descriptions. Trying to provide the readers with detailed descriptions of findings using rich quotations was another measure taken to enable them to reach their own conclusions as to whether transferability of findings can be considered possible.

The descriptions of the community healthcare services in Sub-Studies 2 and 3 are context-specific for the current municipality. Since healthcare services in Norway strive to offer equal services, one might assume that findings could be transferred to other municipalities. Transferability to contexts with diagnoses other than dementia or relations other than those between adult-child caregivers and their parents could also be considered relevant. The transferability must be tested in practice and through new research within these other contexts (Polit & Beck, 2018). Motivation in the caregiver role is quite universal, and the findings address several issues that are also present in international literature. The ways of understanding and supporting the motivation of caregivers of persons with dementia are relevant for the caregivers, themselves, healthcare professionals, and decision-makers. The literature review in Sub-Study 1 provided accumulated knowledge transferable beyond the individual articles included.

Authenticity

Authenticity refers to how researchers show a range of different realities while communicating in a way that allows the reader to better understand the portrayed experiences and their contexts (Denzin & Lincoln, 2003). The findings from Sub-Studies 2 and 3 are presented with quotations from a variety of participants, giving the reader thick descriptions mirroring the participants' experiences. This gives the reader an opportunity to evaluate the extent to which the findings reflect authenticity.

As I used audio recording in all interviews and transcribed the digital files verbatim, this contributed to the authenticity of the data material (Polit & Beck, 2018). I made accurate transcriptions of participants' own words, phrases, and expressions and also noted their non-verbal communication. This made it easier to present quotes that reflected participants' experiences. Another measure was the choice of not displaying the interview guides to the participants prior to interviews, resulting in spontaneous reflections. If participants are allowed to prepare, read up on the topic, or plan a tactic, it can influence data so that authenticity is weakened (Denzin & Lincoln, 2003).

Furthermore, I have been conscious of using quotes from as many participants as possible when presenting the findings. I also chose quotes close to each participant's storey to show respect and increase authenticity.

4.8.2 Reflexivity

In all steps of the research process, reflecting critically on my own role as a researcher is an important criterion for evaluating quality in the PhD project. This is what Malterud (2002) and Denzin and Lincoln (2003) call reflexivity, implying a self-conscious account of the production of knowledge. It is therefore valuable and essential to report, as best as possible, how my position, background, preunderstanding, preconceptions, standpoints, and values may have influenced the research process (Polit & Beck, 2018).

My position refers to my background and experience relative to the research participants or the research context (Malterud, 2002). For several years, I had been working closely with persons with dementia and their caregivers. In 1998, I started working as a district nurse in community homecare services, and in

2004, I was employed as a coordinator at a community health and social office. As a coordinator, I saw the importance of interdisciplinary approaches to provide the best possible healthcare services to patients and their caregivers. My clinical experience has given me a deeper understanding of the empirical context in which the motivation of caregivers of persons with dementia is studied. This position was considered a strength, as profound understanding of the context can be an advantage in connecting the theoretical and empirical parts of the study (Polit & Beck, 2018). On the other hand, being familiar with the context might “blind” me as a researcher, making it difficult to explore new issues while seeking to confirm my preunderstanding.

My academic background is relatively new as I finished my master’s degree in 2014 within health sciences with a specialisation in ageing and dementia. Here, my understanding of the health concept was broadened, incorporating knowledge from other disciplines, such as social sciences, occupational therapy, public health, and psychology. This multi-disciplinary knowledge inspired the selection of theoretical perspectives in the PhD project. Throughout the master’s programme, I developed a special interest in the situation for caregivers of persons with dementia. This was based on a combination of the theoretical knowledge achieved through the programme and my encounters with caregivers as part of my job in the community healthcare services.

My preunderstanding assumed that being a caregiver of a person with dementia was associated with struggle, stress, and burden. I assumed that it would be difficult for them to see the positive sides of caregiving and reflect on their motivation as caregivers. As part of an interdisciplinary research team, I was able to prevent my preunderstanding from “blinding” the findings in the PhD project.

Issues regarding reflexivity should also be raised in relation to focus groups. According to Malterud (2012a), this is especially important when the researcher is involved in all phases of a research project, making it difficult to maintain a critical distance. Sometimes I felt sorry for the participants having experienced challenges in their relationships with their parents and the community healthcare services. As a result, I wanted to acknowledge them for their efforts. This might have challenged the conduct of the interviews in trying to remain neutral. Keeping this critical distance during the interview situation was most

challenging during the focus groups, as I had become familiar with the participants while individually interviewing them. The role of my co-supervisor and a fellow researcher as co-moderators were therefore equally important. They took a meta-position in the group interviews and were especially aware of conditions that I did not notice because I was closer to the participants.

Another measure to increase reflexivity was to pause the complete data analysis of Sub-Studies 2 and 3 until I had finalised Sub-Study 1. This made me gain a distance created by time and adhere to the transcribed material when finalising the analyses. A potential disadvantage is that I could have forgotten the moods and nonverbal communications from the interviews. However, I overcame this possible challenge by utilising detailed notes from the project journal.

4.9 Ethical considerations

Ethical issues were carefully considered throughout the PhD project following the World Medical Association's Declaration of Helsinki (The World Medical Association, 2008).

Since Sub-Study 1 was a literature review of already published scientific articles, we assumed that each of the included articles had handled their ethical concerns securely when conducting their empirical research. Therefore, no ethical approval was sought for Sub-Study 1. Sub-Studies 2 and 3 included caregivers of persons with dementia as participants, seeking knowledge of health aspects, and handling person-sensitive information. Therefore, approval from the Regional Committees for Medical and Health Research Ethics Norway (REC) or an assessment by the Norwegian Centre for Research Data (NSD) was necessary (Fangen, 2015).

Ethical approval

According to the guidelines, REC first conducted a remit assessment of the PhD project and confirmed that a full application was required, including a project plan, interview guides, an information letter, and a consent form (No. 2016/262/REC West). The committee then concluded that the PhD project was not within REC's approval mandate and should be referred to the NSD. Appendix D contains the response from REC. A notification form was

submitted to the NSD for their assessment. The NSD determined that the project complied with the current regulation, and they recommended that the project could begin (No. 48276). Appendix E contains the response from NSD.

Voluntary and informed consent to participate

A project nurse in the municipality exchanged oral information with potential participants. Those who agreed to receive more information received a letter with details about the project stating that participation was voluntary, including a description of how confidentiality and anonymity was ensured (see Appendix A). Most of the participants knew the project nurse from when their parents had moved to nursing homes, as she coordinated the transition process. Since the parent with dementia had already received a long-term place in a nursing home, the adult children no longer had a relationship with the nurse.

I then called the participants who had agreed to receive written information about the project to make appointments for a time and location for their individual interviews. The participants signed and returned a written consent form, in which they indicated whether they consented to participate in Sub-Study 2 or in both Sub-Studies 2 and 3. Some participants had made prior decisions about their participation in both sub-studies, while others requested responses to some questions before making decisions. I provided factual information to answer their questions and to avoid asserting any untoward pressure.

At the start of each individual and focus group interview, information was verbally repeated, and participants were reminded that they could stop the interview or withdraw from the study at any time without stating a reason. They were also informed that the analysed data would be grouped so that no individuals could be identified in any report or publication.

Caregivers as a vulnerable group

The participants were regarded as vulnerable research participants, as caregivers of persons with dementia often experience stress and reduced quality of life due to their roles. The caregiver burden is often largest at the end of the parent's home-dwelling period as the advanced dementia illness progresses and the patient is waiting to be assigned to a nursing home (Chiao et al., 2015; van

Methodology

der Lee et al., 2014; Ydstebø et al., 2020). Therefore, I chose to conduct retrospective interviews in which the parent had moved to a nursing home at least two months prior to the interview so that the caregiver was able to somehow put the demanding period at a distance. The caregiver would then perhaps feel less stressed as the parent was looked after in a nursing home. The participants were also informed that they could contact me if they experienced difficulties after the interview and needed to talk to someone. I was not contacted by any of the participants.

Consideration of third parties

The NSD stated in their response letter (Appendix E) that there is a special need to safeguard the privacy of third parties, meaning the parents with dementia. As participants discussed their caregiving experiences, they revealed information concerning their parents, who had not consented to data collection. To protect such sensitive information, the transcribed material was anonymised with regard to parent identification.

5 Findings

This chapter presents the main findings from Sub-Studies 1-3 and relates them to each of the studies' objectives and research questions. A synthesis of findings across the three sub-studies is then presented.

5.1 A literature review of caregivers' motivations

Dombestein, H., Norheim, A. & Lunde Husebø, A. M. (2019). Understanding informal caregivers' motivation from the perspective of self-determination theory: An integrative review. *Scandinavian Journal of Caring Sciences*, 34(2), 267–279. doi: 10.1111/scs.12735

The objective of Sub-Study 1 was to describe and explore empirical studies of caregivers' motivations from the perspective of SDT. Three themes emerged from the narrative analysis of the literature describing how caregivers' motivations could be understood in light of SDT.

The first theme, *descriptions of caregivers' motivations*, showed that caregivers' motivations were investigated, classified, and described according to different constructs within SDT. These constructs were mainly presented as positioned towards the ends of the SDT motivational continuum (Table 1). This included autonomous or intrinsic motivation (i.e., helping because you enjoy or value this behaviour and experience volition and choice) and controlled or extrinsic motivation (i.e., helping because you feel forced or obligated to do so). Autonomous motivation was positively associated with the satisfaction of caregivers' basic psychological needs for competence, autonomy, and relatedness. Representing the other side of the continuum, thwarting those needs could lead to controlled motivation. For maintenance of intrinsic motivation over time, the requirement of caregivers' internalisation of values and skills is described.

The second theme, *connection between caregivers' motivations and their well-being*, showed that autonomous motivation led to a positive impact, a sense of well-being, greater satisfaction with life, better personal functioning, and less exhaustion as a result of helping someone with a long-term illness. This

Findings

contrasts with the controlled motivational reasons, which led to more stress, increased caregiver burden, less life satisfaction, and diminished well-being.

The third theme, *support of caregivers' motivations*, showed that caregivers of persons with long-term illnesses may benefit from interventions that facilitate their ability to be autonomously motivated. The findings suggested that there could be advantages of supporting caregivers' basic psychological needs for competence, autonomy, and relatedness. Examples of such support related to the need for competence can include health professionals providing caregivers with tailored information about the diagnosis, symptom management, and training in problem solving. Communication skills and maintaining and enhancing relationships can support a caregiver's need for relatedness, while the need for autonomy can be supported through promoting available options, future planning, and freedom of choice with respect to tasks.

Sub-Study 1 addressed the following research question: *How can an adult informal caregiver's motivation for taking care of a friend or relative with a long-term illness be understood from the perspective of self-determination theory?* Satisfaction of the three basic psychological needs for competence, autonomy, and relatedness was considered essential in predicting the quality of caregivers' motivations and their well-being. In this review, autonomous motivation, in contrast to controlled motivation, was the most important determinant of caregivers' well-being. The article concluded that SDT can be applied to identify, categorise, predict, promote, and support motivation among caregivers of persons with long-term illnesses. This lends support for SDT and renders further study and application of the theory as a psychological approach to caregivers' health and health promotion. Furthermore, the article adds to the research field by conducting the first literature review that summarises and analyses previous research combining SDT and the long-term illness caregiver context.

5.2 Adult children's motivational drivers for dementia caregiving

Dombestein, H., Norheim, A. & Aase, K. (2020). Caring for home-dwelling parents with dementia: A qualitative study of adult-child caregivers' motivation. *Nursing Open*. 7(6), 1954-1965. doi:10.1002/nop2.587

The objective of Sub-Study 2 was to explore adult children's motivations in caregiving for their home-dwelling parents with dementia. Based on SDT, three categories labelled the main motivational drivers for adult-child caregivers represented in the empirical data.

The *competence* category described the importance of knowing what the parent needed as useful for the caregiver, but not being able to meet those needs was frustrating and thwarted motivation. When helping their parents, an important driver for caregivers' motivations involved possessing competence about the dementia illness and feeling a sense of capacity, mastery, and effectiveness.

The *autonomy* category described the importance of caregivers being able to decide for themselves when to help their parents and which tasks they wanted to perform. To have the opportunity to set boundaries for not accepting to perform specific tasks, such as helping the parent with toilet visits or in the shower, was emphasised. Also, regarding caregivers, not taking orders but voluntarily performing tasks was a motivational driver. In retrospect, caregivers valued being able to look back on the home-dwelling period with the certainty of knowing they had chosen to do what they could to help their parents. It then seemed like values and nuances of a sense of duty were innate when describing performed tasks and the caregiver efforts appeared natural.

The *relatedness* category described the importance of the adult child's relationship to the parent with dementia, the parent's spouse, and to other persons like the caregiver's siblings, the caregiver's own spouse, grown children, or friends. Here, gaining positive energy from interacting with parents and other people was essential for remaining motivated as a caregiver. This was not always the situation, and bad relationships could drain a caregiver's energy and thwart motivation. It was important to maintain positive relationships with others, because these feelings led to a sense of belonging, being a respected part

of a group, being trusted, and meaning something to others. Also, it was essential to receive understanding and support from these other people.

Sub-Study 2 addressed the following research question: *How can adult children's motivational drivers for caregiving be described using self-determination theory?* Competence, autonomy, and relatedness are basic needs that were essential as the adult-child caregivers' motivational drivers. High-quality motivation in the dementia caregiver role depended on satisfaction of those needs, while thwarting those needs could lead to amotivation. Caregivers reported that relatedness was their key motivational driver. This finding imply that healthcare professionals should value the importance of relatedness when interacting with caregivers of persons with dementia. The study also documents that SDT can be applied in a dementia caregiver context.

5.3 Community healthcare services and motivational caregiver support

Dombestein, H., Norheim, A. & Aase, K. (2021). How to stay motivated: A focus group study of Norwegian caregivers' experiences with community healthcare services to their parents with dementia. *Health and Social Care in the Community*. 00(0), 1–9. doi:10.1111/hsc.13396

The objective of Sub-Study 3 was to describe and explore adult children's experiences with community healthcare services for their home-dwelling parents with dementia and how these influence their motivations. Three categories were identified influencing adult children's sustained motivations as caregivers.

Caregivers prioritise their parents' needs for healthcare services over their own needs for support described how the adult children had experienced specific support services for themselves as being subordinate as long as the parent with dementia was not receiving proper services. The caregivers found it difficult to separate their own needs from their parents' needs. With the progression of dementia, it was vital for the sustained motivation of a caregiver to be free from struggle when getting the parent with dementia appropriate help at the right time. The caregivers valued healthcare services, like the dementia

Findings

team and the day-care centre because they viewed it as targeted and useful assistance that ensured continuity of services and safety for everyone involved.

Caregivers need acknowledgement through respect and involvement described how they wanted community healthcare professionals to value their voices, appreciate their expertise, and acknowledge them as members of the care team. The adult children were not asking for an excessive amount of healthcare services for their parents, but sought mutual respect, more dialogue, and interactions with healthcare professionals. On the other hand, they did not feel motivated, seen, heard, or respected when their knowledge or opinions were disregarded by healthcare professionals.

Caregivers need timely information and competence as the dementia progresses, describing how the caregivers valued increased knowledge about dementia. This included specific information, such as what to expect with each type of dementia, disease development, and functional ability so that they could make informed decisions and provide the best possible help. This also contributed to caregivers remaining motivated, involved, and engaged in the healthcare services provided to their parents. The adult children sought to be considered competent partners in their parents' healthcare services. Therefore, they wanted to learn more about dementia.

Sub-Study 3 addressed the following research questions: 1) *How do adult-child caregivers describe their experiences with their parents' community healthcare services*; 2) *How do these experiences influence their motivations to remain in the caregiver role*? The study found that from the perspective of adult-child caregivers, being involved in a respectful way in their parents' healthcare services, gave them a sense of significance, belonging, and achievement. Timely access to healthcare services for their parents could give the adult children a sense of security, continuity, and purpose. This influenced their motivation to remain in the caregiver role. To stimulate collaboration among adult-child caregivers and community healthcare services, a relationship-centred care framework could be emphasised as part of the services to support their sustained motivations.

5.4 Synthesis of findings across Sub-Studies 1-3

Through synthesising the perspectives of caregivers of persons with long-term illnesses (Article I) and adult-child caregivers of parents with dementia (Articles II and III), four themes led to a deeper understanding of their motivations (see Table 6). When presenting the themes (Tables 7-10), I have provided excerpts of findings across the three articles (Malterud, 2019).

Table 6 Overview of themes across Sub-Studies 1-3

Themes
1. Caregivers' motivations influence how they perceive caregiving
Caregivers must feel motivated to feel good about caregiving, meaning that the quality of caregivers' motivations influence how they perceive caregiving.
2. Relationships are vital to caregivers' motivations
Adult-child caregivers' relationships to parents with dementia, to persons in their social network, and in the parents' healthcare services influence their motivation.
3. Competent caregivers stay motivated
Competent caregivers stay motivated, but they also appreciate competent healthcare professionals as this improves the collaboration between them.
4. Caregivers prioritise the parents' needs over their own
It is more important for the caregivers that their parents were doing well at their homes than satisfying their own needs for competence, autonomy, and relatedness.

5.4.1 Caregivers' motivations influence how they perceive caregiving

Table 7 Excerpts of findings across Sub-Studies 1-3, Theme 1

Excerpt from Article I	Autonomous motivation increased a caregiver's happiness, positive affect, a sense of well-being, greater satisfaction with life, better personal functioning, and less exhaustion as a result of helping someone with a long-term illness.
Excerpt from Article II	Caregivers described caregiving as a "natural" thing to do and "that is how we do it in our family, so the values are inherited". They never thought that not involving themselves in caregiving could be an alternative.
Excerpt from Article III	Caregivers felt discouraged when parents were not provided with timely and accurate healthcare services. They just wanted to give up, and under such circumstances, adult children found it hard to remain motivated for the caregiver role.
Synthesis	Caregivers must feel motivated to feel good about caregiving, meaning that the quality of caregivers' motivations influence how they perceive caregiving.

Autonomous motivation is demonstrated as an important determinant of caregivers' long-term well-being, and it protects them from feeling overstressed and overworked (Article I). In Articles II and III, the association between caregivers' well-being and their motivation was not explicitly addressed. Still, there are clear descriptions of adult-child caregivers' frustrations and feelings of burden, which they relate to their lack of access to timely healthcare services for their parents or not being involved in a respectful way by healthcare professionals (Article III). Caregivers also experienced frustrations with the lack of information, or when the parents were dismissive of receiving help from anyone outside the family. Caregivers expressed these conditions as thwarting their motivations, making them more extrinsically motivated or amotivated (Articles II and III). These findings are supported by Article I, where caregivers who were categorised as extrinsically motivated described feeling forced or obligated to perform caregiver tasks.

Caregivers of persons with long-term illnesses experiencing volition and choice expressed that their intrinsic motivations were helpful as they enjoyed and

Findings

valued caregiving behaviours (Article I). Such motivation in the dementia caregiver context depended on satisfaction of the needs for competence, autonomy, and relatedness, while thwarting those needs led to amotivation (II). Findings from Articles II and III indicate that most caregivers moved along a continuum between amotivation and intrinsic motivation, illuminating the nuances and complexities involved in their roles. Article II supports caregivers' internalising the values and duties of caregiving as they found the efforts meaningful, significant, and useful in making the situation as good as possible for their parents at home. Therefore, caregivers rarely felt forced but chose to help their parents even if they sometimes struggled with the caregiver role (Article II). Across all articles, there is consistency between caregivers of persons with long-term illnesses and persons with dementia, describing their quality of motivations and how they perceived being caregivers (Articles I, II, and III). Three main issues thwarting caregivers' motivations include parents being resistant to or refusing community healthcare services, challenges in getting access to timely healthcare services, and not being involved in those services (Articles II and III).

5.4.2 Relationships are vital to caregivers' motivations

Table 8 Excerpts of findings across Sub-Studies 1-3, Theme 2

Excerpt from Article I	Satisfaction of the basic psychological needs for competence, autonomy, and relatedness are presented as equally important for the quality of motivation among caregivers of people with long-term illnesses.
Excerpt from Article II	Gaining positive energy from interacting with the parents with dementia and other persons are central to caregivers' motivations. This results in feelings of belonging, being trusted, and meaning something to others. Caregivers report relatedness as their key motivational driver.
Excerpt from Article III	Caregivers find it demotivating to have their knowledge or opinions disregarded, or their efforts taken for granted. To feel motivated, the caregivers want a place in the care team alongside healthcare professionals. "Mutual respect is fundamental".
Synthesis	Adult-child caregivers' relationships to parents with dementia, to persons in their social network, and in the parents' healthcare services influence their motivation.

Findings

Adult children's relationships to their parents with dementia, their parent's spouse, and to other persons provided energy and feelings of belonging, being a respected part of a group (e.g., family), being trusted, and meaning something to others (Article II). This was relevant for caregivers' relationships to professionals who worked in the parents' community healthcare services as well (Article III). Caregivers also experienced relationships that drained them of energy, leading to amotivation or extrinsic motivation (Articles II and III).

Satisfaction of the basic psychological needs for competence, autonomy, and relatedness was presented as equally important for predicting the quality of motivation among caregivers of persons with long-term illnesses (Article I), while caregivers of parents with dementia reported relatedness as their key motivational driver (Article II). Adult-child caregivers did not appreciate just a "pat on the back" but rather sought mutual respect, more dialogue, and collaboration with healthcare professionals (Article III).

The importance of relatedness to caregivers of persons with dementia is one of the most consistent findings across the empirical material (Articles II and III). When caregivers perceived positive relationships with others, this automatically accompanied other benefits, such as gaining competence by learning skills, receiving information and advice (Articles II and III), and the exchange of caregiver experiences among peers (Articles I and II). Positive relationships also meant that all people involved in caregiving treated each other respectfully so that they could preserve their autonomy and not feel forced to do their tasks (Articles I, II, and III). The findings imply that healthcare professionals should value relatedness when interacting with caregivers of persons with dementia (Article II) and emphasise a relationship-centred care framework in supporting caregivers as partners in community healthcare services (Article III).

5.4.3 Competent caregivers stay motivated

Table 9 Excerpts of findings across Sub-Studies 1-3, Theme 3

Excerpt from Article I	Maintenance of motivation over time requires that caregivers internalise certain skills. Such skills involve understanding the diagnosis of their relative with long-term illness, management of symptoms, problem solving, communication, and enhancing relationships with the friends of their relative.
Excerpt from Article II	The competence of the adult children allow them to experience different levels of control and predictability in the caregiver role, thus affecting their motivation to remain in it.
Excerpt from Article III	The caregivers expect healthcare professionals to have expertise on dementia when working with these patients. More competence among both caregivers and healthcare professionals would constitute a win-win situation for everyone involved.
Synthesis	Competent caregivers stay motivated, but they also appreciate competent healthcare professionals as this improves the collaboration between them.

To stay autonomously motivated and feel capable of handling caregiver tasks, caregivers of persons with long-term illnesses need competence (Article I). Caregivers of persons with dementia also described the usefulness of having knowledge about dementia in general and at the same time knowing their parents so well that they could better help them (Article II). To make informed decisions when helping their parents at home, they valued accurate and timely information on what to expect with their parents' type of dementia, but also information on available and relevant healthcare services (Article III). This competence contributed to feelings of capacity, mastery, and effectiveness when helping their parents and collaborating with community healthcare services. The possession of skills and feelings competence contributed to caregivers remaining motivated, involved, and engaged in the healthcare services provided to their parents (Article III). For caregivers to remain motivated over time, these skills must be internalised (Article I).

Adult children sought to be considered competent partners in their parents' healthcare services, be acknowledged for their knowledge of how to handle their parents' needs, and therefore wanted to learn more about the dementia

illness (Article III). To support caregivers, enable competence, and provide them with skills in handling long-term illnesses, health professionals should tailor information regarding the diagnosis, symptom management, training in problem solving, and communication skills (Article I). The caregivers of parents with dementia felt amotivated when healthcare professionals lacked the necessary competence in handling dementia patients, when they did not know the caregivers’ legal rights or acknowledged their efforts (Articles II and III). It was important that the professionals had competence in handling dementia to provide services that were targeted, useful, and ensured continuity of services and safety for both patients and caregivers (Article III). Supporting collaboration between caregivers and health professionals required both parties to have the basic level of competence to meet each other with respect, dialogue, and understanding.

5.4.4 Caregivers prioritise the parents’ needs over their own

Table 10 Excerpts of findings across Sub-Studies 1-3, Theme 4

Excerpt from Article I	Caregivers of persons with long-term illnesses benefit from interventions that facilitate their ability to be autonomously motivated by supporting their own needs for competence, autonomy, and relatedness.
Excerpt from Article II	It is more important for caregivers to be able to look back on the home-dwelling period with the certainty of knowing they chose to do what they could to help their parents, “It felt like the right thing to do”.
Excerpt from Article III	Distinct caregiver support services are not seen as useful by the caregivers if the parent with dementia is not doing well at home. “...when the one I’m caring for is doing well, then I’m also doing well”.
Synthesis	It is more important for the caregivers that their parents were doing well at their homes than satisfying their own needs for competence, autonomy, and relatedness.

The caregivers knew their parents well and had experiences with what they needed to function in their homes (Article II), yet this was challenging if the parents were dismissive of healthcare services. Not having to struggle to

Findings

provide parents with dementia with appropriate help at the right time as the illness progressed was vital for caregivers' sustained motivations (Article III). The adult-child caregivers had a clear purpose of providing their parents with the best possible help, and they stretched far to ensure that parents' needs were satisfied (Articles II and III). According to Article I, caregivers of persons with long-term illnesses should be supported in their ability to be autonomously motivated, having their own needs for competence, autonomy, and relatedness met (Article I). The caregivers of parents with dementia experienced specific support services for themselves as subordinate to their parents' needs, especially if the parents not received proper help at home (Article III). The findings from Article I thus prioritise the caregiver's needs, while Articles II and III prioritise the parent's needs in understanding caregiver motivation.

The caregivers found it difficult to separate their own needs from their parents' needs (Articles II and III), and therefore valued healthcare services, such as the day care centre that met their interconnected needs (Article III). Although the adult children were not concerned with support structures for their own sakes, this does not indicate that they have no needs of their own (Article II). Consequently, it is necessary to facilitate interventions that aim to both support caregivers' needs and parents' with dementia (Articles II and III).

6 Discussion

By understanding motivation to remain in a caregiver role through the lenses of self-determination theory and relationship-centred care, this PhD project adds to the field of carer research by highlighting the quality of caregivers' motivations. Adult children's motivational drivers for caring for home-dwelling parents with dementia are influenced by their experiences in the caregiver role. To expand on these issues, this chapter discusses the synthesis of findings in light of existing research and constructs from self-determination theory and relationship-centred care.

6.1 *Quality of caregivers' motivations*

The findings in this thesis indicate that most caregivers move along a continuum between amotivation and intrinsic motivation. This illuminates the nuances and complexity of being the caregiver of a person with long-term illness or dementia. Previous motivational research, within the dementia caregiver context, described motives for caregiving (Greenwood & Smith, 2019; Quinn et al., 2010), while self-determination theory has been applied only to a limited degree.

The findings in this PhD project characterise caregivers' motivations as mostly non-self-determined (i.e., low-quality motivation) or self-determined (i.e., high-quality motivation), placed on each end of the motivational continuum. Table 11 shows the main findings in the PhD project and their placement in the self-determination continuum, according to Ryan and Deci (2000).

Table 11 Caregivers’ motivations

Type of motivation	Amotivation	Extrinsic Motivation				Intrinsic Motivation
Regulatory styles	Non-Regulation	External Regulation	Introjected Regulation	Identified Regulation	Integrated Regulation	Intrinsic Regulation
Perceptions of caregiving	Not feeling involved, feeling ignored, parents dismissing outside help, sense of duty, burden, and frustration				Achieve purpose, “natural thing to do”, positive affect, well-being	
Relationships	Poor relationships with parent, social network, or health-care services, lack of respect and trust, poor dialogue and collaboration				Positive relationships, mutual respect, meaning something to others, a place alongside healthcare professionals	
Competence	Low competence with lack of knowledge about dementia, healthcare professionals lacking competence to handle patients with dementia				Higher competence with timely information about dementia, knowledge about parents, internalisation of skills, feeling capable of handling tasks	
Priority of needs	Struggling to provide parents with appropriate help at progression of illness				“Parents needs first”, parents doing well at home	

In the sub-studies of the PhD project not all regulatory styles (e.g., introjected regulation, identified regulation) were systematically explored. Participants’ focus on each end of the motivational continuum might have been due to the simplicity of finding examples related to low-quality motivation or high-quality motivation. Kindt et al. (2017; 2016) demonstrated fluctuations of caregivers’ quality of motivations from day to day when helping partners with chronic pain. On the other hand, SDT postulates that internalisation of goals and values into an individual’s identity represents more sustainable constructs, leading to high-

quality motivation (Ryan & Deci, 2017). Thus, it can be challenging separating the caregivers' motives as they might be interconnected, such as feelings of love and duty (Greenwood & Smith, 2019). Surveys based on SDT have frequently been applied to categorise different types of motivations in healthcare research (Ng et al., 2012; Ntoumanis et al., 2020), also to some extent in the caregiver context (Badr et al., 2015; Kim et al., 2008). Barry et al. (2020) have exemplified regulatory styles for caregivers to older persons. Nonetheless, within qualitative research, Ng et al. (2016) reflect on issues when identifying and classifying regulatory styles, finding it challenging to differentiate between types of motivation in cancer caregivers' real lives.

The thesis findings indicate that the quality of caregivers' motivations is influenced by how they experience caregiving. This association is also established from a theoretical motivational perspective, as SDT has identified several distinct types of motivation, each of which has specifiable consequences for performance, personal experience, and well-being (Ryan & Deci, 2017). SDT research in caregiver long-term illness contexts (Kim et al., 2015; Kim et al., 2008; Kindt et al., 2017; Kindt et al., 2016; Ng et al., 2016) and in a study of caregivers of persons with dementia (Pierce et al., 2001) has established the same association. In these studies, motivation is connected to caregivers' experiences of burden or their satisfaction and enthusiasm, and thereby to their well-being in the caregiver role.

The close connection between caregivers' experiences, motivations, and well-being is important when arguing for support of caregivers, because they need to sustain their motivations as dementia and other long-term illnesses last for many years. In this respect, SDT is helpful as it articulates a set of principles for how each type of motivation is developed and sustained or thwarted and undermined (Ryan & Deci, 2017).

6.2 The role of relatedness

Adult-child caregivers of parents with dementia report relatedness as their key motivational driver, according to the thesis findings. Caregivers' relationships to parents with dementia are highlighted as most important, but also relationships to persons in their social network and to persons in the parents' community healthcare services. Previous research has found that the quality of

the relationships between persons with dementia and caregivers are directly linked to motivations for providing care and are associated with the meanings of caregiving (Bjørge et al., 2017; Greenwood & Smith, 2019; Quinn et al., 2015; Tretteteig et al., 2017b). Consistent with SDT (Ryan & Deci, 2017), relatedness induces a feeling of belonging, being a respected part of a group (e.g., family), being trusted, meaning something to others, and being an important part of the team caring for the parent with dementia. This is in line with Nolan et al. (2003) describing caregivers' senses of belonging and significance when interacting with persons with who have dementia and healthcare professionals. Satisfaction of the psychological need for relatedness thus allows caregivers to thrive in the caregiver role (Pierce et al., 2001).

Finding relatedness as the most important motivational driver differs from the main assumption of SDT, where the needs for competence, autonomy, and relatedness are valued as equally important for high-quality motivation purposes (Ryan & Deci, 2017). This has also been found in other contexts (Williams et al., 2014), as in the long-term illness caregiver context of Sub-Study 1. Custers et al. (2012) state that within SDT, there is little attention to the relative importance of the three needs, although it is questionable whether competence, autonomy, and relatedness are equally important to patients and presumably caregivers. Nursing home residents considered relatedness with their professional carers as the most important of the three needs, while autonomy and competence were less important (Custers et al., 2012). On the other hand, research shows that people must experience satisfaction of autonomy as well as competence within relationships to promote their personal and relational well-being (Niemic et al., 2014). However, thwarting the need for competence and autonomy may lead to unsatisfying relationships. This interconnection of basic needs is also valid for the adult-child caregivers in this thesis. Positive relationships with others automatically accompany other benefits, such as gaining competence by learning skills and receiving information and advice. Caregivers with positive relationships to family members with dementia are also more competent to make decisions together with or on behalf of patients (Bjørge et al., 2017). This idea seemingly supports both the patient's and the caregiver's need for autonomy.

Findings from the thesis describe a sense of duty as innate in caregivers when performing tasks with confidence and when efforts were experienced as natural

due to the relationship they had with their parents. Traditions and relationships in the family, as well as expectations from society, play a role. SDT has previously been criticised for not sufficiently taking into account the cultural and religious context of different societies. In some cases, the need for autonomy may stand in contrast to the need for relatedness. Some cultures are more individualistic and emphasise autonomy, while others emphasise social and cultural affiliation (Lillemyr, 2016). Filial piety is, for example, a strong motivational driver for caregiving in Asia, as family-oriented cultural values stand strong (Ng et al., 2016). Tan-Ho et al. (2020) recommend that support for caregivers should comprise all three needs to accomplish self-determined motivation. They also recommend that interventions should be offered to family caregivers in a culturally relatable manner.

The adult children in the thesis sought mutual respect, more dialogue, and collaboration with healthcare professionals. This finding is confirmed by a current survey with Norwegian adult caregivers, where they report that they want to be recognised through appropriate involvement in their relatives' or friends' healthcare services (Norwegian Directorate of Health, 2021). According to White Paper 29 (2012-2013) on plans for future care in Norway, it is a prioritised area to develop healthcare professionals' attitudes and expertise so that collaboration with caregivers becomes a natural and integral part of the service provision. Expectations towards co-production that harmonises the relationship between healthcare services and family carers are presented. Regardless, family are considered more as care work contributors than experts and partners (Jenhaug, 2018).

Also, appearing to be an issue that thwarts caregivers' motivations occurs when individuals are not appropriately involved in their parents' healthcare services. Therefore, further development of a partnership approach based on collaboration between professionals and caregivers seems applicable (Nolan et al., 2003). When testing such a partnership approach in homecare services, all involved in the caregiving process needed more time to devote to relational aspects of care (de Witt & Fortune, 2019). This thesis highlights that positive relationships also involve treating each other respectfully so that caregivers can preserve their autonomy and not feel forced to do tasks, indicating a first step to better involvement of informal caregivers.

The thesis highlights that parents with dementia who resist or refuse to receive community healthcare services are a central source of frustration. This situation thwarts caregivers' relationships with their parents and professionals in community healthcare services. The person with dementia might want to remain independent for as long as possible and is therefore reluctant to accept formal help and support. Families may also be unaware of available services or find them to be of poor quality, inflexible, or inadequate (Moholt et al., 2020). Other reasons include the person with dementia not wanting strangers in the house, not wanting to leave the house, or responding poorly to changes in routines (Macleod et al., 2017). The caregivers in Sub-Studies 2 and 3 were frustrated as professionals within the services did not appear persuasive enough making their parents shower, change clothes, or eat their food. It seemed like the caregivers experienced a conflict of interest in the relationship with healthcare professionals in the community. From a healthcare professional perspective, it is considered unethical to pressure or force patients to perform activities against their will (Hengelaar et al., 2018). Facilitators for overcoming this challenging situation can be to create a common understanding across all involved (e.g., person with dementia, caregivers, professionals) through dialogue and cooperation (Macleod et al., 2017) similar to a relationship-centred care approach that is recommended in dementia care (Moholt et al., 2020).

6.3 Caregivers as competent partners

The participants in Sub-Studies 1 and 2 were mainly highly educated, between 50 and 59 years old, and working full-time. This sample can be considered resourceful caregivers, and their motivation to care for their parents might differ from caregivers less likely to seek competence. A total of 72% of the sample had university educations, compared to 35% in the Norwegian population (Statistics Norway, 2020). The caregivers presumably had higher levels of health literacy, like competencies to access, understand, appraise, and apply health information (Yuen et al., 2018). When a caregiver lacks competence and possesses a lower health literacy, it can intensify stress levels and have harmful implications on well-being. Häikiö et al. (2020) claim that a caregiver who has a higher level of health literacy has increased competence, a better quality of

life, less caregiver burden, and spends fewer hours on caregiving for a person who has dementia.

None of the adult children in Sub-Studies 2 and 3 were living together with their parents with dementia and they wanted a partnership with the parents' community healthcare services. Tretteteig et al. (2019) found that adult children not living with family members with dementia were more happy to share caregiving responsibilities with homecare service providers. Spouses or others who cohabit with persons with dementia might need other forms of collaboration and more access to respite care to reduce the demands from caregiving (Moholt et al., 2020; Nolan et al., 1996).

Competence in this thesis contains an understanding of the diagnosis of their relative with long-term illness, management of symptoms, problem solving, communication, and enhancement of relationships. More specifically, this entails that adult-child caregivers obtain knowledge about the dementia illness so that they can help their parents in daily activities, but also information about how to get access to healthcare services. According to SDT, competence involves capability, mastery, and perceptions of performing tasks with confidence (Ryan & Deci, 2017). Expanding on this, Eraut (1998) describes competence both as a task-based ability and a personal characteristic. Professional competence, on the other hand, also includes technical skills, clinical reasoning, emotions, values, and reflection in daily practice (Epstein & Hundert, 2002). These are competencies that caregivers refer to as important, especially when parents are dismissive of receiving services. Examples involve dementia teams simultaneously providing high-quality homecare services to parents and information and support to caregivers. The day-care centre for persons with dementia also contributes to caregivers' competencies by offering information, support, and guidance based on their own values and goals for caregiving (Tretteteig et al., 2017a).

The adult-child caregivers in the thesis wanted to be considered competent partners in their parents' healthcare services and receive acknowledgement for their competence in how to handle their parents' needs. This is in line with the relationship-centred care approach with the potential to empower caregivers, patients, and professionals (Brown Wilson et al., 2013). For healthcare professionals, this requires a change in orientation toward recognising

caregivers as experts. This does not degrade professional expertise, but instead enhances and facilitates joint understanding (Nolan et al., 2002). However, Lapidou et al. (2018) found that lack of training of healthcare professionals means that healthcare services are only to some extent supporting the caregivers as part of the services. Hengelaar et al. (2018) further described professionals who are not confident or qualified to support informal caregivers in a partnership.

6.4 Priority of needs

Adult-child caregivers in this thesis experience specific support services for themselves as subordinate to their parents' needs, especially if the parents do not receive proper help at home. Quinn et al. (2015) found that caregivers' motivations for providing care can be encompassed under an overarching process of balancing needs and constantly struggling to rectify their own needs against those of their relative. The thesis highlights the main issues thwarting caregivers' motivations are parents being resistant or refusing to receive community healthcare services and challenges in getting access to timely healthcare. Still, the caregivers of parents with dementia prioritised their parents' needs over their own. This is also confirmed in previous research (Tatangelo et al., 2018) that is denoted by Pearlin et al. (1990) as role captivity where caregivers help the patients as there are no other available alternatives. Eventually, experiencing there is no other choice leads to amotivation (Ryan & Deci, 2017) with consequences for the caregivers' well-being (Al-Janabi et al., 2018).

When the parent with dementia was dismissive of healthcare services, the caregiver took over some care tasks even if it felt problematic to do so. Thus, a dyadic approach complying with the integrity of the person with dementia and the caregiver's needs for support is necessary in dementia care (Karlsson et al., 2015). According to the thesis findings, healthcare services such as the day-care centre meet these interconnected needs. Tretteteig et al. (2016) also found that the day-care centre could provide a caregiver with a feeling of safety and relief, reduce the burden, and increase motivation. In Norway, 88% of the municipalities have day-care activities adapted to persons with dementia, yet

the demand is not met and the service should be further developed (Ministry of Health and Care Services, 2020).

Even when the caregivers in the thesis did not find every task to have been enjoyable, looking back on the parents' home-dwelling period, they were satisfied with having prioritised their parents' needs first, "having done the right thing". Zarit (2012) also highlights that motivation in the caregiver role appears to be related to more than looking at the pleasant sides of caregiving. Motivation that is directed towards a purpose of finding meaning is essential to staying motivated. This is in line with Nolan et al. (2003) advocating that a caregiver must experience purpose and achievement to perceive satisfaction in the role. According to the new family caregiver strategy in Norway (Ministries, 2020), healthcare professionals should consider caregivers' own accounts of what matters to them. In light of the thesis findings, caregivers might have problems with separating their own needs from those of the patients, probably communicating patients' needs as most important.

According to the Long-term Perspectives on the Norwegian Economy (Meld. St. 14, 2020–2021), increased family care can reduce the need for healthcare professionals and thereby alleviate the future challenges of the healthcare services induced by demographic changes. People over 85 years of age constitute the population group with the most complex care needs, while people aged 50 to 66 years of age will provide most of the informal care. This is identical to the sample of caregivers and their parents with dementia included in this thesis. Even though the caregivers prioritise their parents' needs first, this may not come without costs. Blix et al. (2021) estimate that in the year 2040, each caregiver will on average provide at least twice as much care-time as current levels. Therefore, the authors point at an urgent need for measures to uphold high-quality healthcare services and support caregivers of persons with long-term illnesses such as dementia.

Relying on the findings from this thesis, it is necessary to facilitate interventions that support both the needs of the caregiver and the parent with dementia. Dyadic SDT-based interventions have shown some effect on supporting caregivers and patients with cancer (Badr et al., 2015) and heart failure (Cossette et al., 2016). Badr et al. (2015) tested a telephone-based dyadic psychosocial intervention for patients with lung cancer and their caregivers.

They received tailored manuals and participated in counselling sessions, with homework between each session. The findings from the study suggested that future interventions should contain some joint sessions for the patient and caregiver and some on an independent basis.

6.5 Methodological considerations

In retrospect, some issues could have been handled differently to enhance the overall study design, trustworthiness, and reflexivity of the PhD project. It can be discussed whether the project had a multi-method or a mixed-method approach (Green, 2015). Ideally, the data collection could have been done in a different order. Sub-Study 1 could have been completed prior to the data collection in Sub-Studies 2 and 3. This would have given me a deeper understanding of the theoretical concepts of motivation before planning and conducting the interviews. On the other hand, I was then able to meet the participants in a more open way, listening to their caregiver stories, without trying to guide them in a specific theoretical direction. If the core and complementary components of the PhD project were paced more succinctly, the design could have been defined as mixed-method instead of multi-method (Morse, 2017).

It is considered a strength to conduct the literature review in Sub-Study 1, according to Whitemore and Knafl's (2005) stringent, rigorous, and systematic review procedure. Despite a comprehensive literature search, the inclusion of grey literature (i.e., not academic journal articles) like book chapters and PhD dissertations might have given an expanded sample of studies for inclusion. A scoping review method could then be chosen, as the research area is new and circumscribed.

The imbalance in the samples of Sub-Studies 2 and 3 should be considered methodologically, as the caregivers all had positive relationships with their parents and were dedicated and interested in the PhD project. The findings would presumably be different if I had interviewed caregivers with more negative relationships with their parents. Another issue worth mentioning is that 10 potential participants in Sub-Study 2 and six in Sub-Study 3 declined to partake, claiming that they did not have the time or capacity to participate. According to Tong et al. (2007), the sample may have failed to capture

important perspectives from “difficult-to-reach” participants. Due to ethical guidelines, it was not possible to recruit these participants, as participation had to be voluntary.

To capture the variety of experiences of being a caregiver, retrospective interviews were conducted, as the timing of the interviews would influence the participants’ experiences. Interviewing the participants during the stressful last month before the parent moved to a nursing home, their responses would probably have described experiences thwarting their motivations. On the other hand, giving the participants time to develop some distance made it possible to better reflect on their experiences and describe them.

The findings of all three sub-studies provided some indications on gender issues, but this was not planned as a focus of the PhD project. The sample in Sub-Study 2 consisted of 12 women and nine men, and Sub-Study 3 consisted of 10 women and five men. This does not provide an equal gender balance, and sons and daughters might, to some extent, experience the caregiver role in a different manner (Moholt et al., 2018). These similarities and differences in male and female motivation could have been highlighted in the PhD project. Instead, I chose to describe the sample as resourceful, mainly consisting of caregivers who are highly educated, aged 50 to 59, and working full-time. The caregivers in this sample and their motivations might differ from other caregivers less likely to speak up for themselves and their parents (Henriksen et al., 2020). The recruitment strategy could have emphasised the inclusion of participants characterised as less resourceful.

As data in Sub-Studies 2 and 3 was collected in one municipality, more participants spread over different regions in Norway could have given different or more varied descriptions of motivation in the caregiver role. On the other hand, the studies gave a deeper understanding of one particular context in which all the participants’ parents had access to the same healthcare services. The municipality was large and consisted of both urban areas and rural districts, and therefore had some variation.

In Sub-Studies 2 and 3, due to ethical concerns, I was not allowed to collect data about the parents with dementia. Therefore, the thesis does not include information on, for example, their type of dementia. Variation in challenges and

Discussion

stress faced by caregivers according to different forms of dementia is documented (Svendsboe et al., 2016; Terum et al., 2019). The prevalence of behavioural problems with the persons with dementia and the needs for assistance in activities of daily living also affect caregivers' motivation (Tretteteig et al., 2016). Adding information on diagnosis and level of daily living activities prior to moving to the nursing home could have strengthened the findings of the PhD project. This could have contributed to the elaboration of possible differences in motivation, for example, in being a caregiver to a parent with Alzheimer's as opposed to a parent with frontal temporal dementia.

7 Conclusions

By applying self-determination theory combined with a relationship-centred care approach, this thesis offers a deeper understanding of adult caregivers' motivations in the long-term illness and dementia contexts by considering the perspectives of informal caregivers. A caregiver's motivation is described along a continuum representing different qualities of motivation, focusing on non-self-determined, and self-determined motivation. Addressing caregivers' motivations is necessary, as the quality of their motivations for caregiving has consequences for their health and well-being. As dementia and other long-term illnesses last for many years, supporting caregivers' motivations is vital if they are to remain in the role.

Caregivers' experiences influence their motivations by satisfying or thwarting their basic needs for competence, autonomy, and relatedness. Adult-child caregivers with home-dwelling parents with dementia value relatedness as their main motivational driver, followed by competence and autonomy. To remain motivated throughout a parent's trajectory of dementia, support to fulfil the three needs is required. The adult-child caregiver wants to be acknowledged as a competent partner in the care team, contributing with a significant effort to make the home-dwelling period as positive as possible for the parent. Community healthcare professionals providing support for this group of caregivers as part of the parents' services should consider the quality of the relationships between caregivers, patients, and themselves. This is vital for caregivers' motivations for providing care, in line with the relationship-centred care approach. As adult-child caregivers found it difficult to separate their own needs from their parents', it is recommended that future community healthcare services develop interventions addressing the needs of both groups.

This thesis has shown that self-determination theory can guide research to systematise, understand, and describe adult children's motivations related to caregiving. As SDT has previously been widely used in health research but rarely in a caregiver context, this thesis has expanded the application of the theory.

7.1 Implications for practice

Based on the findings in this thesis, the following suggestions to improve support for informal caregivers as part of community healthcare services should be considered:

- When parents with dementia refuse to accept community healthcare services, this should be on more the agenda in a systematic manner, including ethical, regulatory, and resource challenges. Providing healthcare services without compromising the integrity of the person with dementia, while at the same time supporting caregivers, is warranted.
- Increased competence among healthcare professionals about dementia, and handling of symptoms is necessary in the form of education, courses, and lifelong learning approaches for GPs, community coordinators, and staff in homecare and day-care centres.
- Community healthcare services for persons with dementia, such as dementia teams and specialised day-care centres, should be further prioritised within municipalities as they meet the needs of patients and at the same time support caregivers.

Interventions delivered by healthcare professionals and support given to adult-child caregivers as part of their parents' healthcare services can comprise the following mediators to sustain self-determined motivation:

- Relatedness-targeted mediators: Relationship-centred approaches based on dialogue and collaborative approaches in supporting relatedness among caregivers and persons with dementia, and among caregivers and community healthcare professionals. Interventions to improve interpersonal relationships by teaching patients and caregivers' strategies for problem solving, effective communication, and mobilising support.
- Autonomy-targeted mediators: GPs, community coordinators, and staff in homecare and day-care centres collaborating with caregivers should provide a clear rationale for recommendations and help caregivers see the different options available. Task distribution and responsibility among

healthcare professionals and caregivers should be based on dialogue and freedom of choice.

- **Competence-targeted mediators:** Besides general information on dementia, managing symptoms at home, and overview of available healthcare services, interventions could facilitate peer support between new and experienced caregivers. Clarification between caregiver and healthcare professional regarding each other's competence and what to expect should be made.

The three mediator groups are also recommended for caregivers of patients with long-term illnesses other than dementia. Involving spouses or other caregivers who cohabit with the patient might need adjustments related to, for example, respite care for the patient.

7.2 Implications for future research

More research is needed to confirm or elaborate on the following findings in this thesis:

- Dyadic interventions could be developed and tested in caregiver contexts where patients are newly diagnosed with dementia, while the patient's cognitive impairment still allows for making joint plans for the future (Badr et al., 2015). Tailored manuals with information and participation in counselling sessions with a healthcare professional specialised in dementia are then recommended.
- An updated literature review with identical inclusion criteria as in Sub-Study 1 is suggested. Sub-Study 1 identified research mainly published after 2015, indicating that the field of caregiving and SDT is new and developing.
- Findings from this thesis (Sub-Study 1) have contributed to the development of a measure of caregivers' types of motivation based on self-determination theory, and piloted on caregivers of older people (Barry et al., 2020). This measure can be piloted in other contexts, such as for caregivers of home-dwelling persons with dementia or other long-term illnesses.

Conclusions

- It is necessary to describe more clearly the different motivational regulatory styles for caregivers of persons with dementia, especially the external, introjected, identified, and integrated regulation of motivation. A continuation of this is to link each regulatory style to consequences for caregivers' health and well-being.
- SDT surveys, previously conducted in other health contexts, should be adapted, translated, and validated for the Norwegian caregiver context, mapping their motivation and well-being (Ng et al., 2012). The utilisation of quantitative methods and recruiting participants to a wider sample is suggested. SDT could also be applied to other caregiver settings, for example other patient diagnoses or other types of caregivers such as voluntary organisations.
- SDT-based interventions should also be pursued in caregiver contexts. Such interventions should then comprise all three of the psychological needs (competence, autonomy, relatedness), adjusted to the cultural context, to accomplish self-determined motivation (Ntoumanis et al., 2020; Tan-Ho et al., 2020).
- Studies to gain knowledge on gender issues in caregivers' motivations when caring for home-dwelling parents with dementia are recommended (Quinn et al., 2015).
- An international SDT-based study to compare different caregiver traditions and contexts characterised by different social structures is suggested (Greenwood & Smith, 2019).

National guidelines point to acknowledging and respecting caregivers' efforts (Meld. St. 29, 2012-2013), but research is still needed on how to achieve this in practice. The development of relationship-centred care programmes has the potential to foster positive dementia care experiences in community settings (de Witt & Fortune, 2019). Concerning adult children caring for home-dwelling parents with dementia, guidelines, checklists, or models should be developed for including caregivers as competent and respected partners within community healthcare services.

References

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: a clinical review. *JAMA*, *311*(10), 1052-1060. <https://doi.org/10.1001/jama.2014.304>
- Al-Janabi, H., Carmichael, F., & Oyeboode, J. (2018). Informal care: choice or constraint? *Scandinavian Journal of Caring Science*, *32*(1), 157-167. <https://doi.org/10.1111/scs.12441>
- Alzheimer Europe. (2013). *The prevalence of dementia in Europe - Norway*. <https://www.alzheimer-europe.org/Policy/Country-comparisons/2013-The-prevalence-of-dementia-in-Europe/Norway>
- Alzheimer's Disease International. (2018). *From plan to impact. Progress towards targets of the Global action plan on dementia*. <https://www.alz.co.uk/adi/pdf/from-plan-to-impact-2018.pdf?2>
- Atkinson, J. W. (1964). A theory of achievement motivation. In J. W. Atkinson (Ed.), *An introduction to motivation* (p. 240-268). Van Nostrand.
- Badr, H., Smith, C. B., Goldstein, N. E., Gomez, J. E., & Redd, W. H. (2015). Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: Results of a randomized pilot trial. *Cancer*, *121*(1), 150-158. <https://doi.org/10.1002/cncr.29009>
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, *84*(2), 191-215. <https://doi.org/10.1037/0033-295X.84.2.191>
- Barry, R. A., Bell, J., Batista, S. G., & McKibbin, C. (2020). Why Care? A Self-determination Theory Perspective of Informal Caregiving. In B. Ng & G. Ho (Eds.), *Self-Determination Theory and Healthy Aging: Comparative Contexts on Physical and Mental Well-Being* (p. 93-126). Springer Singapor. https://doi.org/10.1007/978-981-15-6968-5_6
- Beach, M. C., Inui, T., & Relationship-Centered Care Research Network. (2006). Relationship-centered care. A constructive reframing. *Journal of General Internal Medicine*, *21*(1), 3-8. <https://doi.org/10.1111/j.1525-1497.2006.00302.x>
- Beinart, N., Weinman, J., Wade, D., & Brady, R. (2012). Caregiver Burden and Psychoeducational Interventions in Alzheimer's Disease: A Review. *Dementia and Geriatric Cognitive Disorders Extra*, *2*(1), 638-648. <https://doi.org/10.1159/000345777>

References

- Benner, P. (1994). *Interpretive phenomenology: embodiment, caring, and ethics in health and illness*. Sage Publications.
- Bernild, C. (2016). Pårørende mellom system og livsverden. In S. Lehn-Christiansen (Ed.), *Ulykkelig i sundhed* (p. 199-227). Frydenlund Academic.
- Biesta, G. (2010). Pragmatism and the philosophical foundations of mixed methods research. In A. Tashakkori & C. Teddlie (Eds.), *SAGE handbook of mixed methods in social & behavioral research* (2nd ed.). SAGE.
- Bjørge, H., Kvaal, K., Småstuen, M. C., & Ulstein, I. (2017). Relationship Quality and Distress in Caregivers of Persons With Dementia: A Cross-Sectional Study. *American Journal of Alzheimer's Disease & Other Dementias*, 32(3), 157-165.
<https://doi.org/10.1177/1533317517691121>
- Bjørge, H., Sæteren, B., & Ulstein, I. D. (2016). Experience of companionship among family caregivers of persons with dementia: A qualitative study. *Dementia*, 18(1), 228-244.
<https://doi.org/10.1177/1471301216666172>
- Blix, B. H., Stalsberg, H., & Moholt, J.-M. (2021). Demografisk utvikling og potensialet for uformell omsorg i Norge. *Tidsskrift for omsorgsforskning*, 7(1), 1-14. <https://doi.org/10.18261/issn.2387-5984-2021-01-03>
- Brown Wilson, C., Swarbrick, C., Pilling, M., & Keady, J. (2013). The senses in practice: enhancing the quality of care for residents with dementia in care homes. *Journal of Advanced Nursing*, 69(1), 77-90.
<https://doi.org/10.1111/j.1365-2648.2012.05992.x>
- Bruvik, F. K. (2014). *Persons with dementia and their family carers - Quality of life, burden of care, depression and the effect of psychosocial support*. [PhD Thesis]. Universitetet i Oslo.
- Bøckmann, K., & Kjellebold, A. (2015). *Pårørende i helse- og omsorgstjenesten: en klinisk og juridisk innføring* (2. utg. ed.). Fagbokforl.
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, 41(5), 545-547. <https://doi.org/10.1188/14.ONF.545-547>
- Cherryholmes, C. H. (1992). Notes on Pragmatism and Scientific Realism. *Educational Researcher*, 21(6), 13-17.
<https://doi.org/10.3102/0013189X021006013>

References

- Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*, 62(3), 340-350. <https://doi.org/10.1111/inr.12194>
- Conde-Sala, J. L., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J., & López-Pousa, S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: An exploratory comparative design. *International Journal of Nursing Studies*, 47(10), 1262-1273. <https://doi.org/10.1016/j.ijnurstu.2010.03.001>
- Connor, K., Siebens, H., & Chodosh, J. (2015). Person-Centered Approaches to Caregiving. In J. E. Gaugler & R. L. Kane (Eds.), *Family Caregiving in the New Normal*. Elsevier Science & Technology. <http://ebookcentral.proquest.com/lib/uisbib/detail.action?docID=2049243>
- Cossette, S., Belaid, H., Heppell, S., Mailhot, T., & Guertin, M.-C. (2016). Feasibility and acceptability of a nursing intervention with family caregiver on self-care among heart failure patients: a randomized pilot trial. *Pilot and Feasibility Studies*, 2(34). <https://doi.org/10.1186/s40814-016-0077-8>
- Crellin, N. E., Orrell, M., McDermott, O., & Charlesworth, G. (2014). Self-efficacy and health-related quality of life in family carers of people with dementia: a systematic review. *Aging & Mental Health*, 18(8), 954-969. <https://doi.org/10.1080/13607863.2014.915921>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: qualitative, quantitative & mixed methods approaches* (5th edition). Sage Publications.
- Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research* (2nd ed.). Sage.
- Custers, A. F. J., Westerhof, G. J., Kuin, Y., Gerritsen, D. L., & Riksen-Walraven, J. M. (2012). Relatedness, autonomy, and competence in the caring relationship: The perspective of nursing home residents. *Journal of Aging Studies*, 26(3), 319-326. <https://doi.org/10.1016/j.jaging.2012.02.005>
- de Oliveira, D. C., Vass, C., & Aubeeluck, A. (2015). Ageing and quality of life in family carers of people with dementia being cared for at home: a literature review. *Quality in Primary Care*, 23(1), 18-30. <https://primarycare.imedpub.com/ageing-and-quality-of-life-in-family-carers-of-people-with-dementia-being-cared-for-at-home-a-literature-review.php?aid=3759>

References

- de Witt, L., & Fortune, D. (2019). Relationship-Centered Dementia Care: Insights from a Community-Based Culture Change Coalition. *Dementia, 18*(3), 1146-1165. <https://doi.org/10.1177/1471301217708814>
- Deci, E. L. (1975). *Intrinsic motivation* (Vol. 1). Plenum Press.
- Deci, E. L., & Ryan, R. M. (2014). Autonomy and Need Satisfaction in Close Relationships: Relationships Motivation Theory. In N. Weinstein (Ed.), *Human Motivation and Interpersonal Relationships: Theory, Research, and Applications*. Springer Netherlands: Imprint: Springer.
- Denzin, N. K., & Lincoln, Y. S. (2003). *The Landscape of qualitative research: theories and issues* (2nd ed.). Sage.
- Dewar, B., & Nolan, M. (2013). Caring about caring: developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies, 50*(9), 1247-1258. <https://doi.org/10.1016/j.ijnurstu.2013.01.008>
- Dombestein, H., Norheim, A., & Lunde Husebo, A. M. (2019). Understanding informal caregivers' motivation from the perspective of self-determination theory: an integrative review. *Scandinavian Journal of Caring Science, 34*(2), 267-279. <https://doi.org/10.1111/scs.12735>
- Doolen, J. (2017). Meta-Analysis, Systematic, and Integrative Reviews: An Overview. *Clinical Simulation in Nursing, 13*(1), 28-30. <https://doi.org/10.1016/j.ecns.2016.10.003>
- Daatland, S. O., Veenstra, M., & Lima, I. A. (2010). Norwegian sandwiches. *European Journal of Ageing, 7*(4), 271-281. <https://doi.org/10.1007/s10433-010-0163-3>
- Engedal, K., & Haugen, P. K. (2009). *Demens: fakta og utfordringer: en lærebok*. Forlaget Aldring og helse.
- Epstein, R. M., & Hundert, E. M. (2002). Defining and Assessing Professional Competence. *JAMA, 287*(2), 226-235. <https://doi.org/10.1001/jama.287.2.226>
- Eraut, M. (1998). Concepts of competence. *Journal of Interprofessional Care, 12*(2), 127-139. <https://doi.org/10.3109/13561829809014100>
- Fangen, K. (2015). *Ethical considerations - Qualitative methods*. The Norwegian National Research Ethics Committees. <https://www.forskningsetikk.no/en/resources/the-research-ethics-library/methods/qualitative-methods/>
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The Fundamentals of Person-Centered Care for Individuals With Dementia. *The Gerontologist, 58*, 10-19. <https://doi.org/10.1093/geront/gnx122>

References

- Frias, C. E., Garcia-Pascual, M., Montoro, M., Ribas, N., Risco, E., & Zabalegui, A. (2020). Effectiveness of a psychoeducational intervention for caregivers of People With Dementia with regard to burden, anxiety and depression: A systematic review. *Journal of Advanced Nursing*, 76(3), 787-802. <https://doi.org/10.1111/jan.14286>
- Frost, N. A., & Shaw, R. L. (2015). Evolving Mixed and Multimethod Approaches for Psychology. In S. N. Hesse-Biber & R. B. Johnson (Eds.), *The Oxford handbook of multimethod and mixed methods research inquiry*. Oxford University Press.
- Fu, F., Zhao, H., Tong, F., & Chi, I. (2017). A Systematic Review of Psychosocial Interventions to Cancer Caregivers. *Frontiers in Psychology*, 8(834). <https://doi.org/10.3389/fpsyg.2017.00834>
- Gallagher-Thompson, D., Choryan Bilbrey, A., Apesoa-Varano, E. C., Ghatak, R., Kim, K. K., & Cothran, F. (2020). Conceptual Framework to Guide Intervention Research Across the Trajectory of Dementia Caregiving. *The Gerontologist*, 60, 29-40. <https://doi.org/10.1093/geront/gnz157>
- Garcia-Ptacek, S., Dahlrup, B., Edlund, A. K., Wijk, H., & Eriksdotter, M. (2019). The caregiving phenomenon and caregiver participation in dementia. *Scandinavian Journal of Caring Science*, 33(2), 255-265. <https://doi.org/10.1111/scs.12627>
- Gautun, H., & Bratt, C. (2017). Caring too much? Lack of public services to older people reduces attendance at work among their children. *European Journal of Ageing*, 14(2), 155-166. <https://doi.org/10.1007/s10433-016-0403-2>
- Gjøra, L., Kjellvik, G., Strand, B. H., Kvello-Alme, M., & Selbæk, G. (2020). *Forekomst av demens i Norge* [Report]. <https://butikk.aldringoghelse.no/demens/forekomst-av-demens-i-norge>
- Gough, D., Thomas, J., & Oliver, S. (2012). Clarifying differences between review designs and methods. *Systematic Reviews*, 1(28). <https://doi.org/10.1186/2046-4053-1-28>
- Green, J. C. (2015). Preserving Distinctions within the Multimethod and Mixed Methods Research Merger. In S. N. Hesse-Biber & R. B. Johnson (Eds.), *The Oxford handbook of multimethod and mixed methods research inquiry*. Oxford University Press.
- Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with dementia: a systematic review of qualitative literature. *BMC Geriatrics*, 19(1), 169. <https://doi.org/10.1186/s12877-019-1185-0>

References

- Hanssen, H., & Sommerseth, R. (2015). Den familiære relasjonens betydning for pårørendes behov i møte med helsetjenesten. *Nordisk Tidsskrift for Helseforskning*, 10(2), 62-75. <https://doi.org/10.7557/14.3323>
- Haugen, I. (2020). *Constructions of user participation in home-based dementia care* [PhD Thesis]. VID vitenskapelige høyskole.
- Hengelaar, A. H., van Hartingsveldt, M., Wittenberg, Y., van Etten-Jamaludin, F., Kwekkeboom, R., & Satink, T. (2018). Exploring the collaboration between formal and informal care from the professional perspective: A thematic synthesis. *Health & Social Care in the Community*, 26(4), 474-485. <https://doi.org/10.1111/hsc.12503>
- Henriksen, N., Moholt, J.-M., & Blix, B. H. (2020). Perceptions of Family Caregivers of Home-Dwelling Persons with Dementia regarding Access to Information and Involvement in Decisions. *Journal of Aging & Social Policy*, 32(3), 260-275. <https://doi.org/10.1080/08959420.2019.1707058>
- Hesse-Biber, S., Rodriguez, D., & Frost, N. A. (2015). A Qualitatively Driven Approach to Multimethod and Mixed Methods Research. In S. Hesse-Biber & R. B. Johnson (Eds.), *The Oxford handbook of multimethod and mixed methods research inquiry*. Oxford University Press.
- Hesse-Biber, S. N., & Johnson, R. B. (2015). *The Oxford handbook of multimethod and mixed methods research inquiry*. Oxford University Press.
- Hoffmann, F., & Rodrigues, R. (2010). *Informal Carers: Who Takes Care of Them?* [Report]. <https://www.euro.centre.org/publications/detail/387>
- Holt Clemmensen, T., Hein Lauridsen, H., Andersen-Ranberg, K., & Kaae Kristensen, H. (2020). Informal carers' support needs when caring for a person with dementia – A scoping literature review. *Scandinavian Journal of Caring Sciences*, 0(0). <https://doi.org/10.1111/scs.12898>
- Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M. P., Griffiths, F., Nicolau, B., O' Cathain, A., Rousseau, M. C., Vedel, I., & Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, 34(4), 285-291. <https://doi.org/10.3233/EFI-180221>
- Hunter, A., & Brewer, J. (2015). Designing Multimethod Research. In S. N. Hesse-Biber & R. B. Johnson (Eds.), *The Oxford Handbook of Multimethod and Mixed Methods Research Inquiry*. Oxford: Oxford University Press, Incorporated.

References

- Häikiö, K., Cloutier, D., & Rugkåsa, J. (2020). Is health literacy of family carers associated with carer burden, quality of life, and time spent on informal care for older persons living with dementia? *PLoS ONE*, *15*(11), e0241982. <https://doi.org/10.1371/journal.pone.0241982>
- Jenhaug, L. M. (2018). Myndighetenes forventninger til pårørende som samprodusenter i omsorgstjenester. *Tidsskrift for velferdsforskning*, *21*(1), 39-58. <https://doi.org/10.18261/issn.2464-3076-2018-01-03>
- Karlsson, S., Bleijlevens, M., Roe, B., Saks, K., Martin, M. S., Stephan, A., Suhonen, R., Zabalegui, A., Hallberg, I. R., & the RightTimeCarePlace, C. (2015). Dementia care in European countries, from the perspective of people with dementia and their caregivers. *Journal of Advanced Nursing*, *71*(6), 1405-1416. <https://doi.org/10.1111/jan.12581>
- Kim, Y., Carver, C., & Cannady, R. (2015). Caregiving Motivation Predicts Long-Term Spirituality and Quality of Life of the Caregivers. *Annals of Behavioral Medicine*, *49*(4), 500-509. <https://doi.org/10.1007/s12160-014-9674-z>
- Kim, Y., Carver, C. S., Deci, E. L., & Kasser, T. (2008). Adult attachment and psychological well-being in cancer caregivers: the mediational role of spouses' motives for caregiving. *Health Psychology*, *27*(2), 144-154. <https://doi.org/10.1037/0278-6133.27.2>
- Kindt, S., Vansteenkiste, M., Cano, A., & Goubert, L. (2017). When is your partner willing to help you? The role of daily goal conflict and perceived gratitude. *Motivation and Emotion*, *41*(6), 671-682. <https://doi.org/10.1007/s11031-017-9635-5>
- Kindt, S., Vansteenkiste, M., Loeys, T., Cano, A., Lauwerier, E., Verhofstadt, L. L., & Goubert, L. (2015). When Is Helping your Partner with Chronic Pain a Burden? The Relation Between Helping Motivation and Personal and Relational Functioning. *Pain Med*, *16*(9), 1732-1744. <https://doi.org/10.1111/pme.12766>
- Kindt, S., Vansteenkiste, M., Loeys, T., & Goubert, L. (2016). Helping motivation and well-being of chronic pain couples. *PAIN*, *157*(7), 1551-1562. <https://doi.org/10.1097/j.pain.0000000000000550>
- Kitwood, T., Høeg, D., & Johnsen, N. (1999). *En revurdering af demens: personen kommer i første række*. Dafolo.
- Krueger, R. A., & Casey, M. A. (2015). *Focus groups: a practical guide for applied research* (5th ed.). Sage.
- Kvale, S., & Brinkmann, S. (2009). *Interviews: learning the craft of qualitative research interviewing* (2nd ed.). Sage.

References

- Laparidou, D., Middlemass, J., Karran, T., & Siriwardena, A. N. (2018). Caregivers' interactions with health care services – Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia – A qualitative study. *Dementia*, 18(7-8), 2526-2542. <https://doi.org/10.1177/1471301217751226>
- Larsen, L. S. S. (2017). *Speaking in behalf of the person with dementia in home-based care. A qualitative study of collaboration between formal and family caregivers in Sami and Norwegian municipalities* [PhD Thesis]. The Arctic University of Norway.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer.
- Lillemyr, O. F. (2016). *Motivasjon og selvforståelse: hva ligger bak det vi gjør?* (3rd ed.). Universitetsforlaget.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage.
- Lincoln, Y. S., & Guba, E. G. (2003). Paradigmatic Controversies, Contradictions, and Emerging Confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Landscape of qualitative research: theories and issues* (2nd ed., p. 253-291). Sage.
- Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*, 15(6), 1534-1561. <https://doi.org/10.1177/1471301214564792>
- Locke, E. A. (1968). Toward a theory of task motivation and incentives. *Organizational Behavior and Human Performance*, 3(2), 157-189. [https://doi.org/10.1016/0030-5073\(68\)90004-4](https://doi.org/10.1016/0030-5073(68)90004-4)
- Lyonette, C., & Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Ageing & Society*, 23, 487-506. <https://doi.org/10.1017/S0144686x03001284>
- Macleod, A., Tatangelo, G., McCabe, M., & You, E. (2017). "There isn't an easy way of finding the help that's available." Barriers and facilitators of service use among dementia family caregivers: a qualitative study. *International Psychogeriatrics*, 29(5), 765-776. <https://doi.org/10.1017/S1041610216002532>
- Magnusson, L., & Hanson, E. (2004). Working with Older People and Their Carers to Research and Develop Responsive ICT Support Services. *Health Informatics Journal*, 10(1), 83-88. <https://doi.org/10.1177/1460458204040673>
- Malterud, K. (2002). Reflexivity and metapositions: strategies for appraisal of clinical evidence. *Journal of Evaluation in Clinical Practice*, 8(2), 121-126. <https://doi.org/10.1046/j.1365-2753.2002.00353.x>

References

- Malterud, K. (2012a). *Fokusgrupper som forskningsmetode for medisin og helsefag*. Universitetsforl.
- Malterud, K. (2012b). Systematic text condensation: A strategy for qualitative analysis. *Scandinavian Journal of Public Health*, 40(8), 795-805. <https://doi.org/10.1177/1403494812465030>
- Malterud, K. (2019). *Qualitative metasynthesis: a research method for medicine and health sciences*. Routledge.
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qualitative Health Research*, 26(13), 1753-1760. <https://doi.org/10.1177/1049732315617444>
- Meld. St. 14. (2020–2021). *Long-term Perspectives on the Norwegian Economy 2021*. In *Norwegian: Perspektivmeldingen 2021* (Meld. St. 14,). <https://www.regjeringen.no/no/dokumenter/meld.-st.-14-20202021/id2834218/>
- Meld. St. 15. (2017-2018). *A full life - all your life - A Quality Reform for Older Persons*. In *Norwegian: Leve hele livet - En kvalitetsreform for eldre* Ministry of Health and Care Services. <https://www.regjeringen.no/en/dokumenter/meld.-st.-15-20172018/id2599850/>
- Meld. St. 29. (2012-2013). *Future Care*. In *Norwegian: Morgendagens omsorg* (Meld. St. 29). <https://www.regjeringen.no/en/dokumenter/meld.-st.-29-2012-2013/id723252/>
- Milyavskaya, M., & Koestner, R. (2011). Psychological needs, motivation, and well-being: A test of self-determination theory across multiple domains. *Personality and Individual Differences*, 50(3), 387-391. <https://doi.org/10.1016/j.paid.2010.10.029>
- Ministries. (2020). Ministry of Health and Care Services, Ministry of Labour and Social Affairs, Ministry of Children and Families, Ministry of Culture, Ministry of Local Government and Modernisation. *Family caregivers strategy 2021-2025*. In *Norwegian: Vi – de pårørende Regjeringens pårørendestrategi og handlingsplan 2021-2025* <https://www.regjeringen.no/contentassets/08948819b8244ec893d90a66deb1aa4a/vi-de-parorende.pdf>

References

- Ministry of Health and Care Services (MHCH). (2015). *Dementia Plan 2020 - A more dementia-friendly society. In Norwegian: Demensplan 2020 - Et mer demensvennlig samfunn.*
https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/dementia_plan_2020_long.pdf
- Ministry of Health and Care Services (MHCH). (2020). *Dementia Plan 2025. In Norwegian: Demensplan 2025.*
<https://www.regjeringen.no/no/dokumenter/demensplan-2025/id2788070/>
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLOS Medicine*, 6(7).
<https://doi.org/10.1371/journal.pmed.1000097>
- Moholt, J.-M. (2019). *Utilization of community healthcare services and family caregivers' needs for support. A survey of family caregivers for older, home-dwelling persons with dementia in Northern Norway* [PhD Thesis]. The Arctic University of Norway.
- Moholt, J.-M., Friberg, O., Blix, B. H., & Henriksen, N. (2018). Factors affecting the use of home-based services and out-of-home respite care services: A survey of family caregivers for older persons with dementia in Northern Norway. *Dementia*, 19(5), 1712-1731.
<https://doi.org/10.1177/1471301218804981>
- Moholt, J.-M., Friberg, O., Henriksen, N., Hamran, T., & Blix, B. H. (2020). Non-use of community health-care services – an exploratory cross-sectional study among family care-givers for older, home-dwelling persons with dementia. *Ageing and Society*, 0(0), 1-25.
<https://doi.org/10.1017/S0144686X2000015X>
- Moniz Cook, E. D., Swift, K., James, I., Malouf, R., De Vugt, M., & Verhey, F. (2012). Functional analysis-based interventions for challenging behaviour in dementia. *Cochrane Database of Systematic Reviews*, 2, Art. No.: CD006929.
<https://doi.org/10.1002/14651858.CD006929.pub2>
- Morgan, D. L. (1997). *Focus groups as qualitative research* (2nd ed.). Thousand Oaks, C.A.: SAGE Publications.
- Morse, J. M. (2011). What is qualitative health research? In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (4th ed., p. 401-414). Sage.

References

- Morse, J. M. (2015). Issues in Qualitatively-Driven Mixed-Method Designs: Walking Through a Mixed-Method Project. In S. N. Hesse-Biber & R. B. Johnson (Eds.), *The Oxford Handbook of Multimethod and Mixed Methods Research Inquiry*. Oxford: Oxford University Press, Incorporated.
- Morse, J. M. (2017). *Essentials of qualitatively-driven mixed-method designs* (14th ed.). Routledge.
- Morse, J. M., & Niehaus, L. (2009). *Mixed method design: principles and procedures* (4th ed.). Left Coast Press.
- Maayan, N., Soares-Weiser, K., & Lee, H. (2014). Respite care for people with dementia and their carers. *Cochrane Database of Systematic Reviews*(1), Art. No.: CD004396.
<https://doi.org/10.1002/14651858.CD004396.pub3>
- Ng, H. Y., Griva, K., Lim, H. A., Tan, J. Y., & Mahendran, R. (2016). The burden of filial piety: A qualitative study on caregiving motivations amongst family caregivers of patients with cancer in Singapore. *Psychology & Health, 31*(11), 1293-1310.
<https://doi.org/10.1080/08870446.2016.1204450>
- Ng, J. Y., Ntoumanis, N., Thogersen-Ntoumani, C., Deci, E. L., Ryan, R. M., Duda, J. L., & Williams, G. C. (2012). Self-Determination Theory Applied to Health Contexts: A Meta-Analysis. *Perspectives on Psychological Science, 7*(4), 325-340.
<https://doi.org/10.1177/1745691612447309>
- Niemiec, C. P., Soenens, B., & Vansteenkiste, M. (2014). Is Relatedness Enough? On the Importance of Need Support in Different Types of Social Experiences. In N. Weinstein (Ed.), *Human Motivation and Interpersonal Relationships: Theory, Research, and Applications*. Springer Netherlands: Imprint: Springer.
- Nolan, M., Brown, J., Davies, S., Nolan, J., & Keady, J. (2006). *The SENSES framework: Improving care for older people through a relationship-centred approach. Getting Research Into Practice (GRiP) Report No. 2.* <https://core.ac.uk/download/pdf/99946.pdf>
- Nolan, M., Davies, N., & Grant, G. (2001). *Working with older people and their families*. GB: Open University Press.
- Nolan, M., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of Clinical Nursing, 13*(1), 45-53.
<https://doi.org/10.1111/j.1365-2702.2004.00926.x>

References

- Nolan, M., Grant, G., & Keady, J. (1996). *Understanding family care: a multidimensional model of caring and coping*. Open university press.
- Nolan, M., Lundh, U., Grant, G., & Keady, J. (2003). *Partnerships in Family Care*. McGraw-Hill Education.
- Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a More Inclusive Vision of Dementia Care Practice and Research. *Dementia*, 1(2), 193-211. <https://doi.org/10.1177/147130120200100206>
- Nordtug, B. (2011). *Caring burden of cohabitants living with partners suffering from chronic obstructive pulmonary disease or dementia* [PhD Thesis]. NTNU Trondheim.
- Norwegian Directorate of Health. (2018). *The Norwegian national guidelines for dementia care*. In *Norwegian: Nasjonal faglig retningslinje om demens*. <https://www.helsedirektoratet.no/retningslinjer/demens>
- Norwegian Directorate of Health. (2019). *The National Guidelines about Caregivers in the Health Care Services*. In *Norwegian: Veileder om pårørende i helse- og omsorgstjenesten* <https://www.helsedirektoratet.no/veiledere/parorendeveileder>
- Norwegian Directorate of Health. (2021). *National caregiver survey*. In *Norwegian: Nasjonal pårørendeundersøkelsen – fra Opinion for Helsedirektoratet*. <https://www.helsedirektoratet.no/nyheter/nasjonal-parorendeundersokelse>
- Norwegian Health Association. (2020). *What is Dementia? In Norwegian: Hva er demens?*. Retrieved 22 December from <https://nasjonalforeningen.no/demens/hva-er-demens/>
- Ntoumanis, N., Ng, J. Y. Y., Prestwich, A., Quested, E., Hancox, J. E., Thøgersen-Ntoumani, C., Deci, E. L., Ryan, R. M., Lonsdale, C., & Williams, G. C. (2020). A meta-analysis of self-determination theory-informed intervention studies in the health domain: effects on motivation, health behavior, physical, and psychological health. *Health Psychology Review*, 1-31. <https://doi.org/10.1080/17437199.2020.1718529>
- OECD, Organisation for Economic Co-operation and Development. (2018). *Care Needed - Improving the Lives of People with Dementia* (OECD Health Policy Studies, Issue. <http://www.oecd.org/health/care-needed-9789264085107-en.htm>
- Overgaard, D., & Bovin, J. S. (2014). Hvordan bliver forskning i sygepleje bedre med NVivo? *Nordisk sygeplejeforskning*, 4(3), 241-250. <http://www.idunn.no/nsf/2014/03/hvordan-bliver-forskning-i-sygepleje-bedre-med-nvivo>

References

- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the Stress Process: An Overview of Concepts and Their Measures. *The Gerontologist*, 30(5), 583 - 594.
<https://doi.org/10.1093/geront/30.5.583>
- Pierce, T., Lydon, J. E., & Yang, S. (2001). Enthusiasm and Moral Commitment: What Sustains Family Caregivers of Those With Dementia. *Basic & Applied Social Psychology*, 23(1), 29-41.
<https://doi.org/10.1207/153248301750123050>
- Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: a meta-analytic comparison. *Psychol Aging*, 26(1), 1-14. <https://doi.org/10.1037/a0021863>
- Pluye, P., Gagnon, M.-P., Griffiths, F., & Johnson-Lafleur, J. (2009). A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *International Journal of Nursing Studies*, 46(4), 529-546.
<https://doi.org/10.1016/j.ijnurstu.2009.01.009>
- Polit, D. F., & Beck, C. T. (2018). *Essentials of nursing research: appraising evidence for nursing practice* (9th ed.). Wolters Kluwer.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & Dementia*, 9(1), 63-75.
<https://doi.org/10.1016/j.jalz.2012.11.007>
- QSR International. (2019). *NVIVO 12 for Windows*. NVIVO Web Page. Retrieved 10. octocer from <https://qsrinternational.com/nvivo/home>
- Quinn, C., Clare, L., & Woods, R. T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *International Psychogeriatrics*, 22(1), 43-55.
<https://doi.org/10.1017/S1041610209990810>
- Quinn, C., Clare, L., & Woods, R. T. (2012). What predicts whether caregivers of people with dementia find meaning in their role? *International Journal of Geriatric Psychiatry*, 27(11), 1195-1202.
<https://doi.org/10.1002/gps.3773>
- Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia*, 14(2), 220-237. <https://doi.org/10.1177/1471301213495863>
- Reeve, J. (2018). *Understanding motivation and emotion* (Seventh edition). John Wiley.

References

- Reilly, S., Miranda-Castillo, C., Malouf, R., Hoe, J., Toot, S., Challis, D., & Orrell, M. (2015). Case management approaches to home support for people with dementia. *Cochrane Database of Systematic Reviews*(1). <https://doi.org/10.1002/14651858.CD008345.pub2>
- Ribeiro, O., Brandão, D., Oliveira, A. F., Teixeira, L., & Paúl, C. (2020). Positive aspects of care in informal caregivers of community-dwelling dementia patients. *Journal of Psychiatric and Mental Health Nursing*, 27(4), 330-341. <https://doi.org/10.1111/jpm.12582>
- Rigby, C. S., & Ryan, R. M. (2018). Self-Determination Theory in Human Resource Development: New Directions and Practical Considerations. *Advances in Developing Human Resources*, 20(2), 133-147. <https://doi.org/10.1177/1523422318756954>
- Robson, C. (2002). *Real world research: a resource for social scientists and practitioner-researchers* (2nd ed.). Blackwell.
- Romain, A. J., Bernard, P., Akkrass, Z., St-Amour, S., Lachance, J.-P., Hains-Monfette, G., Atoui, S., Kingsbury, C., Dubois, E., Karelis, A. D., & Abdel-Baki, A. (2020). Motivational theory-based interventions on health of people with several mental illness: A systematic review and meta-analysis. *Schizophrenia Research*, 222, 31-41. <https://doi.org/10.1016/j.schres.2020.05.049>
- Romero-Moreno, R., Márquez-González, M., Losada, A., & López, J. (2011). Motives for caring: relationship to stress and coping dimensions. *International Psychogeriatrics*, 23(4), 573-582. <https://doi.org/10.1017/S1041610210001821>
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: a reappraisal from population-based studies. *Gerontologist*, 55(2), 309-319. <https://doi.org/10.1093/geront/gnu177>
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68-78. <https://doi.org/10.1037/0003-066X.55.1.68>
- Ryan, R. M., & Deci, E. L. (2017). *Self-determination theory: basic psychological needs in motivation, development, and wellness*. Guilford Press.
- Ryan, R. M., & Deci, E. L. (2019). Chapter Four - Brick by Brick: The Origins, Development, and Future of Self-Determination Theory. In A. J. Elliot (Ed.), *Advances in Motivation Science* (6th ed., p. 111-156). Elsevier. <https://doi.org/10.1016/bs.adms.2019.01.001>

References

- Sansone, C., & Harackiewicz, J. M. (2000). *Intrinsic and Extrinsic Motivation: The Search for Optimal Motivation and Performance*. Elsevier Science & Technology.
<http://ebookcentral.proquest.com/lib/uisbib/detail.action?docID=313671>
- Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas*, *66*, s191-200.
<https://doi.org/10.1016/j.maturitas.2010.02.009>
- Schulz, R., Beach, S. R., Czaja, S. J., Martire, L. M., & Monin, J. K. (2020). Family Caregiving for Older Adults. *Annu Rev Psychol*, *71*, 635-659.
<https://doi.org/10.1146/annurev-psych-010419-050754>
- Skogli, E., Karttinen, E., Stokke, O., & Vikøren, S. (2020a). *Alzheimers og annen demenssykdom utredning og behandling* (NR. 63/2020). MENON. <https://www.menon.no/wp-content/uploads/2020-63-Alzheimers-og-annen-demenssykdom-utredning-og-behandling.pdf>
- Skogli, E., Karttinen, E., Stokke, O., & Vikøren, S. (2020b). *Samfunnskostnader knyttet til alzheimers og annen demenssykdom* (NR 64/2020). MENON. <https://www.menon.no/wp-content/uploads/2020-64-Samfunnskostnader-knyttet-til-Alzheimers-og-annen-demenssykdom.pdf>
- Statistics Norway. (2020). *Educational attainment of the population*. Retrieved 12 August from <https://www.ssb.no/en/utdanning/statistikker/utniv>
- Strekalova, Y. A. (2016). Finding Motivation: Online Information Seeking Following Newborn Screening for Cystic Fibrosis. *Qualitative Health Research*, *26*(9), 1180-1190.
<https://doi.org/10.1177/1049732315614580>
- Sullivan, A. B., & Miller, D. (2015). Who is Taking Care of the Caregiver? *Journal of Patient Experience*, *2*(1), 7-12.
<https://doi.org/10.1177/237437431500200103>
- Svendsboe, E., Terum, T., Testad, I., Aarsland, D., Ulstein, I., Corbett, A., & Rongve, A. (2016). Caregiver burden in family carers of people with dementia with Lewy bodies and Alzheimer's disease. *International Journal of Geriatric Psychiatry*, *31*(9), 1075-1083.
<https://doi.org/10.1002/gps.4433>

References

- Tan-Ho, G., Choo, P. Y., Patinadan, P. V., Low, C. X., & Ho, A. H. Y. (2020). Blessings or burdens: an Interpretative Phenomenological Analysis (IPA) study on the motivations and their impact on end-of-life caregiving among Asian family caregivers. *BMC Palliative Care*, 19(1), 132. <https://doi.org/10.1186/s12904-020-00638-6>
- Tatangelo, G., McCabe, M., Macleod, A., & You, E. (2018). "I just don't focus on my needs." The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. *International Journal of Nursing Studies*, 77, 8-14. <https://doi.org/10.1016/j.ijnurstu.2017.09.011>
- Terum, T. M., Testad, I., Rongve, A., Aarsland, D., Svendsboe, E., & Andersen, J. R. (2019). The association between specific neuropsychiatric disturbances in people with Alzheimer's disease and dementia with Lewy bodies and carer distress. *International Journal of Geriatric Psychiatry*, 34(10), 1421-1428. <https://doi.org/10.1002/gps.5134>
- Teshuva, K., Cohen-Mansfield, J., Iecovich, E., & Golander, H. (2019). Like one of the family? Understanding relationships between migrant live-in care workers and older care recipients in Israel. *Ageing and Society*, 39(7), 1387-1408. <https://doi.org/10.1017/S0144686X1800003X>
- The Health Personnel Act. (1999). Act of 2 July 1999 No. 64 relating to Health Personnel etc. In Norwegian: Lov 2. juli 1999 nr. 64 Lov om helsepersonell m.v. (helsepersonelloven), <https://lovdata.no/dokument/NL/lov/1999-07-02-64?q=helsepersonell%20loven>
- The Municipal Health Services Act. (2011). Act of 24 June 2011 No. 30 relating to Municipal Health and Care Services. In Norwegian: Lov 24. juni 2011 nr. 30. Lov om kommunale helse- og omsorgstjenester m.m. (helse- og omsorgstjenesteloven), <https://lovdata.no/dokument/NL/lov/2011-06-24-30>
- The Patients and User Rights Act. (1999). Act of 2 July 1999 No. 63 relating to Patients and User Rights. In Norwegian: LOV-1999-07-02- nr. 63. Lov om pasient- og brukerrettigheter (pasient- og brukerrettighetsloven), <https://lovdata.no/dokument/NL/lov/1999-07-02-63>
- The World Medical Association. (2008). *Ethical principles for medical research involving human subjects. In Declaration of Helsinki, Seoul*. Retrieved 10.07.2020 from <https://www.wma.net/what-we-do/medical-ethics/declaration-of-helsinki/>

References

- Tong, A., Craig, J., & Sainsbury, P. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357. <https://doi.org/10.1093/intqhc/mzm042>
- Tretteteig, S., Thorsen, K., & Mork Rokstad, A. M. (2019). Pårørendes erfaringer av kvalitet i helse- og omsorgstjenester til personer med demens og pårørende. En longitudinell narrativ studie. *Tidsskriftet aldring og helse* 23(4), 56-64. [https://www.aldringoghelse.no/ah-archive/documents/P%C3%A5r%C3%B8rendes erfaringer av kvalitet et i helse- og omsorgstjenester til personer med demens.pdf](https://www.aldringoghelse.no/ah-archive/documents/P%C3%A5r%C3%B8rendes%20erfaringer%20av%20kvalitet%20i%20helse-og%20omsorgstjenester%20til%20personer%20med%20demens.pdf)
- Tretteteig, S., Vatne, S., & Mork Rokstad, A. M. (2016). The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature. *Aging & Mental Health*, 20(5), 450-462. <https://doi.org/10.1080/13607863.2015.1023765>
- Tretteteig, S., Vatne, S., & Mork Rokstad, A. M. (2017a). The influence of day care centres designed for people with dementia on family caregivers – a qualitative study. *BMC Geriatrics*, 17(1), 5. <https://doi.org/10.1186/s12877-016-0403-2>
- Tretteteig, S., Vatne, S., & Mork Rokstad, A. M. (2017b). Meaning in family caregiving for people with dementia: a narrative study about relationships, values, and motivation, and how day care influences these factors. *Journal of Multidisciplinary Healthcare*, 10, 445-455. <https://doi.org/10.2147/jmdh.S151507>
- Ugreninov, E. (2013). Offspring in Squeeze: Health and Sick Leave Absence among Middle-aged Informal Caregivers. *Journal of Population Ageing*, 6(4), 323-338. <https://doi.org/10.1007/s12062-013-9091-2>
- Ulstein, I. (2007). *Dementia in the family* [PhD Thesis]. Universitetet i Oslo, Det medisinske fakultet. Oslo.
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & Health Sciences*, 15(3), 398-405. <https://doi.org/10.1111/nhs.12048>
- van der Lee, J., Bakker, T. J. E. M., Duivenvoorden, H. J., & Dröes, R.-M. (2014). Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Research Reviews*, 15, 76-93. <https://doi.org/10.1016/j.arr.2014.03.003>
- Vangen, H. (2020). The Impact of Informal Caregiving on Labour Supply Before and After a Parent's Death. *Journal of Population Ageing*. <https://doi.org/10.1007/s12062-020-09279-2>

References

- Vossius, C., Selbæk, G., Ydstebø, A. E., Benth, J. S., Godager, G., Lurås, H., & Bergh, S. (2015). *Ressursbruk og sykdomsforløp ved demens (REDIC) langversjon*. https://sykehuset-innlandet.no/Documents/REDIC_Rapport_Fullversjon.pdf
- Vroom, V. H. (1964). *Work and motivation*. New York, NY: Wiley.
- Watson, J. (2016). Developing the Senses Framework to support relationship-centred care for people with advanced dementia until the end of life in care homes. *Dementia*, 18(2), 545-566. <https://doi.org/10.1177/1471301216682880>
- Weinstein, N., & Ryan, R. M. (2010). When helping helps: autonomous motivation for prosocial behavior and its influence on well-being for the helper and recipient. *Journal of Personality and Social Psychology*, 98(2), 222-244. <https://doi.org/10.1037/a0016984>
- Wennerberg, M. M., Eriksson, M., Danielson, E., & Lundgren, S. M. (2016). Unravelling Swedish informal caregivers' Generalised Resistance Resources. *Scandinavian Journal of Caring Science*, 30(3), 602-613. <https://doi.org/10.1111/scs.12292>
- White, R. W. (1959). Motivation reconsidered: The concept of competence. *Psychological Review*, 66(5), 297-333. <https://doi.org/10.1037/h0040934>
- Whittemore, R., Chao, A., Jang, M., Minges, K. E., & Park, C. (2014). Methods for knowledge synthesis: An overview. *Heart & Lung: The Journal of Acute and Critical Care*, 43(5), 453-461. <https://doi.org/10.1016/j.hrtlng.2014.05.014>
- Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, 52(5), 546-553. <https://doi.org/doi:10.1111/j.1365-2648.2005.03621.x>
- WHO, World Health Organization. (2016). *Framework on integrated people-centred health services*. Retrieved 13.12.2020 from <https://www.who.int/servicedeliverysafety/areas/people-centred-care/framework/en/>
- WHO, World Health Organization. (2019). *International Classification of Diseases, ICD-10 Version:2019*. <https://icd.who.int/browse10/2019/en#/F00-F09>
- WHO, World Health Organization. (2020). *Dementia - Key facts*. Retrieved 01.12. from <https://www.who.int/news-room/fact-sheets/detail/dementia>

References

- Williams, G. C. (2014). Self-Determination and the Patient-Health Practitioner Relationship. In N. Weinstein (Ed.), *Human Motivation and Interpersonal Relationships: Theory, Research, and Applications*. Springer Netherlands: Imprint: Springer.
- Williams, G. C., Frankel, R. M., Campbell, T. L., & Deci, E. L. (2000). Research on relationship-centered care and healthcare outcomes from the Rochester biopsychosocial program: A self-determination theory integration. *Families, Systems, & Health*, 18(1), 79-90.
<https://doi.org/10.1037/h0091854>
- Williams, G. C., Halvari, H., Niemiec, C. P., Sorebo, O., Olafsen, A. H., & Westbye, C. (2014). Managerial support for basic psychological needs, somatic symptom burden and work-related correlates: A self-determination theory perspective. *Work and Stress*, 28(4), 404-419.
<https://doi.org/10.1080/02678373.2014.971920>
- Ydstebø, A. E., Benth, J. Š., Bergh, S., Selbæk, G., & Vossius, C. (2020). Informal and formal care among persons with dementia immediately before nursing home admission. *BMC Geriatrics*, 20(1), 296.
<https://doi.org/10.1186/s12877-020-01703-8>
- Yu, D. S. F., Cheng, S. T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies*, 79, 1-26.
<https://doi.org/10.1016/j.ijnurstu.2017.10.008>
- Yuen, E. Y. N., Knight, T., Ricciardelli, L. A., & Burney, S. (2018). Health literacy of caregivers of adult care recipients: A systematic scoping review. *Health & Social Care in the Community*, 26(2), 191-206.
<https://doi.org/10.1111/hsc.12368>
- Zahed, S., Emami, M., Bazargan-Hejazi, S., Eslami, A. A., Barekatin, M., & Zamani-Alavijeh, F. (2019). What motivates informal caregivers of people with dementia (PWD): a qualitative study. *BMC Palliative Care*, 18(1), 105. <https://doi.org/10.1186/s12904-019-0491-9>
- Zarit, S. H. (2012). Positive aspects of caregiving: More than looking on the bright side. *Aging & Mental Health*, 16(6), 673-674.
<https://doi.org/10.1080/13607863.2012.692768>
- Zigante, V. (2018). *Informal care in Europe, Exploring Formalisation, Availability and Quality*. [Report].
<https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8106&type=2&furtherPubs=no>

References

- Øydgard, G. W. (2018). *Forhandlinger i omsorg. En institusjonell etnografi om pårørendes omsorgsarbeid og tilgang til helse- og omsorgstjenester* [PhD Thesis]. Nord Universitet.
- Aasgaard, H. S., Disch, P. G., Fagerström, L., & Landmark, B. T. (2014). Pårørende til aleneboende personer med demens - Erfaringer fra samarbeid med hjemmetjenesten etter ny organisering. *Nordisk sygeplejeforskning*, 4(2), 114-128.
http://www.idunn.no/nsf/2014/02/paaroerende_til_aleneboende_personer_med_demens_-_erfaringer

Part II



List of articles

Article I

Dombestein, H., Norheim, A. & Lunde Husebø, A. M. (2019). Understanding informal caregivers' motivation from the perspective of self-determination theory: An integrative review. *Scandinavian Journal of Caring Sciences*. 34(2), 267–279. doi: 10.1111/scs.12735

Article II

Dombestein, H., Norheim, A. & Aase, K. (2020). Caring for home-dwelling parents with dementia: A qualitative study of adult-child caregivers' motivation. *Nursing Open*. 7(6), 1954-1965. doi:10.1002/nop2.587

Article III

Dombestein, H., Norheim, A. & Aase, K. (2021). How to stay motivated: A focus group study of Norwegian caregivers' experiences with community healthcare services to their parents with dementia. *Health and Social Care in the Community*. 00(0), 1–9. doi:10.1111/hsc.13396

Article I



Understanding informal caregivers' motivation from the perspective of self-determination theory: an integrative review

Heidi Dombestein MHSc, RN (PhD candidate)¹ , Anne Norheim RN (Professor, Nursing Science)² and Anne Marie Lunde Husebø MHSc, RN, PhD (Associate Professor)³

¹Department of Quality and Health Technology, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway, ²Department of Caring and Ethics, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway and ³Department of Public Health, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway

Scand J Caring Sci; 2020; 34: 267–279. Dombestein H, Norheim A, Lunde Husebø AM.

Understanding informal caregivers' motivation from the perspective of self-determination theory: an integrative review.

Background: A long-term illness is stressful both for the person with the diagnosis and for his or her informal caregivers. Many people willingly assume the caregiving role, so it is important to understand why they stay in this role and how their motivation affects their health. Self-determination theory (SDT) is a theory of human motivation that has been successfully applied in human research domains. To our knowledge, there is no literature review on the application of SDT in a caregiver context. A systematic review of the literature could improve the understanding of motivation in caregiver work and contribute to the utility of SDT.

Aim: To describe and explore empirical studies of caregivers' motivation from the perspective of self-determination theory.

Methods: An integrative literature review according to Whittemore and Knaf was conducted with systematic repetitive searches in the MEDLINE, Scopus, PsychInfo,

PsycNET, China, Cochrane Library and EMBASE databases. The searches were performed from May through December 2018. The PRISMA diagram was used for study selection, and papers were assessed for quality based on the Mixed Methods Appraisal Tool. Data analysis consisted of a four-stage narrative analysis method.

Result: Of 159 articles, 10 were eligible for inclusion. All studies considered satisfaction of the three basic psychological needs for competence, autonomy and relatedness as essential in predicting the quality of caregivers' motivation and thereby their well-being. In this review, autonomous motivation was the most important determinant of caregivers' well-being.

Conclusions: Findings showed that SDT can be applied to identify, categorise, explain, predict, promote and support motivation among caregivers. This lends interesting support for SDT and promotes further study and application of the theory as a psychological approach to caregivers' health and health promotion.

Keywords: informal caregiver, long-term illness, well-being, motivation, self-determination theory, integrative review.

Submitted 29 April 2019, Accepted 12 June 2019

Introduction

Long-term serious illness such as dementia, Parkinson's, multiple sclerosis, and cancer are demanding and often debilitating conditions that affect both the care recipients themselves and their informal caregivers on several levels (1,2).

Correspondence to:

Heidi Dombestein, Department of Quality and Health Technology, Faculty of Health Sciences, University of Stavanger, P.O. Box 8600 Forus, N-4036 Stavanger, Norway.
E-mail: heidi.dombestein@uis.no
Funding No funding was obtained for this study.

© 2019 The Authors. *Scandinavian Journal of Caring Sciences* published by John Wiley & Sons Ltd on behalf of Nordic College of Caring Science.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

As the illness progresses, the need for care and assistance increases for the person living with a long-term condition. Family members or other informal caregivers, either instead of or in addition to professional caregivers (3,4) attend to the person with a patient's needs. Informal caregiving consists of the ongoing activities and experiences involved in offering unpaid help to relatives or friends who are unable to take care of themselves (5,6). In Norway, informal caregivers provide approximately 50% of all care (7). Across the EU, family carers account for more than 80% of all care (4,8). Informal caregiving will continue to be essential in the light of the future demographic makeup of the population and the cost pressure on long-term care systems. Supporting and

267

maintaining the supply of family care appears to benefit the care recipient, the caregiver and the public system (3,4). Accordingly, the research literature recommends tailored interventions (1) and support services (9), to caregivers who are struggling to remain motivated (10).

Motivation for long-term caregiving is crucial for the way in which the informal carers experience caregiving (10). The perceived burden on the caregiver, the caregiver's approach to caring and his or her coping strategies depend on the type of illness or condition (2); family relations (11); volition in caregiving (12); and caregiver's resources (13). The present understanding of caregiving, still based on a stress-coping paradigm to reduce the burden on caregivers has become the main goal in the health services (6,14). The promotion of the positive aspects of caregiving, such as the sense of satisfaction, autonomy and expertise among caregivers as specific and legitimate goals (5,6,14,15) deserves greater attention. Many people offer informal caregiving so it is important to understand their motivation for assuming and remaining in this role (10) and these topics are not fully understood (5). Motivational processes energise behaviour, initiate, generate and increase task engagement and direct actions towards certain goals. Support for healthy motivation by important others influences a person's motivational orientations over time and shape his or her sense of well-being, psychological growth and resilience over the long-term (16). Studying motivation within a theoretical framework can illuminate the ways in which different motivations can positively or negatively influence caregivers' well-being (10).

Self-determination theory (SDT) is a broad framework that conceptualises the empirical study of human motivation (17,18). SDT identifies three innate psychological needs as a key drivers of motivation that influence well-being and thriving: autonomy, competence and relatedness. The need for *autonomy* refers not to independence but rather to volition – the sense that one's actions are endorsed by oneself, that one has a feeling of choice and ownership of his or her actions. The need for *competence* relates to the mastery and to the perception of performing a task with confidence; the need for *relatedness* is a feeling of mutual belonging and of supporting and being supported by others (17–19). Fulfilment of these basic needs promotes autonomous motivation and intrinsic aspirations, reflecting innate psychological nutrients essential for functioning, psychological health and well-being (17,18,20). SDT is particularly concerned with how social contextual factors support or thwart people's ability to thrive through the satisfaction of their basic psychological needs (18,19,21). According to SDT, motivation is not characterised by frequency or amount, like little or much motivation, but rather by a continuum from amotivation or controlled motivation to high-quality motivation distinguished by autonomous regulated behaviour

(18,22). From the perspective of SDT, a high quality of motivation predicts beneficial health outcomes like well-being, thriving and psychological growth (22).

No literature review to date on the application of SDT in a caregiver context has been identified in scientific databases or as protocols for literature reviews in Cochrane Library or Prospero, International Prospective Register of Systematic Reviews. A systematic review of literature could aid the understanding of motivation in caregiver work and might contribute to the utility of SDT. The theory has been applied in many research domains, such as education, work, sport, religion, psychotherapy, health care and behaviour change (20,23). Within these contexts, the theory has been used to identify, understand, explain, predict, promote and support individual motivation (19–21). According to the theory developers, the SDT perspective may predict the motivation of family caregivers for becoming caregivers, influencing the effect of the role on them. Preliminary evidence shows that autonomous versus controlled motivation for giving care to ill family members tends to affect the well-being and health outcomes of caregivers (18). Thus, further exploration of the role of SDT in understanding caregiving motivation is recommended.

Aim

To describe and explore empirical studies of caregivers' motivation from the perspective of self-determination theory.

Method

This integrative review was conducted as outlined by Whittemore and Knafl (24). An integrative review incorporates evidence from studies conducted using a wide variety of research methodologies (25). This approach is especially useful when the research topic may lend itself to theoretical, quantitative and qualitative methods of investigation (24). An integrative literature review is suitable when the topic has not been extensively researched (26). A preliminary literature search revealed a limited research area that consisted of diverse methodologies. Therefore, the integrative review method by Whittemore and Knafl (24) was considered as the most efficient approach. This allowed the inclusion of both qualitative and quantitative studies in order to more fully understand the research topic of caregivers motivation, and provide more solid evidence base with the potential for contributing to SDT theory development (24).

Research question and eligibility criteria

Having identified the research area of interest, the research question that guided the review process was formulated as follows:

How can an adult informal caregiver's motivation for taking care of a friend or relative with a long-term illness be understood from the perspective of self-determination theory?

Table 1 shows the priori inclusion and exclusion criteria.

Literature search

Eligible studies were identified from database searches, a manual search of reference lists, and consultation with experts. The literature search in databases used combinations of the following search terms: 'caregiver', 'family care', 'next of kin', 'informal care' and 'self-determination theory'. Relevant MeSH and thesaurus terms were applied when possible. The search strategy began with the union ('OR') of terms to capture articles related to the main concept 'caregiver', and then the intersection ('AND') of the term 'self-determination theory' to identify the full range of articles that combined the two main concepts. In databases that allowed limitations, peer reviewed articles were preferred, and no limitations were placed on publication year or language. The searches were done under the supervision of a specialised librarian at the University of Stavanger.

An initial systematic literature search of bibliographic databases MEDLINE, Scopus, PsychInfo, PsycNET, Chinal and Cochrane Library was conducted in May 2018, resulting in 105 titles. An updated and extended search was performed in December 2018, including the search terms 'spouse', 'filial' and 'relatives', and by adding the EMBASE database. The updated search identified 54 new titles, and entries for two new eligible papers were added to the annotated bibliography. The new papers tended to confirm or extend, rather than challenge, the initial synthesis. See Table 2 for an example of search strings from the database MEDLINE.

Study selection

A total of 159 titles were identified. After removal of duplicate items (N = 100), none of the remaining records (N = 59) were excluded after scanning of titles. Guided by the eligibility criteria (Table 1), the remaining abstracts were independently evaluated by the authors. Reasons for exclusion abstracts were mostly studies not reporting from a health context (N = 15), and studies reporting patient outcomes only (N = 19). Of the reviewed abstracts, 14 articles were selected for a full-text read. After screening the full-text records identified in the database search, eight articles were included in the review. Manual searches were performed in the reference lists of included studies and two additional studies were included. Figure 1 details and describes the identification and selection process using the PRISMA flow diagram (27).

Data evaluation

Data evaluation is crucial to enhance the rigour of an integrative review (24). The Mixed Methods Appraisal Tool (MMAT), version 2018 (28), was used to evaluate the methodological quality of the included articles. The MMAT (29) is designed for methodological quality appraisal when performing complex systematic reviews, and assesses the quality of qualitative, quantitative and/or mixed methods studies (28). For this review, checklists for qualitative, randomised and descriptive quantitative research studies were used. Rating and reporting a total score for each article is not recommended, but is rather used to give a description of study quality (30). Data evaluation was performed by all authors who independently rated the articles, followed by a discussion to achieve consensus. The quality of the included studies was above moderate, with MMAT remarks on four of them. See Table 3, spreadsheet on the MMAT for more

Table 1 Inclusion and exclusion criteria

Inclusion	Exclusion
Health context	Not health context
Adult informal caregivers	Children under 18 years as caregivers
Patient/person cared for must have a long-term illness	Caregiving in an acute illness setting
Informal caregiver perspective	Formal/professional caregiver perspective only
Reporting informal caregiver outcome	Studies reporting patient outcomes only
Specified use of self-determination theory	
Peer reviewed articles	Books, book chapters, protocols, reviews, study protocols, conference and poster abstracts

Table 2 Example of systematic literature search in MEDLINE, conducted December 2018

Search modes - Boolean/PhraseInterface - EBSCOhost	Research Databases MEDLINE	Result
S1	"self-determination theory"	1250
S2	"caregiv*" OR (MH "Caregivers")	69 488
S3	"family care"	1727
S4	"informal care"	4659
S5	"next of kin"	1292
S6	"filial*"	1383
S7	"spous*" OR (MH "Spouses")	30 055
S8	"relatives"	53 260
S9	S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8	153 830
S10	S1 AND S9	29

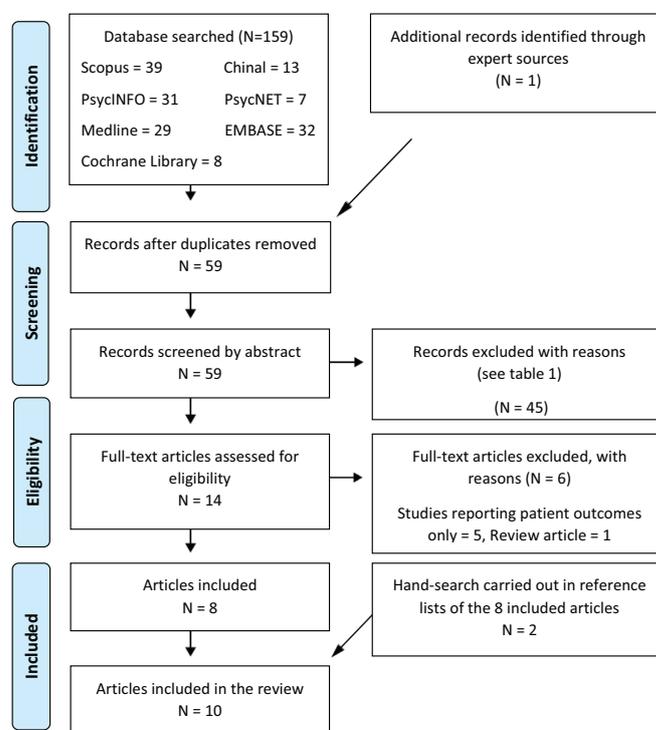


Figure 1 Paper selection strategy flow chart. PRISMA workflow of the identification, screening, eligibility and inclusion of the studies in the integrative review (27)

information. No papers were excluded based on the quality assessment.

Data analysis

The included articles are presented in Table 4, comprising information on first author, publication year, origin, study aim, study design, sample description and short summary of main findings relevant to our research question. The data analysis comprised four stages, (1) *data reduction*, (2) *data display*, (3) *data comparison* and (4) *conclusion drawing and verification* (24). The synthesis of evidence was performed as a narrative analysis allowing for a movement from descriptions of patterns and relationships to higher levels of abstraction from the particular to the general (24,26).

The data analysis was carried out during two analysis workshops in which all authors participated. In the first stage, relevant data from each article were extracted and compiled into a matrix (Table 4) (*data reduction*). In the second stage, extracted data were converted into a display to visualise patterns and relationships among the primary

sources (*data display*). The tabulation of quantitative and qualitative findings within a single matrix supported the synthesis of both statistical and narrative data, facilitating a systematic comparison of the primary data sources (24). The third stage involved coding of text by the first author and a read-through by the authors to identify new themes or data suggesting variance or dissonance within or between articles (*data comparison*). In the fourth stage, an interpretive approach was used to describe how caregivers' motivation could be understood from an SDT perspective. The data synthesis was then verified by the findings from the included articles for confirmability and accuracy (*conclusion drawing and verification*).

Results

Three themes emerged from the narrative analysis. The first theme address descriptions of caregivers' motivation. The second theme contains information on the connection between caregivers' motivation and their well-being; the third theme describes how caregivers' motivation can be supported.

Table 3 Quality appraisal of the selected studies (N = 10) spreadsheet on the Mixed Methods Appraisal Tool (MMAT)(28)

First author, Year	Screening questions		Qualitative studies					Comments
	Are there clear research questions?	Do the collected data allow to address the research questions?	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?	
No et al., (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Strekalova, (2016)	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Do not describe the process of analysis
Randomised controlled trials (RCT)								
Badr et al., (2015)	Yes	Yes	Yes	Yes	No	Yes	Yes	Not blinded RCT
Cossette et al., (2016)	Yes	Yes	Yes	Yes	No	Yes	Yes	Not blinded RCT
Quantitative descriptive studies								
Kim et al., (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Kim et al., (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Kindt et al., (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Kindt et al., (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	

Table 3 (Continued)

Quantitative descriptive studies		Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?
Kindt et al., (2017)	Yes	Yes	Yes	Yes	Yes	Yes
Pierce et al., (2001)	Yes	Yes	Yes	Yes	Can't tell	No
						Do not describe the analysing process

Description of caregivers' motivation

All studies included here lent insight to the situational demands that influenced adult caregivers' motivation for providing care to a friend or relative with a long-term illness. Most of the studies had investigated caregivers' quality of motivation and classified it according to different constructs in SDT such as intrinsic motivation, identified motivation, introjected motivation, external motivation (31–38) and amotivation (35). In these studies, SDT terminology has been used to identify, measure, classify, categorise or describe caregivers' quality of motivation. In several of the studies, SDT constructs were presented as categories of autonomous motivation like intrinsic motivation (i.e. helping because you enjoy/value this behaviour and experience volition and choice), or controlled motivation, understood as extrinsic motivation (i.e. helping because you believe you should) (31–37,39). One qualitative study reported that in real life, the constructs and categories of motivation are more ambiguous than, and not as easy to identify as, in the theory (37).

Two studies did not assess quality of motivation in particular, but were concerned with how caregivers could fulfil their need for autonomy, competence and relatedness (40) or the importance of internalisation where caregivers have integrated the duties and responsibilities resulting from their friend's or relative's illness (38). Pierce et al. (38) found that maintenance of motivation over time requires caregivers to internalise values and skills for caregiving and to experience self-determination. This could lead to greater identification with caregiving and could foster enthusiasm and well-being among caregivers. Several studies found that caregivers' feelings of caregiving as voluntary and that the need for autonomy was fulfilled, was especially important for high quality of motivation (31,32,34,36,38,39).

The majority of studies presented evidence for caregivers' helping motivation and the contribution to changes in their daily outcomes through the improvement of their need satisfaction and a decrease in their need frustration. Two studies explicitly concluded that the autonomous helping motivation was positively associated with the satisfaction of basic psychological needs (32,34), while most of the other studies merely implied it. Several studies found that autonomously motivated help compared with controlled motivated help, had beneficial effects on caregivers (31–37,39).

Caregivers' motivation and well-being

Most of the studies reported on outcomes for caregivers' well-being (31–38). In addition, equivalent terms like psychological well-being (32), mental health (33,37) physical health (33), life satisfaction (32), quality of life

Table 4 Characteristics of the included studies

Author/year/ country	Aims	Study design	Setting and sample	Summary of findings
Ng et al. (2016) Singapore	To explore the motivations and challenges facing family caregiving and to suggest a possible framework to guide culturally sensitive future work on caregivers	Qualitative Individual interviews Inductive thematic analysis	Caregivers of patients being treated for cancer N = 20 Female = 12 Male = 8 Age: 21–64 Mean age: 45 Relation: parents, spouse or other	Autonomous motivated caregivers cited learning points and reprioritised more effectively. Less autonomous caregivers reported more internal conflict and less control over their situation. Sociocultural values of family caregiving were not uniformly experienced as positive, and were burdensome for caregivers who gave care primarily for extrinsic motivations. The study's qualitative approach expands the framework of SDT
Strekalova (2016) USA	To understand how caregivers of newborns diagnosed with cystic fibrosis (CF) use online community forums to satisfy their need for competence, autonomy and Relatedness	Qualitative Conceptual-thematic analyses of the online forum discussions	106 threads with 645 responses written by parents on active CF online community forums Relation: Parents	Through online communication with parents in a similar situation, caregivers sought and received support for their autonomy (control over lifestyle changes and future planning), competence (understanding the diagnosis and recognising the health care needs) and relatedness (relate to the community of other families with same diagnosis, knowing they were not alone)
Badr et al. (2015) USA	To examine feasibility, acceptability and effects from a dyadic SDT intervention for patients with lung cancer and their informal caregivers	Quantitative randomised controlled trial (RCT)	Dyads of patients and caregivers Caregivers N = 39 Female = 27 Male = 12 Age: >35 Mean age: 51 Relation: spouse/partner or other close primary caregiver	The intervention was found feasible and acceptable by the participants, proven by a recruiting rate of 60%, and by participants' ratings of the intervention as helpful, relevant and convenient. The interventions found large decreases in participants' depression and anxiety, improved patient and caregiver competency and relatedness, and caregiver autonomous motivation, and a decrease in caregiver burden
Cossette et al. (2016) Canada	To test feasibility, acceptability and effects from a SDT-based nursing intervention for caregivers to support heart failure (HF) patients' self-care	Quantitative RCT	Dyads of HF patients and their caregivers Caregivers N = 32 Female = 23 Male = 9 Age: >18 Mean age: 64 Relation: Spouse, adult child, sibling, or significant other	The caregivers were overall satisfied with the intervention. The intervention proved acceptable in terms of content and structure, and highly appropriate to help HF self-management. Caregivers reported provision of high levels of support and feeling less amotivated in their supportive work
Kim et al. (2008) USA	To examine the prediction of caregiver well-being from the relationship qualities specified by attachment theory and from motives specified by SDT	Quantitative cross-sectional study Benefit finding in cancer caregiving experience, life satisfaction, and depressive symptoms were assessed to measure caregiver's psychological adjustment	Caregivers N = 314 to cancer survivors Female = 160 Male = 154 Age: >18 Mean age: 57 Relation: Spousal relationship	Autonomous motivation was associated with positive outcomes for caregivers, including less depression in men and increased benefit-finding in women. For both genders, attachment security related positively to autonomous motives for finding benefit in caregiving. Attachment anxiety related to introjected motives for caregiving and less life satisfaction, less well-being and more depression

Table 4 (Continued)

Author/year/ country	Aims	Study design	Setting and sample	Summary of findings
Kim et al. (2015) USA	To investigate the extent to which caregiving motives earlier in a relative's cancer pathway predict caregivers' spirituality and Quality of Life (QoL) years after	Quantitative longitudinal study Caregiving motives were measured after 2 years and spirituality and QoL (mental and physical health) were measured at 5 years postdiagnosis	Family caregivers N = 369 who were caring for cancer survivors Female = 233, Male = 136 Age: 19-90 Mean age: 55 Relation: family members and close friends	Internal reasons for caregiving were personal endorsement of caring as meaningful, important and valuable. Having a greater sense of autonomy correlated with having long-term greater spirituality and better mental health among male caregivers. Among female caregivers, having higher caregiving demands resulted in worse long-term physical health. Being peaceful predicted better mental health for both genders, and better physical health among men. Findings were fully consistent with SDT and therefore the theory was evaluated as useful when applied in the cancer caregiving context
Kindt et al. (2015) Belgium	To examine the relationship between autonomous versus controlled motivation to help in caregivers of individuals with chronic pain and caregivers' personal and relational function	Quantitative, cross-sectional study Outcomes tested among caregivers were life satisfaction, positive and negative affect, helping motivation, helping exhaustion, relationship quality, psychological distress, and need satisfaction	Sample of 48 couples, of which one partner had chronic pain Caregivers N = 48 Female = 12 Male = 36 Age: 31-67 Mean age: 54 Relation: Spouses and other definition of partners	Autonomous motives for helping among partners related positively to partners' well-being and relationship quality, and negatively to distress and helping exhaustion. Relationship-based need satisfaction in partners was positively associated with their personal well-being relational function. Controlled motivated partners gained little well-being from helping their partner with chronic pain. Applying SDT in a context of pain provided new insights into why chronic pain affected partners' outcome
Kindt et al. (2016) Belgium	To examine associations between day-to-day fluctuations in partners' type of helping motivation and several outcomes, among partners and chronic pain patient	Quantitative diary survey Outcomes tested among caregivers included daily helping motivation together, daily affect, relational conflict, and relational-based need satisfaction	Dyads of 70 where one partner had chronic pain Caregivers N = 70 Female = 17 Male = 53 Age: >18 Mean age: 55 Relation: Spouses and other definition of partners	Fluctuations in partners' daily autonomous helping motivation related positively to improvements in positive affect and decreases in negative affect, relational conflict, and helping exhaustion among partners. Providing autonomous help related to improvements in partners' daily relationship-based psychological need satisfaction The SDT-perspective proved useful and applying the theory within pain research has the potential of providing more clinically relevant directions
Kindt et al. (2017) Belgium	To examine whether perceived gratitude (i.e., received appreciation for providing support) in partners and goal conflicts in partners predicted partners' helping motivation	Quantitative diary study during 14 days For partners, daily goal conflict, perceived gratitude and helping motivation were assessed	Dyads of chronic pain patients (ICP) and partners. Caregivers N = 64 Female = 6 Male = 58 Age: >18 Mean age: 51 Relation: Spouses and other definition of partners	Caregivers provided more autonomously motivated help on days when they experienced fewer goal conflicts and perceived more gratitude from their partner. Perceived gratitude predicted an increase in caregivers' autonomous helping motivation the same day and the day after On days that partners experience a lot of interference between helping the ICP and other life goals, they felt more pressured to provide help

Table 4 (Continued)

Author/year/ country	Aims	Study design	Setting and sample	Summary of findings
Pierce et al. (2001) Canada	To further our understanding of the factors associated with the well-being of family caregivers by examining the contributions of commitment and self-determination	Quantitative interviews and questionnaire Outcomes tested were commitment, internalisation, caregivers' satisfaction with providing care and well-being	Caregivers of persons with dementia N = 50 Female = 35, Male = 15 Age: >18 Mean age: 54 Relation: spouse, siblings, adult children or other	Greater identification with caregiving generated enthusiasm, which then was a significant predictor of caregivers' general well-being. Enthusiasm stems from a more self-determined internalisation of caregiving. A more identified internalisation of their role lead caregivers to appraise difficult situations as less threatening

(37) and long-term health (37) were presented. All studies except Strekalova's (40) found that caregivers' different reasons for engaging in helping behaviour indicated why some caregivers experienced more stress and worse well-being than others. In five studies, variations in reasons for providing care were discussed as important elements in understanding caregivers' psychological well-being (32–34,37,38). Two studies explicitly presented satisfaction of the basic psychological needs for autonomy, competence and relatedness as mediators for predicting the quality of motivation and thereby psychological health and well-being among caregivers (32,34).

Common among the studies was the examination of the relationship between caregivers' controlled versus autonomous motivation to help, and the consequences for their well-being (32–37). These studies found that controlled (extrinsic) motivated reasons for providing care as feeling forced or obligated to take care, led to diminished well-being among caregivers. Kindt and colleagues (35) found that controlled-motivated caregivers gained little well-being from helping a partner with chronic pain and experienced increased exhaustion and stress. In other studies, caregivers reported more internal relational conflicts (34), negative affect (36) tensions in their relationship (34), and less control over their caregiver situation (37). Extrinsic motives for caregiving predicted greater depressive symptoms (36), less life satisfaction (32), more stress (36) and increased caregiver burden (33).

Six studies found that caregivers who were autonomously motivated to help experienced less stress and exhaustion than did those who viewed caregiving as an obligation (32–37). In Kindt et al. (34) partners who did not experience external or internal pressure, but who were committed to helping and derived enjoyment from it reported better well-being (34). Caregiving motivation was characterised as autonomous when caregivers' psychological needs for relatedness, autonomy and competence were met within the caregiving context (34–36). Satisfaction of these needs was

associated with life satisfaction, subjective vitality and positive affect among spousal caregivers (32–36). Caregivers who perceived gratitude from the patient (36) or who were enthusiastic about caregiving (38), were more willing to provide help. Autonomous motivated caregivers reported fewer depressive symptoms (32), greater spirituality and better mental health (33), greater personal growth and saw benefits in caregiving (32). Autonomous motivation led to increased happiness, positive affect, a sense of well-being, greater satisfaction with life (36,38) and better personal functioning and less exhaustion as a result of helping someone with a long-term illness (34–36).

Support of caregivers' motivation

All studies presented implications for further research and recommended finding better ways to support caregivers. Most of the studies argued for the value of mapping variation in the reasons for providing care and for considering the underlying motives of helping behaviour (32,34,36–38). Some studies pointed out that considering the reasons for providing informal care is important to identify caregivers who experience diminished well-being (32,38) and who might benefit from support services or counselling (34,38). Caregivers' helping motivation predicted (32–36,38), described (37) or supported (31,39) their health outcomes. Strekalova (40) addressed the psychological needs for competence (i.e. information and understanding the diagnosis), autonomy (i.e. making choices and planning for the future) and relatedness (i.e. contact and support from other families in a similar situation). She found that early identification of caregivers' needs may lead to better psychological coping and improved health outcomes (40). To increase caregivers' self-determination, Pierce et al. (38) suggested that healthcare professionals support caregivers by helping them see the options available to them and allowing them greater freedom of choice with respect to caregiving tasks. Findings from Kim et al. (33) suggest that

caregivers may benefit from interventions that facilitate their ability to be autonomously motivated.

Several studies concluded that the development and testing of SDT-based support services and interventions in a caregiver context might be useful for development of effective motivational support to caregivers (31–39). Only two studies had developed, tested and evaluated interventions to support motivation in caregivers. Badr et al. (31) tested an SDT intervention to improve quality of life for patients with advanced lung cancer and their family caregivers. The intervention consisted of standardised, tailored manuals on self-care, stress and coping, symptom management, communication skills, problem solving, and maintaining and enhancing relationships. In addition, dyads of patient and caregiver participated in weekly telephone counselling sessions. The intervention group reported improvements in depression and anxiety, a significant decrease in caregiver burden, and caregivers' increased autonomous motivation (31). Cossette and colleagues (39) tested an SDT-based intervention on dyads of heart failure patients and their caregivers. While the patient was hospitalised, the dyads were offered two face-to-face meetings with a project nurse; after the patient was discharged, they were offered three telephone-based meetings. The caregivers reported that they were less amotivated in their caregiver work and felt they provided better support to the patient (39). Results from the two intervention studies reported that the caregivers were generally satisfied with the interventions and found them helpful, relevant and convenient (31,39). Ng and colleagues (37) suggested that models of supporting caregiver wellness and intervention work ought to focus not just on reducing anxiety and depression, but also consider meaning and motivation as foundations for caregivers' long-term health and well-being.

Discussion

To our knowledge, this is the first review of the research literature that explores and discusses caregiving motivation from the SDT perspective. In sum, the analysis of the included articles has found that all studies considered satisfaction of the three basic psychological needs for autonomy, competence and relatedness as essential for predicting caregivers' quality of motivation and thus their well-being. The review holds the potential to form an important foundation for future research, and for the development of interventions that will increase caregivers' sense of self-determination.

Caregivers' motivation and well-being in a long-term illness context

The most significant finding was that fulfilment of caregivers' psychological needs and autonomous

motivation was strongly associated with their greater well-being. Our findings are consistent with Milyavskaya and Koestner (23) who found that need satisfaction is universally linked to motivation and well-being across important life domains. Other researchers have come to the same conclusion in workplace studies (19,22), among patient populations in health care, and in health promotion contexts (20). Moreover, Weinstein and Ryan (21) found that intrinsic motivation for helping yielded benefits for the helper through greater need satisfaction. Perception of choice in entering the caregiver role is positively associated with well-being among caregivers, and internalised values about the importance of caregiving are essential (12). This is consistent with our findings, where the maintenance of motivation over time requires that caregiver's internalise certain values, duties, responsibilities and skills. Moreover, this review suggests that the feelings of caregiving as voluntary and fulfilment of the need for autonomy is especially important for high-quality motivation. Also, caregivers' perception of support for their autonomy from family and friends, from their workplace and from health professionals may be associated with less depression and increased well-being and life satisfaction. In line with this, high-quality motivation is a central marker of well-being and associated with high performance (22) and personal growth (20,21). In extension of this, we see the need for health professionals supporting the caregivers' volunteering behaviour and offering guidance towards caregiving solutions to support sense of autonomy.

Our findings support the theoretical proposition that fulfilment of the basic needs for autonomy, competence and relatedness is a primary form of psychological nurturance that facilitates well-being (17,18) in caregivers. Intrinsic motivation is distinguished by autonomous motivation and self-determined behaviour where the person acts out of interest, engagement and enjoy the activity (18,20). The review show that fulfilment of the three basic psychological needs for autonomy, competence and relatedness are important determinants of caregivers' well-being, protecting them from high levels of psychological distress associated with ill-being and caregiver burden. In a job satisfaction context, amotivation, where the motivational quality is lowest and the employee finds no value or interest in acting, is associated with poor well-being and performance (19,22). The employee appears to have no self-determination and the motivation for acting is controlled, resulting in poorer well-being (17). Our narrative analyses confirmed this by showing that caregivers who reported feeling forced or obligated to offer care were extrinsically motivated or amotivated, which predicted more depressive symptoms, less life satisfaction, and greater stress and caregiver burden.

Targeting caregivers' autonomous motivation

We found that a motivational perspective on helping, as provided by SDT, is useful in explaining variations in personal and relational well-being and distress among caregivers. Early identification of caregivers who are struggling or at risk of struggling is crucial (4). It is important to identify this subgroup of caregivers so that they can receive evidence-based services (6). SDT constructs can identify, clarify and explain why caregivers in apparently similar situations differ in terms of well-being and in their desire to continue offering care. According to Roth et al. (6) it is important to target evidence-based services to the subgroup of caregivers who are under stress or at risk in other ways (6). In line with this, we found that by identifying caregivers who were intrinsically motivated or amotivated and suffering from the caregiver experience, health professionals might better understand why certain caregivers experience worse well-being than others, and how these caregivers will benefit from receiving support services or counselling.

Our results highlight the need for improved ways of supporting caregivers' motivation. Moreover, it is crucial for health professionals to understand when the provision of caregiver support is considered helpful and beneficial for the caregivers' well-being. According to previous caregiver research, health services ought to see informal carers as no less important than the patient (2,4,11). Different kinds of caregivers need different kinds of support and interventions based on, that is, types or severity of the relatives' long-term illness (1,9). Support and services to caregivers are indispensable to caregivers' psychological well-being by preventing burnout (4,8). This is consistent with our findings that well-being is facilitated by perceived support, especially support for autonomy from health professionals, the patient and from others. Given the critical role of autonomous helping motivation, health professionals can meet caregivers' needs by being autonomous supportive. Promising result from the two pilot interventions in the fields of cancer and heart failure encourage further development and testing of interventions that support caregivers. The interventions recommend that health professionals reinforce caregivers' autonomous motivation by offering choices rather than restrictions, showing the range of options available to them, avoiding criticism and giving encouragement (31,39). Accordingly, health providers should view caregivers as partners (5), and take into account caregivers' resources (13). Here, a more balanced image of the caregiver as a resilient and capable ally is useful (6). Health professionals could work more effectively and systematically with patients to identify, inform and collaborate with their informal caregivers (6). According to Quinn et al. (10) efficacious interventions should be developed

and implemented to support caregivers' motivation and thus their well-being.

Future directions for SDT in the caregiver context

Our findings suggest that models of understanding caregiver well-being ought to focus not just on the absence of stress and caregiver burden, but also consider motivation as the foundation for caregivers' long-term health and well-being. These findings meet previous research calls for promotion of benefits of caregiving, such as sense of satisfaction, autonomy and expertise among caregivers that may act as specific and legitimate goals for motivational support (5,6,14,15). The existing dominance of a stress-coping approach pathologies caregiving (6,14). In contrast, SDT represents greater attention to health promotion (20) and offers a promising theoretical framework for future research, by shifting the focus from health threat to health resources in the caregiving context.

All of the included articles described how SDT was applied in their respective studies, depicting SDT as an effective framework for understanding caregivers' motivation. In this context, it would be valuable to know more about the application of SDT in research on caregiving, and in particular, qualitative research is warranted to identify the SDT constructs' application in real life. Moreover, all of the reviewed articles included both male and female caregivers, while only two studied SDT constructs with respect to gender (32,33). The gender issue in current SDT research has provided inconsistent findings (41) representing a knowledge gap in the SDT research on caregiver motivation.

Most of the studies included in this review used SDT measurements and questionnaires validated in or adapted from other contexts. Accordingly, the development, testing and validation of SDT-based instruments and questionnaires in different languages adapted to a caregiver context are warranted. Further development of qualitative research approaches to identify methods of promoting caregivers' autonomous motivation is recommended. This could add value to a field of SDT research that is already dominated by quantitative methods. Future SDT research on caregivers should endorse reporting and reflecting on the application of SDT.

Methodological considerations

It can be methodologically challenging to include mixed evidence within one literature review. The integrative review method has been successfully adapted to allow diverse primary sources and multiple perspectives to be combined, to gain in-depth understanding of complex phenomena (26). Whittemore and Knaff's integrative

review method (24) provided a stringent approach to the current review study, represented by its rigorous and systematic review procedure.

Our search strategy was comprehensive, comprising two searches (initial and follow-up) in seven multidisciplinary bibliographical databases. This allowed for an updated and interprofessional approach to the literature search. Even though no limitations on year or language were added to the literature search, only 159 articles were found, most of them published since 2015 and published in English. This indicates a circumscribed research area, but at the same time the combination of caregiving and SDT seems new and upcoming in both research and practice. Despite a comprehensive literature search, the inclusion of grey literature might have given expanded access to the research area. To enhance the rigor of our review, a priori and well-defined selection criteria were used. All authors participated in study selection, ensuring that the identified documents were eligible for inclusion. Choosing a single motivational theory (SDT) as a theoretical perspective might be considered a strength of this review, but may have narrowed the knowledge base. The inclusion of other motivational theories might have contributed to a broader view on caregiving motivation.

Conclusions

This integrative literature review found that SDT can be applied to identify, categorise, explain, predict, promote and support motivation among caregivers. The findings are an initial demonstration of the differential effects of caregivers' autonomous versus controlled motivation for helping a friend of relative with a long-term illness. Autonomous motivation is demonstrated as an important determinant of caregivers' well-being and may protect them from feeling overstressed and overworked. When

caregivers voluntarily offer their help, they experience a greater sense of autonomy, relatedness and competence; and need satisfactions that in turn appear to enhance caregivers' sense of well-being. This review gives important support for SDT and promotes further study and application of the theory as a psychological approach to health and health promotion in the caregiver context. The further development and implementation of autonomy-supportive interventions and services to caregivers as the target group are endorsed. For future SDT research in the caregiver context, more reporting and reflection on the application of SDT are recommended. Furthermore, contributing a fresh theoretical perspective to a familiar field is a strong argument for applying SDT to the caregiver context in future research and practice.

Acknowledgements

The authors would like to thank Grete Mortensen, Specialized Librarian, University of Stavanger, for assistance with data collection for this study and Professor Chris Niemiec, University of Rochester, United States, for contributing to the development of the idea to this article.

Conflicts of interest

The authors state explicitly that there are no conflicts of interest in connection with this article.

Author contribution

HD is the main author and takes responsibility for the content of this article. Data collection and analysis were guided by AN and AMLH. All authors critically revised the manuscript. This study is a part of a PhD thesis for which AN is a supervisor.

References

- 1 Fu F, Zhao H, Tong F, Chi Iris. A systematic review of psychosocial interventions to cancer caregivers. *Front Psychol* 2017; 8: 834.
- 2 Sullivan AB, Miller D. Who is taking care of the caregiver? *J Patient Exp* 2015; 2(1): 7–12.
- 3 Colombo F, Llena-Nozal A, Mercier J, Tjadens F. Help Wanted? Providing and Paying for Long-Term Care 2011. Available from: <https://www.oecd-ilibrary.org/content/publication/9789264097759-en>.
- 4 Zigarette V. Informal care in Europe, Exploring Formalisation, Availability and Quality. European Commission, Directorate-General for Employment, Social Affairs and Inclusion Directorate A — Employment and Social Governance. 2018.
- 5 Nolan M, Grant G, Keady J. *Partnerships in Family Care*. 2003, McGraw-Hill Education, Berkshire, Great Britain.
- 6 Roth D, Fredman L, Haley W. Informal caregiving and its impact on health: a reappraisal from population-based studies. *Gerontologist* 2015; 55(2): 309–19.
- 7 Norwegian Ministry of Health- and Care Services. Helse- og omsorgsdepartementet. Meld. St. 15 (2017–2018) Leve hele livet — En kvalitetsreform for eldre. (Report no.15 (2017-2018) To live the whole life, a quality reform for people of old age). Retrieved from <https://www.regjerin.no/no/dokumenter/meld.-st.-15-20172018/id2599850/>
- 8 Hoffmann F, Rodrigues R. *Informal Carers: Who Takes Care of Them?*. 2010, European Centre for Social Welfare Policy and Research, Vienna.
- 9 Brimblecombe N, Fernández J-L, Knapp M, Rehill A, Wittenberg R. Review of the international evidence on support for unpaid carers. London School of Economics and Political Science (LSE). 2018.

- 10 Quinn C, Clare L, Woods RT. The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *Int Psychogeriatr* 2010; 22(1): 43–55.
- 11 Hanssen H, Sommerseth R. Den familiære relasjonens betydning for pårørendes behov i møte med helsetjenesten. (The Significance of Family relations to Informal Carers' Needs in interaction with Health Services). *Nordisk Tidsskrift Helseforskning*. 2014; 10(2): 62–75.
- 12 Al-Janabi H, Carmichael F, Oyeboode J. Informal care: choice or constraint? *Scand J Caring Sci* 2018; 32(1): 157–67.
- 13 Wennerberg M, Eriksson M, Danielson E, Lundgren S. Unravelling Swedish informal caregivers' generalised resistance resources. *Scand J Caring Sci* 2016; 30(3): 602–13.
- 14 Brown RM, Brown SL. Informal caregiving: a reappraisal of effects on caregivers. *Soc Issues Policy Rev* 2014; 8(1): 74–102.
- 15 Yu DSE, Cheng S-T, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *Int J Nurs Stud*. 2018; 79: 1–26.
- 16 Weinstein N, DeHaan CR. On the Mutuality of Human Motivation and Relationships. In: *Human Motivation and Interpersonal Relationships: Theory, Research, and Applications*. (Weinstein N, ed), 2014, Springer, Dordrecht, Netherlands, 3–25.
- 17 Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *Am Psychol* 2000; 55(1): 68–78.
- 18 Ryan RM, Deci EL. *Self-determination theory: basic psychological needs in motivation, development, and wellness*. 2017, Guilford Press, New York.
- 19 Williams G, Halvari H, Niemiec CP, Sørebo Ø, Olafsen A, Westbye C. Managerial support for basic psychological needs, somatic symptom burden and work-related correlates: A self-determination theory perspective. *Work Stress* 2014; 28(4): 1–16.
- 20 Ng J, Ntoumanis N, Thøgersen-Ntoumani C, Deci E, Ryan R, Duda J, et al. Self-determination theory applied to health contexts: a meta-analysis. *Psychol Health*. 2012; 27: 325–49.
- 21 Weinstein N, Ryan RM. When helping helps: Autonomous motivation for prosocial behavior and its influence on well-being for the helper and recipient. *J Pers Soc Psychol* 2010; 98(2): 222–44.
- 22 Rigby CS, Ryan RM. Self-determination theory in human resource development: new directions and practical considerations. *Adv Develop Human Res* 2018; 20(2): 133–47.
- 23 Milyavskaya M, Koestner R. Psychological needs, motivation, and well-being: a test of self-determination theory across multiple domains. *Pers Individ Differ* 2011; 50(3): 387–91.
- 24 Whittemore R, Knaf K. The integrative review: updated methodology. *J Adv Nurs* 2005; 52(5): 546–53.
- 25 Doolen J. Meta-analysis, systematic, and integrative reviews: an overview. *Clin Simul Nurs* 2017; 13(1): 28–30.
- 26 Whittemore R, Chao A, Jang M, Minges KE, Park C. Methods for knowledge synthesis: an overview. *Heart Lung* 2014; 43(5): 453–61.
- 27 Moher D, Liberati A, Tetzlaff J, Altman Douglas G. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009; 6(7): e1000097.
- 28 Hong QN, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, et al. The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Educ Inform* 2018; 34(4): 285–91.
- 29 Pluye P, Gagnon M-P, Griffiths F, Johnson-Lafleur J. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *Int J Nurs Stud* 2009; 46(4): 529–46.
- 30 Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M. Mixed Methods Appraisal Tool (MMAT), version 2018, User guide. 2018. Available from: <http://mixedmethodsappraisaltoolpublic.pbworks.com/w/page/24607821/FrontPage>
- 31 Badr H, Smith CB, Goldstein NE, Gomez JE, Redd WH. Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: results of a randomized pilot trial. *Cancer* 2015; 121(1): 150–8.
- 32 Kim Y, Carver CS, Deci EL, Kasser T. Adult attachment and psychological well-being in cancer caregivers: the mediational role of spouses' motives for caregiving. *Health Psychol*. 2008; 27(2 SUPPL. 2): S144–54.
- 33 Kim Y, Carver C, Cannady R. Caregiving motivation predicts long-term spirituality and quality of life of the caregivers. *Ann Behav Med*. 2015; 49(4): 500–9.
- 34 Kindt S, Vansteenkiste M, Loeys T, Goubert L. Helping motivation and well-being of chronic pain couples. *Pain* 2016; 157(7): 1551–62.
- 35 Kindt S, Vansteenkiste M, Loeys T, Cano A, Lauwerier E, Verhofstadt LL, et al. When is helping your partner with chronic pain a burden? The relation between helping motivation and personal and relational functioning. *Pain Med*. 2015; 16(9): 1732–44.
- 36 Kindt S, Vansteenkiste M, Cano A, Goubert L. When is your partner willing to help you? The role of daily goal conflict and perceived gratitude. *Motivat Emot* 2017; 41(6): 671–82.
- 37 Ng HY, Griva K, Lim HA, Tan JY, Mahendran R. The burden of filial piety: a qualitative study on caregiving motivations amongst family caregivers of patients with cancer in Singapore. *Psychol Health*. 2016; 31(11): 1293–310.
- 38 Pierce T, Lydon JE, Yang S. Enthusiasm and moral commitment: what sustains family caregivers of those with dementia. *Basic Appl Soc Psychol* 2001; 23(1): 29–41.
- 39 Cossette S, Belaid H, Heppell S, Mailhot T, Guertin M-C. Feasibility and acceptability of a nursing intervention with family caregiver on self-care among heart failure patients: a randomized pilot trial. *Pilot Feasibility Stud* 2016; 2(1): 34.
- 40 Strekalova YA. Finding motivation: online information seeking following newborn screening for cystic fibrosis. *Qual Health Res* 2016; 26(9): 1180–90.
- 41 Guérin E, Bales E, Sweet S, Fortier M. A meta-analysis of the influence of gender on self-determination theory's motivational regulations for physical activity. *Can Psychol* 2012; 53(4): 291–300.



Article II

Caring for home-dwelling parents with dementia: A qualitative study of adult-child caregivers' motivation

Heidi Dombestein MHSc, RN, PhD Candidate¹  | Anne Norheim RN, Professor² |
Karina Aase MSc, Professor¹ 

¹Centre for Resilience in Healthcare, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway

²Department of Caring and Ethics, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway

Correspondence

Heidi Dombestein, Centre for Resilience in Healthcare, Faculty of Health Sciences, University of Stavanger, P.O. Box 8600 Forus, N-4036 Stavanger, Norway.
Email: heidi.dombestein@uis.no

Abstract

Aim: To explore adult children's motivation in caregiving for their home-dwelling parents with dementia.

Design: Qualitative design with a phenomenological approach.

Methods: Semi-structured individual interviews with 21 adult sons and daughters who were caregivers for a parent with dementia. Data were analysed using systematic text condensation.

Results: Inspired by self-determination theory, three categories were identified in the empirical data representing the main motivational drivers for adult-child caregivers: *relatedness* (to the parent with dementia, the parent's spouse, other persons), *competence* (in handling dementia, in the parent's need) and *autonomy* (freedom of choice, innate values and tasks). Caregivers report relatedness as their key motivational driver.

These results imply that nurses and other health professionals should value the importance of relatedness when interacting with dementia caregivers and establish belonging support structures. Further research should generate more knowledge of the positive motivational drivers, including interventions to improve relatedness, competence and autonomy.

KEYWORDS

adult-child caregivers, dementia, home-dwelling, motivation, qualitative method, self-determination theory

1 | INTRODUCTION

Dementia is recognized as a public health priority because an estimated 50 million people are living with dementia worldwide (WHO, 2019). Most of these persons experience that dementia leads to increased impairments affecting memory, personality, meaningful activities, social contacts and self-care (Bjørkløf et al., 2019).

Dementia symptoms can disrupt collaboration between patients and healthcare professionals. For this reason, focus often shifts to informal caregivers and relatives who become important resources for both the person with dementia (PWD) and the professionals (Garcia-Ptacek, Dahlrup, Edlund, Wijk, & Eriksdotter, 2019). Therefore, it is necessary for nurses and other healthcare professionals to be aware of caregivers' situation to identify potential

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2020 The Authors. *Nursing Open* published by John Wiley & Sons Ltd

challenges and initiate support (Chiao, Wu, & Hsiao, 2015; Koren, Laidsaar-Powell, Tilden, Latt, & Butow, 2018). Informal caregivers of home-dwelling persons with dementia often experience stress and reduced quality of life because of their caregiver role (van der Lee, Bakker, Duivenvoorden, & Dröes, 2014; Pearlin, Mullan, Semple, & Skaff, 1990). The perceived caregiver burden, caring approach and coping strategies depend on the type of dementia (Svendsboe et al., 2018), caregivers' resources (Chen & Bailey, 2018; Wennerberg, Eriksson, Danielson, & Lundgren, 2016) family relations (Bjørge, Kvaal, Småstuen, & Ulstein, 2017) and received support (Lee, Puga, Pickering, Masoud, & White, 2019). Most research in the caregiver field has examined family caregivers as a homogenous group, without differentiating spouses from adult children of a PWD (Tatangelo, McCabe, Macleod, & You, 2018). Adult children are likely to juggle caregiving and other roles such as work and responsibilities to their own families; spouse caregivers are more likely to undertake a full-time caregiving role (Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, & López-Pousa, 2010). This study therefore contributes to a more differentiated knowledge of caregiving regarding adult children to PWD.

2 | BACKGROUND

So far, research has focused on the challenges of being a caregiver to a PWD. There is a need to draw attention to other elements of caregiving (Lloyd, Patterson, & Muers, 2016) such as satisfaction, autonomy and expertise (Yu, Cheng, & Wang, 2018). Motivation for caregiving in the dementia context is crucial in informal carers' experience of their role (Quinn, Clare, & Woods, 2015) as it energizes behaviour, initiate, generate and increases task engagement and direct actions. Motivation is thus understood as the energy in people that drives their actions or non-actions. Motivational support increases caregivers' sense of well-being, psychological growth and resilience (Weinstein & DeHaan, 2014). In a review article, Greenwood and Smith (2019) found the motives of family caregivers to persons with dementia, for example reciprocity, commitment, love, duty, loyalty, obligations and responsibility, to be identical with their reasons to sustain as caregivers. Still, the motivations for taking on and staying in the caregiver role remain an area not fully understood (Greenwood & Smith, 2019; Quinn, Clare, & Woods, 2010). Thus, studying caregiving using a theoretical motivation framework is recommended as it can further help identify and categorize motivational aspects (Quinn et al., 2010).

In this study, caregivers' motivation is addressed using self-determination theory (SDT) (Ryan & Deci, 2000, 2017) whose premise is the three psychological drivers of motivation: the need for autonomy, competence and relatedness. Their satisfaction would be essential for individual psychological growth, subjective well-being and optimal human functioning, while thwarting those needs can lead to amotivation (Ryan & Deci, 2000, 2017; Weinstein & Ryan, 2010; Williams et al., 2014). When the need for *autonomy* is satisfied, one

experiences a sense of volition and the sense that one's actions are endorsed by oneself, conferring a feeling of ownership over actions. The need for *competence* relates to mastery and perceptions of performing tasks with confidence, effectiveness and being capable of achieving desired outcomes. The need for *relatedness* is a feeling of mutual belonging, genuine connection with others and experiencing giving support to and being supported by others (Ryan & Deci, 2000, 2017).

Self-determination theory has been applied to several healthcare contexts (Ng et al., 2012; Ntoumanis et al., 2020) such as caregivers' motivation for persons with cancer (Kim, Carver, & Cannady, 2015; Ng, Griva, Lim, Tan, & Mahendran, 2016) and chronic pain (Kindt, Vansteenkiste, Cano, & Goubert, 2017) as well as to caregivers caring for relatives with different long-term illnesses (Dombestein, Norheim, & Lunde Husebø, 2019). To our knowledge, SDT has not yet been applied to adult children caring for home-dwelling parents with dementia. There is a lack of qualitative studies expanding the SDT framework and understanding the phenomenon of caregivers' motivation, (Ng et al., 2016) also in a dementia context (Pierce, Lydon, & Yang, 2001). Therefore, this qualitative study explores adult children's motivation in caregiving for their home-dwelling parents with dementia. This aim will be addressed through the following research question:

How can adult children's motivational drivers for caregiving be described using self-determination theory?

3 | METHODS

3.1 | Context

In Norway, about 80,000 persons live with dementia. Approximately the same number are primary caregivers for these persons, while about 270,000 are secondary caregivers (Norwegian Ministry of Health & Care Services, 2015). As in other Nordic countries, Norway's public healthcare system is constructed for taking care of PWD with supplements from informal caregivers. Specialist care is provided by regional health services and consists of hospitals and specialized units such as memory clinics and geriatric hospital wards. More than 300 Norwegian municipalities are responsible for primary care like general practitioners, home care, day care centres and nursing homes (Norwegian Ministry of Health & Care Services, 2018). In Norway, adult children are not legally required to assume care of their parents, but many do (Bøckmann & Kjelleveid, 2015). The care provided by adult children to PWD includes for example transportation, assistance with practical tasks, support for personal care and medical treatment, but mostly emotional support including spending time talking with the parent, visiting or calling to ensure that the parent is safe. In the home-dwelling period, home care services are common, often starting small and increasing as the dementia progresses. PWD usually live at home as long as justifiable possible but moving the parent into a nursing home is often normal at an advanced stage of the illness (Norwegian Directorate of Health, 2018).

The participants in this study had home-dwelling parents with dementia in different parts of a large municipality in Western Norway containing urban areas and rural districts.

3.2 | Study design

This research study adopted a qualitative design (Malterud, 2001; Polit & Beck, 2018) with a phenomenological approach (Creswell & Creswell, 2018) to explore the lived experiences with motivation in the caregiver role as described by the participants. The method for data collection was individual face-to-face interviews (Polit & Beck, 2018). This was chosen out of consideration for the participants who would be sharing personal information on a potentially sensitive topic. Data were analysed by systematic text condensation (Malterud, 2012). The COREQ, 32-item checklist is used in reporting the study (Tong, Craig, & Sainsbury, 2007).

3.3 | Participant selection and recruitment

Purposive sampling (Polit & Beck, 2018) was used and involved selecting participants who shared particular characteristics and had the potential to provide rich, relevant and diverse data pertinent to the research question. To be included in the study, the participants had to be over 18 years old and registered as a primary or secondary caregiver as their parent diagnosed with dementia was receiving healthcare services in the municipality. In addition, the parent should have moved to a nursing home for between 2 and 12 months prior to the interview. The reason for conducting retrospective interviews was that the last home-dwelling period—waiting for a place in the nursing home—could be especially stressful for both patients and their caregivers. Caregivers might find it difficult to express the positive elements of the caregiver role. Thus, by interviewing the caregivers at least 2 months or more after the parent has moved to a nursing home, the caregiver will have had the time to create some distance from the parents' home-dwelling period and be better able to reflect on the situation, add meaning to this experience and articulate it. The upper limit (12 months) was set so the participants could still remember their experiences with the caregiver role. Adult daughters and sons who met the inclusion criteria were identified and recruited by a project nurse working as a coordinator in the community. She was instructed to recruit both male and female caregivers. She telephoned 31 people. Five declined to participate, claiming that they did not have the time, energy or capacity to do so. Author HD called the participants who had agreed to be contacted by the researchers and of those five declined to participate for the same reasons. In sum, ten people who were asked to participate declined. 21 persons consented to be interviewed and none withdrew from the study.

TABLE 1 Characteristics of participants, N = 21 (%)

Characteristics	N = 21
Gender, N (%)	
Female	12 (57)
Male	9 (43)
Age group, years, N (%)	
40–49	5 (24)
50–59	11 (52)
60–69	5 (24)
Education, N (%)	
Public school	2 (10)
High school	5 (24)
University	14 (66)
Job status, N (%)	
Full-time	19 (90)
Part-time	2 (10)
Retired	0 (0)
Parents' household status, N (%)	
Mothers living alone	7 (33)
Mothers living with spouse	5 (24)
Fathers living alone	5 (24)
Fathers living with spouse	4 (19)

Note: Table 1 shows the variation in caregivers' age, gender, education, job status and the parents' household status.

3.4 | Sample

The participants were 12 daughters and nine sons. Biological, adoptive- and foster children were given equal status. At the time of interest when the parent with dementia was still living at home, none of the participants had been sharing a household with the care recipient. 12 of the participants had parents living alone, and in nine cases, the parent with dementia had lived with her or his spouse. All caregivers were holding paid jobs in addition to being informal caregivers. Table 1 contains information on the participants.

3.5 | Interview setting

The interviews took place at times and places that were convenient for the participants, such as their workplace, their home or a meeting room at the university. A few of the interviews started with the participants seeming a bit nervous, but after a while, a trusting atmosphere was established where the participants were able to share their experiences and express their opinions. In each interview session, only the participant and the interviewer were present and the participants seemed willing to speak openly.

3.6 | Data collection

A semi-structured interview guide (Polit & Beck, 2018) with open-ended questions was informed by previous research, the self-determination theory and through discussions in the research group. The interview guide was tested on a daughter who met the inclusion criteria and she contributed to the interview guide and the interview itself. For example, she found it hard to answer the vague question of *why* she had put so much effort in helping her father. She recommended breaking the question into smaller themes to encouraging participants to start talking about their motivation. She requested a more precise question about her relationship to her father before and after the dementia diagnosis; her knowledge of dementia and of her father's symptoms; and the importance of being able to decide for herself what she should and should not do as a caregiver. Her feedback led to a more detailed and expanded interview guide [see Appendix S1]. This pilot interview contributed with rich data and was therefore included in the sample.

Data were obtained from individual face-to-face interviews (Polit & Beck, 2018) conducted by HD in 2017. HD is an experienced nurse trained in interviewing and consulting elderly patients and their caregivers. All participants were informed that she was a PhD student writing her PhD thesis on caregivers. The interviewer was unknown to all the participants except for the pilot interview; that participant was an acquaintance. The same interview guide was used in all interviews except for the pilot interview. All participants were interviewed once and each interview lasted from 56 min to 1 hr and 47 min; the median length was 1 hr and 11 min. The data material was digitally audio-recorded and later transcribed, mainly by HD. A professional transcriptionist was hired to transcribe parts of the last seven interviews. The transcripts were not returned to participants for comments as their intuitive experiences were considered essential for the research question. Permitting elaboration and corrections could have resulted in a data set that did not represent spontaneous answers to the interview questions.

The recruitment process lasted for several months. The participants were interviewed until no new relevant knowledge was generated (i.e. after 21 interviews). The research group discussed the point of data saturation (Polit & Beck, 2018). A bias in retrospective interviews might be that some participants easily could switch from the past to the present time and talk about the parent in the nursing home. Therefore, there was a risk of obtaining irrelevant information. This was handled in the interview situation by asking the participants to recall examples from the home-dwelling period. Data on caregiving after the parent had moved to a nursing home were excluded from the analysis because it was not relevant to the research question.

3.7 | Analysis

Systematic text condensation, a four-step method for thematic analysis of qualitative data (Malterud, 2012, 2017), was adopted because

we wanted to explore the sustained motivation across caregivers. A single designated participant might have illustrated a typical case but not demonstrated variations in caregivers' motivation. Analysing the data consisted of the following steps: (a) reading all of the data material to obtain an overall impression, identifying preliminary themes; (b) identifying meaning units representing different aspects of themes and describing codes and code groups; (c) condensing the contents into subgroups; and (d) summarizing the content of each subgroup.

The three first phases of analysis had an open approach. Once the themes, code groups and subgroups were identified and described, the SDT framework was an aid when categorizing subgroups and finding category headings in the fourth step. In this way, the analysis was data-driven, but the SDT helped to weave the grouped data into meaningful categories. This deductive approach of placing subgroups together in the fourth step may risk the exclusion of relevant data (Overgaard & Bovin, 2014). This issue has been addressed by collecting, summarizing and reporting findings not categorized according to the SDT. Two authors (HD, AN) read all the transcribed interviews and the third author (KA) read one-third of them. The three authors independently listed the emerging themes and through discussions agreed on preliminary themes. HD identified meaning units and quotes reflecting each theme and developed descriptions of code groups. The descriptions reflecting the code groups were discussed among all authors before reorganizing, renaming and eliminating code groups. Subsequently, consensus on three categories was achieved after four analysis workshops where all authors participated. The data material was organized with NVivo 12 (QSR International, 2019) that was used to systematize 402 pages of transcribed data material.

HD is a registered nurse with a MHS in ageing and dementia, working with people with dementia and their caregivers for several years. She assumed that being a caregiver is stressful and it might be difficult to see the positive sides of caregiving. Author AN is a registered nurse and professor of nursing science; and author KA is an engineer and professor of quality and patient safety. The authors' range of backgrounds led to fruitful discussions, bringing new perspectives and preventing the first author's assumptions from leading to bias in the analysis process.

3.8 | Ethics

The PhD thesis of which this study forms a part has been approved by the Norwegian Centre for Research Data (NSD), reference number 48,276. The study has been conducted according to the recommendations of the Helsinki Declaration (World Medical Association, 2013). The project nurse gave oral information to possible participants. Those who agreed to receive more information got a letter with details about the study stating that participation was voluntary, including a description of how confidentiality and anonymity were ensured. The participants signed and returned a written consent form to the research team. Identical information was

verbally repeated at the start of each interview, and participants were also reminded that they could stop the interview or withdraw from the study at any time without stating any reason.

4 | RESULTS

All 21 of the adult-child caregivers willingly told their caregiver story, reflecting on the reasons for helping their mother or father. In the following, we describe the findings of our analysis according to the three main categories of *competence*, *autonomy* and *relatedness* with the associated subgroups (Table 2).

4.1 | Competence

Caregivers described their competence as the capability to master their daily life with the PWD. The competence of the adult children allowed them to experience different levels of control and predictability in their role as caregivers, thus affecting their motivation to remain in the caregiver role.

4.1.1 | The parent with dementia's needs

All caregivers experienced their parent gradually losing the ability to perform daily activities. The adult children were therefore in contact

with their parents at least once a week and sometimes several times a day, trying assist their parents with activities of everyday life:

It started with her not being able to pay her bills because she couldn't handle the internet anymore and she needed help to pay bills and sort out her finances. Then she needed help running errands because she lost her driver's licence and she couldn't get around as she used to. Then it piled up with different needs like help with taking her tablets, grocery shopping, preparing meals and remembering to eat them. She needed help cleaning her apartment, doing her laundry and eventually she didn't know how the shower worked so she needed help with her personal hygiene and so on and so on....

(Daughter, participant G)

Knowing what the parent needed was useful for the caregiver, but not being able to meet those needs was frustrating and thwarted their motivation. When caregivers succeeded in meeting their parent's needs, they felt competent, satisfied and pleased with their capacity to do so: *"I could see that my effort was helping her and that is motivating in itself. Then helping her was not an energy loss, but gave me good energy"* (Daughter, participant C).

The mastery of meeting the PWD's daily needs for support was an essential driver for motivation among adult children: *"What's motivated me as a caregiver was that my mother should have the best*

Category	Subgroups	Descriptions
Competence	The parent with dementia's needs	Thorough knowledge of the parent to identify what he/she needs. Different levels of coping and capacity in performing tasks for the mother/father and in meeting their needs.
	Handling dementia	Knowledge of the dementia illness and related professional help affects caregivers' feelings of mastery or helplessness in their role.
Autonomy	Freedom of choice	The ability to choose when and how to help the parent.
	Innate values and tasks	The naturalness of performing tasks to help the parent without thinking about why they do so, combined with a nuanced feeling of a sense of duty.
Relatedness	The parent with dementia	The relationship with the parent before and after the dementia diagnosis and how well the adult child thrives with the parent.
	The parent's spouse	The close relationship with the healthy parent, mutual belonging and support to the parent with dementia's spouse having the primary burden of daily caregiving.
	Other persons	Collaboration and relationships with other people such as siblings, friends, colleagues and healthcare professionals. Being listened to, treated with respect and receiving support.

TABLE 2 Categories, subgroups and descriptions of caregivers' motivational drivers

possible life while staying at home" (Son participant M). A daughter illustrates her expertise on her mother's needs: "Making her feel as good as possible was driving me to meet her needs. When I knew her so well, I could see what she needed and I could see when she was happy and feeling ok." (Participant U).

4.1.2 | Handling dementia

Several of the adult children initially described a feeling of incompetence and helplessness when they did not know the reason for the decline in the parent's cognitive function and behaviour. At the same time, they were struggling to get access to professional help. Therefore, it was a relief to receive the diagnosis and obtain knowledge on how to handle the symptoms. To have competence in dementia and feel a sense of mastery and effectiveness when helping the parent was an important source for their motivation. A daughter was frustrated and exhausted by trying to get her father to wear clean clothes, but after the diagnosis, she understood how to handle this behaviour:

If I feel that this is working, what I'm doing is making my father better in one way or another, then I have a feeling of mastery and it gives me something. When it doesn't work, you somehow lose that motivation, you go on the same track over and over again and it gets worse and worse actually. So I think maybe that is where mastering is important and that is part of my motivation.

(Participant R)

Some caregivers felt a lack of competence, confused and lost in the health system trying to obtain professional assistance for their parent sometimes leading to a sense of amotivation:

At first I didn't know where to start. I spent a lot of time and effort trying to find out where and how to get help for my mom... It felt like a waste of energy to struggle against the system. I wish I had known five years ago what I know now and then I would have avoided spending so much time and effort trying to figure things out.

(Daughter, participant V)

Knowing how the healthcare system is organized and whom to contact in different situations was an advantage in caregivers gaining a sense of perceiving control, predictability and competence. Competence in dementia and the healthcare system was obtained in different ways using various sources. Only a few caregivers had attended dementia information meetings or courses; others had consulted the internet or booklets on dementia. Common among caregivers was the helpfulness of information and advice from friends or colleagues whose own parents had had dementia:

I often went hiking with a friend of mine. Her mother recently died of dementia... We frequently talked about what I could expect at different phases of the illness, how to collaborate with the health care professionals and what I could say and do to handle my father's sometimes challenging behaviour. It was good to talk to my friend and she supported me for years.

(Daughter, participant J)

4.2 | Autonomy

The adult children expressed the importance of the ability to choose when and how to help the parent as essential for their motivation in the caregiver role. At the same time, values and nuances of sense of duty were innate when describing tasks as natural.

4.2.1 | Freedom of choice

All caregivers agreed on the importance of deciding for themselves with which tasks to help their parents. Not taking orders but voluntarily performing tasks was a driver: "If someone is squeezing you like a lemon on what you have to do, I would probably just shake it off and say, 'No, I want to decide for myself'. It was my own will or my own motive to help my parents, which I really have no other answer to" (Son, participant E). Another son stated: "I feel that what I did, I did it of my own free will, I could have said no" (Participant F).

It was also important for caregivers to have the opportunity to set boundaries for not accepting to perform specific tasks: "To help my mother was perfectly fine up to a certain point. Therefore, I couldn't go into the shower with her. It got too close" (Daughter, participant G).

Several caregivers mentioned the uncertainty around the point where it was time to level up and accept more help from professionals in the PWD's home. Some daughters had felt guilty but were content that they had decided to accept help:

I think since we got the offer, I chose to use it to be able to be the daughter who is not completely exhausted. So I would rather be the one visiting him and socialising with him instead of being a nurse and a home maid. I could probably have done more, but I chose to receive help. I know myself pretty well eventually, having to make my choices, be a little conscious that you need to be yourself as well.

(Daughter, participant A)

4.2.2 | Innate values and tasks

It was challenging for caregivers to explicitly describe their motivation for taking care of their father or mother with dementia. Everyone described it as a "natural" thing to do and "that is how we do

it in our family, so the values are inherited". They had never thought of it as an alternative not to involve themselves in caregiving: "No, that's just the way it should be, she is my mother! So I never thought about that" (Daughter, participant U).

These descriptions indicate caregiving as part of their innate values and tasks. Eventually, after talking more about the topic several caregivers expressed how they felt it valuable and important to perform tasks and help their parent and how this was done without a feeling of obligation, this feeling was part of their "backbone":

I think motivation comes from what I have learned, experienced or what is right to do, what makes you the person you are. Of course, it's your whole life that has influenced you and the motivation for caring for my mother lies within myself.

(Daughter participant T)

None of the caregivers reported that someone outside or inside the family had told them to help their parent, but several had felt the pressure to do so. The desire to take care of their parents came mostly from within themselves but sometimes from a sense of duty:

My father took it as a matter of course that I should provide care for him, he probably did. I never thought that there was any compulsion in a way, but there wasn't anyone else. So in a way, maybe indirectly... It can be an expectation from others and an expectation from yourself, what you expect of yourself.

(Daughter, participant J)

Most of the caregivers seemed to have accepted these sentiments and they were not preoccupied with the thought of having acted out of a sense of duty or out of free will. In retrospect, it was more important to be able to look back on the home-dwelling period with the certainty of knowing they had chosen to do what they could to help their parent: "It felt like the right thing to do" (Son, participant P).

4.3 | Relatedness

The caregivers talked first and foremost about their relations with other people when describing their motivational drivers. Here, gaining positive energy from interacting with the parents and other persons was central to their motivation. A feeling of belonging being a respected part of a team was essential for remaining motivated as a caregiver.

4.3.1 | The parent with dementia

All caregivers talked about the relationship with the parent before they developed dementia. None of the adult children in this study indicated that they had previously had a markedly difficult relationship

with that parent. Instead, they stated that they were genuinely fond of their parent and this made it easier to help them even with the less pleasant tasks:

If your mother has been fond of you, then you are motivated to return that kindness and when she begins to struggle, you are much more motivated. You've had a good relationship all these years and that makes you contribute to something you don't think is very nice, such as going home to her when she was living at home then, picking up clothes that she had peed in and taking them home and washing them.

(Son, participant O)

Some were concerned with the relationship after the dementia diagnosis. The PWD could be discontented and bad-tempered and then the caregiver sometimes felt like a nagging child not being welcomed in their parent's house: "...on those days the visit to mom did not give me positive energy" (Son, participant D). A daughter had similar experiences: "When I think about how tired I became from helping mom, it may not be how much time I spent, but how much energy I used" (Participant C).

Several caregivers had not experienced difficulties when visiting and helping their parent. Some said that their parent had never made them feel guilty and were just grateful for the help they received. It was also seen as confirmation of a good relationship when socializing and other ways of helping the parent were perceived as enjoyable. Having a good relationship and enjoying time spent with the parent was an important source of motivation:

We've always had a good relationship and his behaviour was my motivation to visit him. So we had enjoyable times together and it motivated me. But had it been harder to visit him, then I would probably not have had the motivation to see him as much as I did.

(Daughter, participant B)

4.3.2 | The parent's spouse

Both parents of nine of 21 caregivers were alive and the parent with dementia had lived with his/her spouse. In most cases, these spouses had been in good health and had been the one taking on the major burden of daily caregiving with the support of the adult child. These adult children pointed out the close relationship with the healthy parent as a key reason for their willingness to offer support:

I felt satisfied when I had contributed in a way that was good for my mother or for instance, made her happy, then I was motivated by this. Mother wouldn't have been able to keep him [the participant's father] home unless I had supported her. However, I think even more that I have seen in retrospect with what mom was struggling. She didn't want to worry me

either, so it's her way of showing her care for me. So to make sure that I could live my life she took most of the burden until she couldn't do it anymore. Mom probably had no regular sleep for the last 4-5 months, which meant that she was also completely exhausted, so I was, in the end, afraid that she would somehow end up with a heart attack or similar.

(Daughter, participant S)

These caregivers wanted to support the healthy parent. They appreciated gratitude but did not necessarily expect it. Several gave examples of the healthy parent's appreciation of being able to share the responsibility:

Mother was very positive and she is like that by nature. She also wrote a small booklet on 40 pages over the last two years where she talks about her experiences and her thoughts. She writes very positively, so it's her way of saying thank you for the period in which we contributed.

(Son, participant K)

4.3.3 | Other persons

The responsibility for caregiving was often shared involving not only the adult child (and the PWDs spouses), but also other people in their social network like the caregiver's siblings, other relatives, the caregiver's spouse or grown children. Having respect, understanding and support from these other persons were important:

I had a spouse with an extensive understanding of my situation. He was supportive and never accused me of not being at home and stuff like that. During times when I thought it was mentally difficult, he has been invaluable. I've been the only caregiver for my mother, but I've always had him as support.

(Daughter, participant T)

Good relations with other caregivers gave a feeling of belonging, being trusted and meaning something to others. To experience themselves as an essential part of a team caring for the PWD was important to the caregivers. The caregiving also had positive outcomes, like bringing siblings closer:

We are a family with mother, father and four siblings ... We have been in a situation where the family has been central and we have been very focused on caring for each other and being friends. There are no conflicts. We have spent a lot of time reflecting on how this has changed us and what has changed. We siblings have actually become even closer. We talk

about other things and feelings more than we did before.

(Daughter, participant S)

The caregivers rarely mentioned their relations to healthcare professionals. If they did mention these professionals, the relationship was usually negative but with some exceptions. These professionals could have been a family doctor, a community nurse, a professional at the day care centre or a service coordinator. The caregivers expressed being treated with respect, acknowledgement, understanding and support. A son mentioned that even though his father's health services were not always delivered as planned, he was satisfied with the long-term follow-up:

We had telephone conversations on demand and she listened to me... She was, as I experienced her, genuinely concerned with trying to find alternatives and things that could help. So, she was very good indeed.

(Son, participant E)

4.4 | The importance of telling the caregiver story

To prevent the exclusion of important finding when using a deductive approach (Malterud, 2012) in our fourth stage of analysis (see 3.7 Analysis), the transcribed material was searched for data that might fall outside the findings of the current analysis. In that respect, we found that caregivers were devoted to telling their caregiver history concentrating on practical issues, psychological stress, lack of support and respite services in their everyday assistance to their parent with dementia and how this also influenced their motivation negatively. Most caregivers had never had someone outside the family take an interest in them as caregivers. Therefore, they said it felt good to speak about what was important to them. In this analysis, these issues were not described in detail as they were outside the scope of the study.

5 | DISCUSSION

Three categories represent caregivers' main motivational drivers: *relatedness*, *competence* and *autonomy*. Despite the challenges and burden, the adult children in this study expressed positive reasons for becoming and remaining caregivers for their parents with dementia while they were still living at home. Their relatedness to other persons was the key driver for motivation. Relatedness included the importance of being treated with respect, understanding, acknowledgement, being listened to and supported. Other drivers included having competence on dementia and resources to help the parent, often gained through relatedness with others. At the same time, caregivers needed to feel autonomous and to voluntarily perform their caregiver tasks.

Relatedness to the person with dementia is a well-known factor for how caregivers experience their role (Bjørge et al., 2017; Bjørge, Sæteren, & Ulstein, 2019; Quinn et al., 2015). Relationship quality is directly linked to motivations for providing care and associated with the meaning of caregiving (Greenwood & Smith, 2019; Quinn et al., 2015). Essential in our study was the fact that adult children with two living parents were motivationally driven by the relationship with the healthy parent defining their role as supporting the primary caregiver. Greenwood and Smith (2019) found some similar caring motives described by spousal and adult children like, for example reciprocity, commitment, love, duty, loyalty, obligations and responsibility. On the other hand, previous empirical research has documented different experiences between caring for a parent or a spouse with dementia and between being a primary caregiver or a support for the primary caregiver (Conde-Sala et al., 2010; Tatangelo, McCabe, Macleod, & You, 2018). This is confirmed in our study from the perspective of adult-child caregivers.

The adult children in our study reported the importance of relationship quality with other persons (family members, friends, co-workers, healthcare professionals) where the essence was to be met with respect, understanding and acknowledgement, being listened to and supported. Consistent with self-determination theory (Ryan & Deci, 2017), this relatedness gave them a feeling of meaning something to others and being an important part of the team caring for the parent with dementia. Thus, satisfying the psychological need for relatedness allowed the caregivers to thrive and become more enthusiastic about caregiving (Pierce et al., 2001).

Our study also confirmed that positive and supportive relationships were important drivers for increasing adult-child caregivers' competence in assisting parents with dementia. Common was the usefulness of retrieving information and advice from friends or colleagues whose own parents had dementia. This led to the sense of mastery in their daily life with the parent with dementia. Pierce et al. (2001) described how caregivers, who considered themselves as competent, experienced more meaning and enthusiasm in their role. The caregivers in our study sometimes felt incompetent and amotivated when they repeatedly tried to do their best to help their parents, but the situation still became worse. To avoid amotivation, it is necessary for caregivers to understand dementia and have the resources to do so (Chen & Bailey, 2018; Conde-Sala et al., 2010; van der Lee et al., 2014). According to Williams and colleagues (2014), amotivational behaviour is the belief that there is no clear connection between the individual's performance of an activity and the outcome.

One way of avoiding amotivation is to experience self-determination and autonomy and caregivers should decide for themselves which tasks to perform (Ng et al., 2016). In our study, self-determination was expressed by caregivers' ability to decide which tasks they would do to help their parents and when to do them. Feeling obligated to assume in caregiving responsibilities can lead to a heavier subjective burden among adult children (Conde-Sala et al., 2010;

Tatangelo, McCabe, Macleod, & Konis, 2018). Therefore, being autonomous in the caregiver role is important and, in our study, adult children often seemed to have internalized the value of caregiving, performing tasks without talking about the need for autonomy. Looking back on their parents' home-dwelling period, they expressed that whether they had become caregivers willingly or out of a sense of duty was not important to them. The most valuable motive for them was knowing they had done the right thing by keeping their parent comfortable at home for as long as possible. These findings differ from a main assumption of the SDT framework, where being autonomous and self-determined are premises for high-quality motivation (Ng et al., 2012; Ryan & Deci, 2017; Weinstein & Ryan, 2010). In work-related contexts, satisfying the needs for autonomy, competence and relatedness is valued as equally important (Williams et al., 2014), as is the case for the long-term caregiver context (Dombestein et al., 2019). In this study, dementia caregivers' needs for competence and autonomy were important, but not as important as relatedness. In other health contexts, use of self-determination theory has been well-tested with individual patients as the focus (Ng et al., 2012). Caregiving implies a relationship between the giver and the recipient of care. Reinforcing this, the adult-child caregiver and the parent with dementia are parts of a community relating and collaborating with family members, healthcare professionals and others.

5.1 | Methodological considerations

Limitations of the qualitative approach applied in this study should be noted. On the one hand, semi-structured questions provided in the interview guide may have influenced the final categories, in contrast to allowing the participants to speak freely about their experiences without any prompts. On the other hand, the phenomena motivation is an abstract concept and according to the pilot interview, it was hard to answer open questions like: "What made you help your mother/father with dementia when she/he was living at home?" The questions in the interview guide might also have led the participants to focus mostly on the positive aspects of caregiving, substantiating a possible exclusion of negative aspects and barriers to motivation. There is also a bias in using retrospective interviews as the data collection could obtain irrelevant information or miss vital information. We handled these issues by focusing on specific episodes from the parent with dementia's home-dwelling period and by excluding information not related to the home-dwelling period from the analysis.

Another limitation might be that since 10 of 31 potential participants declined for various reasons, we can discuss if our sample, in fact, was a convenience sample. According to Tong et al. (2007), this sample may have failed to capture important perspective from "difficult-to-reach" participants. Our results might have been different if these participants had been interviewed and we had the knowledge of their experience in the caregiver role.

The last issue was caused by ethical considerations. We were not allowed to collect data on recipients of care and therefore we had no information on, for example, the type of dementia they had. Adding this information to our study could have strengthened our findings and contributed to the elaboration of possible differences in motivation, for example, in being a caregiver to a parent with Alzheimer as opposed to a parent with frontal temporal dementia. Further research may explore these issues if ethical approval allows it.

6 | CONCLUSION

In this study, we demonstrated that adult-child caregivers report relatedness as the key motivational driver for performing their caregiver role for home-dwelling parents with dementia. The knowledge of motivational drivers presented in this study can inform the work of nurses and other health professionals in dementia care. They should value relatedness when interacting with dementia caregivers and establish belonging support structures such as systematic involvement of the adult children in the parents' healthcare services or tailored respite care to the parent when needed. From our results, a possible intervention given to adult-child caregivers could be psychoeducational programmes aimed at increasing their competence on dementia in addition to providing them with customized support and guidance. In our study, we investigated motivation at an individual level, including support and acknowledgement from private networks, colleagues and healthcare professionals. Future research could examine how societal attitudes and other macro-level factors affect adult children's motivation for caregiving. Further research should increase knowledge of the positive motivational drivers for adult-child caregivers including interventions to improve their relatedness, competence and autonomy. It could also be interesting to study the interconnection of the SDT core aspects in a dementia caregiver context as this has not been done before.

ACKNOWLEDGEMENTS

We thank the caregivers who generously shared their experiences with us. We also thank the local community project nurse who recruited participants for the study.

CONFLICT OF INTEREST

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

Authors HD and AN contributed to the conception and design of the study. HD was responsible for recruitment, data collection, data analysis and drafting of the manuscript. AN and KA participated in four analysis workshops and contributed in the data analysis and interpretation of the data material. All authors critically revised the manuscript and have read and approved the final version of the manuscript.

ATTACHMENT/SUPPLEMENTARY MATERIAL FOR ONLINE PUBLISHING

Interview guide.

ORCID

Heidi Dombestein  <https://orcid.org/0000-0001-7478-2429>

Karina Aase  <https://orcid.org/0000-0002-5363-5152>

REFERENCES

- Bjørge, H., Kvaal, K., Småstuen, M. C., & Ulstein, I. (2017). Relationship quality and distress in caregivers of persons with dementia: A cross-sectional study. *American Journal of Alzheimer's Disease & Other Dementias*, 32(3), 157–165. <https://doi.org/10.1177/1533317517691121>
- Bjørge, H., Sæteren, B., & Ulstein, I. D. (2019). Experience of companionship among family caregivers of persons with dementia: A qualitative study. *Dementia*, 18(1), 228–244. <https://doi.org/10.1177/1471301216666172>
- Bjørkløf, G. H., Helvik, A.-S., Ibsen, T. L., Telenius, E. W., Grov, E. K., & Eriksen, S. (2019). Balancing the struggle to live with dementia: A systematic meta-synthesis of coping. *BMC Geriatrics*, 19(1), 295. <https://doi.org/10.1186/s12877-019-1306-9>
- Bøckmann, K., & Kjellevoid, A. (2015). *Pårørende i helse- og omsorgstjenesten: En klinisk og juridisk innføring. (Caregivers in the health- and social service: An introduction to clinical practice and legislation)* (2 utg ed.). Bergen: Fagbokforl.
- Chen, C. K., & Bailey, R. W. (2018). Episodic memories of relationship quality, procedural knowledge of attachment scripts and the experience of daughters caring for a parent with dementia. *Dementia*, 17(1), 61–77. <https://doi.org/10.1177/1471301216632963>
- Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*, 62(3), 340–350. <https://doi.org/10.1111/inr.12194>
- Conde-Sala, J. L., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J., & López-Pousa, S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: An exploratory comparative design. *International Journal of Nursing Studies*, 47(10), 1262–1273. <https://doi.org/10.1016/j.ijnurstu.2010.03.001>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative & mixed methods approaches* (5 th ed.). Los Angeles, California: Sage.
- Dombestein, H., Norheim, A., & Lunde Husebø, A. M. (2019). Understanding informal caregivers' motivation from the perspective of self-determination theory: An integrative review. *Scandinavian Journal of Caring Sciences*, 34(2), 267–279. <https://doi.org/10.1111/scs.12735>
- García-Ptacek, S., Dahrlup, B., Edlund, A.-K., Wijk, H., & Eriksson, M. (2019). The caregiving phenomenon and caregiver participation in dementia. *Scandinavian Journal of Caring Sciences*, 33(2), 255–265. <https://doi.org/10.1111/scs.12627>
- Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatrics*, 19(1), 169. <https://doi.org/10.1186/s12877-019-1185-0>
- Kim, Y., Carver, C., & Cannady, R. (2015). Caregiving motivation predicts long-term spirituality and quality of life of the caregivers. *Annals of Behavioral Medicine*, 49(4), 500–509. <https://doi.org/10.1007/s12160-014-9674-z>
- Kindt, S., Vansteenkiste, M., Cano, A., & Goubert, L. (2017). When is your partner willing to help you? The role of daily goal conflict and

- perceived gratitude. *Motivation and Emotion*, 41(6), 671–682. <https://doi.org/10.1007/s11031-017-9635-5>
- Koren, D., Laidsaar-Powell, R., Tilden, W., Latt, M., & Butow, P. (2018). Health care providers' perceptions of family caregivers' involvement in consultations within a geriatric hospital setting. *Geriatric Nursing*, 39(4), 419–427. <https://doi.org/10.1016/j.gerinurse.2017.12.013>
- Lee, K., Puga, F., Pickering, C. E. Z., Masoud, S. S., & White, C. L. (2019). Transitioning into the caregiver role following a diagnosis of Alzheimer's disease or related dementia: A scoping review. *International Journal of Nursing Studies*, 96, 119–131. <https://doi.org/10.1016/j.ijnurstu.2019.02.007>
- Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*, 15(6), 1534–1561. <https://doi.org/10.1177/1471301214564792>
- Malterud, K. (2001). The art and science of clinical knowledge: Evidence beyond measures and numbers. *The Lancet*, 358(9279), 397–400. [https://doi.org/10.1016/S0140-6736\(01\)05548-9](https://doi.org/10.1016/S0140-6736(01)05548-9)
- Malterud, K. (2012). Systematic text condensation: A strategy for qualitative analysis. *Scandinavian Journal of Public Health*, 40(8), 795–805. <https://doi.org/10.1177/1403494812465030>
- Malterud, K. (2017). *Kvalitative forskningsmetoder for medisin og helsefag. (Qualitative research methods for medicine and health sciences)* (4 utg ed.). Oslo: Universitetsforl.
- Ng, H. Y., Griva, K., Lim, H. A., Tan, J. Y., & Mahendran, R. (2016). The burden of filial piety: A qualitative study on caregiving motivations amongst family caregivers of patients with cancer in Singapore. *Psychology & Health*, 31(11), 1293–1310. <https://doi.org/10.1080/08870446.2016.1204450>
- Ng, J., Ntoumanis, N., Thøgersen-Ntoumani, C., Deci, E., Ryan, R., Duda, J., & Williams, G. (2012). Self-determination theory applied to health contexts: A meta-analysis. *Psychology and Health*, 27, 325–340. <https://doi.org/10.1177/1745691612447309>
- Norwegian Directorate of Health (2018). *Nasjonale faglige retningslinjer om demens (The Norwegian national guidelines for dementia care)*. Retrieved from <https://www.helsedirektoratet.no/retningslinjer/demens>
- Norwegian Ministry of Health and Care Services (2015). *Dementia plan 2020 - A more dementia friendly society*. Retrieved from https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/dementia_plan_2020_long.pdf
- Norwegian Ministry of Health and Care Services (2018). *Meld. St. 15 (2017-2018) Leve hele livet - En kvalitetsreform for eldre.* (Report no.15 (2017-2018). To live the whole life, a quality reform for people of old age) Regjeringen.no. Retrieved from <https://www.regjeringen.no/no/dokumenter/meld.-st.-15-20172018/id2599850/>
- Ntoumanis, N., Ng, J. Y. Y., Prestwich, A., Quested, E., Hancox, J. E., Thøgersen-Ntoumani, C., ... Williams, G. C. (2020). A meta-analysis of self-determination theory-informed intervention studies in the health domain: Effects on motivation, health behavior, physical and psychological health. *Health Psychology Review*, 1–31. <https://doi.org/10.1080/17437199.2020.1718529>
- Overgaard, D., & Bovin, J. S. (2014). *Hvordan bliver forskning i sygepleje bedre med NVivo? (How is the quality of nursing research improved through the use of software programs such as NVivo?)* Nordisk sygeplejeforskning, 4(3), 241–250. Retrieved from http://www.idunn.no/nsf/2014/03/hvordan_blicher_forskning_i_sygepleje_bedre_med_nvivo
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583–594. <https://doi.org/10.1093/geront/30.5.583>
- Pierce, T., Lydon, J. E., & Yang, S. (2001). Enthusiasm and moral commitment: what sustains family caregivers of those with dementia. *Basic & Applied Social Psychology*, 23(1), 29–41. https://doi.org/10.1207/S15324834BASP2301_3
- Polit, D. F., & Beck, C. T. (2018). *Essentials of nursing research: Appraising evidence for nursing practice*, (9 th ed.). Philadelphia, Pa: Wolters Kluwer.
- QSR International (2019). NVIVO 12 for windows. NVIVO Web Page: Retrieved from <https://qsrinternational.com/nvivo/home>
- Quinn, C., Clare, L., & Woods, R. T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: A systematic review. *International Psychogeriatrics/PA*, 22(1), 43–55. <https://doi.org/10.1017/S1041610209990810>
- Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia*, 14(2), 220–237. <https://doi.org/10.1177/1471301213495863>
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development and well-being. *American Psychologist*, 55(1), 68–78. <https://doi.org/10.1037/0003-066X.55.1.68>
- Ryan, R. M., & Deci, E. L. (2017). *Self-determination theory: Basic psychological needs in motivation, development and wellness*. New York, NY: Guilford Press.
- Svendsboe, E. J., Testad, I., Terum, T., Jörg, A., Corbett, A., Aarsland, D., & Rongve, A. (2018). Patterns of carer distress over time in mild dementia. *International Journal of Geriatric Psychiatry*, 33(7), 987–993. <https://doi.org/10.1002/gps.4882>
- Tatangelo, G., McCabe, M., Macleod, A., & Konis, A. (2018). I just can't please them all and stay sane: Adult child caregivers' experiences of family dynamics in care-giving for a parent with dementia in Australia. *Health & Social Care in the Community*, 26(3), e370–e377. <https://doi.org/10.1111/hsc.12534>
- Tatangelo, G., McCabe, M., Macleod, A., & You, E. (2018). "I just don't focus on my needs". The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. *International Journal of Nursing Studies*, 77, 8–14. <https://doi.org/10.1016/j.ijnurstu.2017.09.011>
- Tong, A., Craig, J., & Sainsbury, P. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- van der Lee, J., Bakker, T. J. E. M., Duivenvoorden, H. J., & Dröes, R.-M. (2014). Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Research Reviews*, 15, 76–93. <https://doi.org/10.1016/j.arr.2014.03.003>
- Weinstein, N., & DeHaan, C. R. (2014). On the mutuality of human motivation and relationship in Weinstein. In N. Weinstein (Eds.). *Human motivation and interpersonal relationships: Theory, research and applications*, (pp. 3–25). The Netherlands: Springer.
- Weinstein, N., & Ryan, R. M. (2010). When helping helps: Autonomous motivation for prosocial behavior and its influence on well-being for the helper and recipient. *Journal of Personality and Social Psychology*, 98(2), 222–244. <https://doi.org/10.1037/a0016984>
- Wennerberg, M., Eriksson, M., Danielson, E., & Lundgren, S. (2016). Unravelling Swedish informal caregivers' generalised resistance resources. *Scandinavian Journal of Caring Sciences*, 30(3), 602–613. <https://doi.org/10.1111/scs.12292>
- WHO, World Health Organization (2019). *Dementia - Key facts*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/dementia>
- Williams, G., Halvari, H., Niemiec, C. P., Sørebo, Ø., Olafsen, A., & Westbye, C. (2014). Managerial support for basic psychological needs, somatic symptom burden and work-related correlates: A self-determination theory perspective. *Work & Stress*, 28(4), 1–16. <https://doi.org/10.1080/02678373.2014.971920>
- World Medical Association (2013). *Ethical principles for medical research involving human subjects*. In Declaration of Helsinki, Seoul. Retrieved from <https://www.wma.net/policies-post/wmadeclaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>

Yu, D. S. F., Cheng, S.-T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies*, 79, 1–26. <https://doi.org/10.1016/j.ijnurstu.2017.10.008>

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Dombestein H, Norheim A, Aase K. Caring for home-dwelling parents with dementia: A qualitative study of adult-child caregivers' motivation. *Nursing Open*. 2020;7:1954–1965. <https://doi.org/10.1002/nop2.587>

Article III

How to stay motivated: A focus group study of Norwegian caregivers' experiences with community healthcare services to their parents with dementia

Heidi Dombestein MHS, RN¹  | Anne Norheim RN² | Karina Aase MSc, PhD¹ 

¹Centre for Resilience in Healthcare, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway

²Department of Caring and Ethics, Faculty of Health Sciences, University of Stavanger, Stavanger, Norway

Correspondence

Heidi Dombestein, Centre for Resilience in Healthcare, Faculty of Health Sciences, The University of Stavanger, PO Box 8600 Forus, N-4036 Stavanger, Norway.
Email: heidi.dombestein@uis.no

Funding information

No external funding was obtained for the study.

Abstract

Motivation to provide care is a significant predictor of informal caregiving among family caregivers of persons with dementia. Adequate support is an important source of help and relief to caregivers, but fragmentation of dementia care services is common and better ways of supporting these caregivers are needed. Knowledge of adult-child caregivers' motivation and how this motivation is influenced by community healthcare services is lacking. The aim of this study is therefore to describe and explore adult children's experiences with community healthcare services for their home-dwelling parent with dementia and how these influence their caregiver motivation. The study applied a qualitative design based on three focus group interviews with 15 of these caregivers (40–69 years) in Norway in 2017. The study results indicate three categories supporting adult children's sustained motivation as caregivers: (a) caregivers prioritize their parent's need for healthcare services over their own need for support; (b) caregivers need acknowledgement through respect and involvement; and (c) caregivers need timely information and competence as the dementia progresses. To stimulate collaboration among adult-child caregivers, their parents with dementia, and community healthcare services, we claim that a relationship-centred care framework could be emphasised as a way of supporting sustained motivation among caregivers to parents with dementia as part of community healthcare services.

KEY WORDS

adult-child caregiver, community healthcare services, dementia, home-dwelling, motivation, qualitative method

What is known about this topic

- Being the caregiver of a home-dwelling parent with dementia is characterised as burdensome.
- Motivation is essential for becoming and remaining engaged in the caregiver role throughout the dementia course.
- Dementia care services are fragmented and only partially successful in supporting the caregivers.

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2021 The Authors. *Health and Social Care in the Community* published by John Wiley & Sons Ltd.

What this paper adds

- Knowledge of how adult-child caregivers' experiences with community healthcare services influence their motivation to remain caregivers for their parent with dementia.
- Detailed descriptions of how adult-child caregivers value access to healthcare services for their parent while the caregivers are involved in a respectful way.
- A discussion of how sustained motivation among adult-child caregivers is rooted in a relationship-centred care framework.

1 | INTRODUCTION

Dementia affects approximately 50 million persons worldwide and is one of the main causes of disability and dependency among older persons (WHO, 2020). In line with the current aging policies, the majority of older persons with dementia live as long as possible in their own homes. Although a range of community healthcare services is available to support home-dwelling parents with dementia, informal care provided by family caregivers constitutes a major portion of that care (OECD, 2018). With the need to handle a wide range of physical tasks and distressing emotional and behavioural symptoms in the home-dwelling period, caregiving has been described as progressively demanding, stressful and frustrating (Chiao et al., 2015; Yu et al., 2018). Previous research has often focused on the drawbacks of caregiving, while some studies emphasise the importance of a more balanced view (Lloyd et al., 2016) with a shift from 'reducing stress' to 'optimising positive experience' in the development of caregiving support services. Still, studies that have tried to explain the more rewarding aspects of caregiving are at a relatively early stage and the topic deserves greater attention (Lloyd et al., 2016; Yu et al., 2018).

The motivation to provide care is a significant predictor of the benefits of being a family caregiver of a person with dementia (Quinn et al., 2012; Yu et al., 2018) and has an important role in the development and maintenance of caregiving (Quinn et al., 2015). Given the challenging nature of caregiving, it is important to understand what motivates people to become caregivers for persons with dementia and especially to understand why they continue in the caregiver role, despite the growing needs of the care recipient (Greenwood & Smith, 2019). By motivation, we mean the energy in people that drives their action or inaction (Ryan & Deci, 2017; Weinstein & DeHaan, 2014).

Caregivers' sustained motivation is influenced by factors that include individual characteristics and skills, family relations, access to health care services and the quality of those services (Greenwood & Smith, 2019; Quinn et al., 2015). Adequate formal support may provide help and relief to family caregivers and lighten the burden of caregiving (Alzheimer's Disease International, 2018). An approach that balance the integrity of the persons with dementia with the family caregivers' need for support is necessary in dementia care (Karlsson et al., 2015; Morrisby et al., 2018). Still, new research has found a fragmentation of dementia care services, meaning that they are only partially supporting the caregivers (Hengelaar et al., 2018; Lapidou et al., 2018). It is therefore crucial to gain knowledge of how caregivers experience community healthcare services in supporting their continued

motivation for caring for persons with dementia. With the focus on interrelations among caregivers, persons with dementia, and health-care professionals, a relationship-centred care framework that informs better ways of supporting caregivers is relevant (Nolan et al., 2003). Such relationship-centred approach should promote senses of significance, belonging, achievement, security, continuity and purpose (Nolan et al., 2001). These senses can describe the aspects of informal care often provided by family members (Wilson-Brown et al., 2013).

Caregivers of persons with dementia are a vastly diverse population. Still, most research has treated family caregivers as a homogenous group, with a few studies comparing spouse-caregivers with adult-child caregivers (Pinquart & Sørensen, 2011; Tatangelo et al., 2018). This study contributes differentiated knowledge on how adult children of parents with dementia experience community healthcare services and how these services influence their motivation to continue caregiving. The aim of this study is therefore to describe and explore adult children's experiences with community healthcare services for their home-dwelling parent with dementia and how these influence their caregiver motivation.

2 | METHODS**2.1 | Study design**

A qualitative design was chosen to gain insight into caregivers' descriptions of their experiences with healthcare services when caring for home-dwelling parents with dementia. Their experiences are embedded in and formed by their social contexts (Creswell & Creswell, 2018). The study used focus group interviews to describe the caregivers' experiences with healthcare services, leading to a deeper understanding through interactions and discussions (Morgan, 1997). The 32-item COREQ checklist is used in reporting the study (Tong et al., 2007).

2.2 | Context

Like that of other Nordic countries, Norway's public welfare model is constructed to take care of persons with dementia with supplements from informal caregivers (Norwegian Ministry of Health & Care Services, 2015). Specialist care is provided by regional health services and consists of hospitals and specialised units such as memory clinics and geriatric hospital wards. Norwegian municipalities are through community healthcare services responsible

for primary care like general practitioners, home care, day-care centres and nursing homes (Norwegian Ministry of Health & Care Services, 2018). The informal care provided by adult children to parents with dementia includes for example assistance with practical tasks, transportation, support for personal care and medical treatment, but mostly emotional support, including spending time talking with the parent, visiting or calling to ensure that he or she is safe (Norwegian Ministry of Health & Care Services, 2015). According to national legislation, healthcare professionals in the community are obligated to give information, training and support to caregivers with especially onerous tasks (Health Personnel Act, 1999; Municipal Health Services Act, 2011). The Norwegian national guidelines for dementia care recommend services for persons with dementia and their caregivers to be person-centred, holistic and well-coordinated. Most of the support offered to caregivers takes the form of general information, courses in caregiving and respite stays in day-care centres and nursing homes (Norwegian Directorate of Health, 2018). The participants in this study had home-dwelling parents with dementia. They lived in urban areas or rural districts in different parts of a large municipality in western Norway.

This study is part of a PhD project, where a previous study focused on caregivers' individual motivational drivers (Dombestein et al., 2020). Caregivers' experiences with healthcare services are explored in this focus group study. A sample of participants from the first study volunteered to join the focus group interviews.

2.3 | Recruitment procedure

Purposive sampling (Polit & Beck, 2018) was used to select participants who shared certain characteristics and had the potential to provide rich, relevant and diverse data. To be included in the study, the participants had to be over 18 years old and registered as a primary or secondary caregiver of a parent diagnosed with dementia receiving healthcare services in the municipality. Adult daughters and sons who met the inclusion criteria were identified and recruited by a project nurse working as a coordinator in the community. She was instructed to recruit both male and female caregivers. She telephoned 31 caregivers. Five declined to participate, citing limited time or energy. Author HD called the participants who had agreed to be contacted, and 21 were interviewed individually (Dombestein et al., 2020). Of those, 15 agreed to participate in the focus group interviews.

2.4 | Data collection procedures

A semistructured interview guide (Malterud, 2012a, 2012b) with open-ended questions was developed with three main themes (see Table 1). The three themes were based on information required through the preceding individual interviews in which participants were asked to describe support structures that influenced their motivation to continue caring for their parents. Their responses were

TABLE 1 Interview guide with three main themes and belonging illustrative questions

1. Experiences with caregiver support and parent's healthcare services
Can you tell us about measures for support that you experienced positively?
In what ways do you think your parent's healthcare services could provide you with better support as a caregiver?
2. Acknowledgement of adult children's efforts as caregivers
Can you tell us about a situation in which you felt that your effort as caregiver was appreciated by healthcare professionals?
In what ways can caregivers' efforts be visualized and recognized?
3. Prioritising support to sustain caregivers' motivation
Can you describe important issues within the healthcare services that influence your motivation to continue to care for your parents?

summarised and formed the basis for the contents of the interview guide.

The data collection was conducted over a 2-month period in 2017, and the focus group interviews took place in a meeting room at the university. Author HD moderated all three focus groups; coauthor AN was a comoderator in two of the groups, and a research fellow in one group. HD facilitated the group discussions while the comoderators made important clarifications, and took notes on group dynamics, participant interaction and nonverbal communication (Malterud, 2012a). HD is an experienced nurse trained in interviewing and consulting older persons and their caregivers. All participants were informed that the study was part of a PhD project. In the beginning of the focus group interviews the participants appeared a bit reserved, having met only the moderator once before. After some ice-breaker questions around the table, a trusting atmosphere was established in which the participants felt comfortable discussing their experiences and expressing their opinions.

Each interview was conducted in one session that lasted 92–106 min. The same interview guide was used in all focus groups. The participants did not see the list of questions prior to the interviews to reduce the risk of predetermined responses and support an open discussion. The focus group interviews were digitally audio recorded and then transcribed verbatim by author HD. The transcripts were not returned to participants for comments; their intuitive experiences were essential for the aim of the study.

2.5 | Participants

Practical concerns decided the combination of participants in each focus group; participants signed up for the time and date most suitable for them. The 15 participants were therefor randomly assigned to each of the three focus groups. Group 1 consisted of two daughters and three sons; group 2 of five daughters; and group 3 of three daughters and two sons.

A total of 10 daughters and five sons participated. None of the participants had recently been sharing a household with the care recipient, and all caregivers were also holding paid jobs. Eight of the

participants had parents living alone, and in seven cases, the parent with dementia lived with her or his spouse. Table 2 shows the participants' characteristics.

2.6 | Data analysis

Systematic text condensation was used to analyse the data as it allows focusing on the particular and contextual while abstracting data (Malterud, 2012a, 2012b). The analysis consisted of four steps:

1. All authors independently read the focus group transcripts to obtain an overall impression and to identify preliminary

themes. This was followed by a data analysis workshop where discussions led to revised themes.

2. Author HD identified meaning units and quotes reflecting each theme and developed descriptions of code groups.
3. Descriptions reflecting the code groups were discussed among all authors before reorganising, renaming and eliminating code groups. Units of meaning were then split into subgroups and the contents in each subgroup were condensed.
4. The contents of the condensates were synthesised into three result categories that described caregivers' experiences with community healthcare services to stay motivated as caregivers.

Table 3 contains an excerpt of the analytical process. The data material was organised with NVivo 12 (QSR International, 2019) to systematise and identify meaning units related to the code groups.

TABLE 2 Characteristics of participants, N = 15 (%)

Characteristics	N = 15
Gender, N (%)	
Female	10 (67)
Male	5 (33)
Age group, years, N (%)	
40–49	3 (20)
50–59	8 (53)
60–69	4 (27)
Education, N (%)	
Public school	1 (7)
High school	3 (20)
University	11 (73)
Job-status, N (%)	
Fulltime	13 (87)
Part-time	2 (13)
Retired	0 (0)
Parents' household status, N (%)	
Mothers living alone	6 (40)
Mothers living with spouse	5 (33)
Fathers living alone	2 (13)
Fathers living with spouse	2 (13)

Table 2 shows the variation in caregivers' age, gender, education, job status and the parents' household status.

2.7 | Ethical approval

The study was performed in accordance with the Helsinki Declaration (World Medical Association, 2008) and approved by the Norwegian Centre for Research Data (No. 48,276). All participants gave their written consent to participate and were informed that they could withdraw at any time without repercussion. They were also informed that the analysed data would be grouped so that no individuals could be identified in any reports or publications from the study.

3 | RESULTS

Our analysis has identified three categories that represent adult children's experiences with community healthcare services and how these influence their motivation in caring for home-dwelling parents with dementia. First, caregivers prioritized their parent's need for healthcare services over their own need for support. Second, caregivers needed to be acknowledged through respect and involvement. Third, caregivers need timely information and competence as the parent's dementia progresses. Overall, the adult children painted a nuanced picture of their experiences with their parents' healthcare services. The caregivers could cite occasions that had thwarted their motivation or experiences that sustained their motivation.

TABLE 3 Excerpt of the analysis process using systematic text condensation

Preliminary themes	Code group	Subgroups	Condensate	Result section
Respect and partnership	How caregivers want to be involved and acknowledged in the team supporting the parent (Respect and partnership).	Not just a pat on the back (Involvement).	I want to be recognised for knowing how the illness works for my father and what he needs to be well. It is important to me that my assessment also means something and counts in. It is necessary that there is mutual respect between me and the nurse. 'Mutual respect is fundamental' (Son D). (Involvement).	... caregivers wanted healthcare professionals to value their voice, appreciate their expertise and acknowledge them as members of the care team. As Son D put it, 'mutual respect is fundamental'. (Involvement).

Note: Example on excerpt from the full-text section.

3.1 | Caregivers prioritize their parent's need for healthcare services over their own need for support

Support services specifically directed towards the caregivers were not seen as useful as long as the parent with dementia was not doing well at home. The adult children did not want their needs to be considered separately from those of their parent. It was clear that the adult children prioritised their parent's needs over their own. It was also difficult for them to imagine the forms such support could take. Son E summarised the discussion of support for caregivers:

At least not me! I'm not concerned with support for my own part. There is something about it, as many have already expressed here, and that's when the one I'm caring for is doing well, then I'm doing well also.

All the caregivers were most concerned with having the parent with dementia receive the appropriate healthcare services at the appropriate time as the dementia illness progressed. The adult children believed that they had an important role in helping connect their parent to the services they needed. Such services often started with the parent's general practitioner (GP) diagnosing the parent with dementia and making a referral to the community coordinator who would then assign services like day-care centre, home nursing and eventually respite stays in a nursing home. Several of the caregivers regarded the GP as a gatekeeper who unlocked community healthcare services, so having a good dialogue with that GP was essential:

I think it is important to be secured that the GP also refers to other healthcare services in the community. That you don't have to stand crying at every gate to get access to services, that would be important.

(Son, D)

Most of the adult children reported varying degrees of resistance from the parent in receiving help from outside the family. This was a source of frustration and conflict between the caregiver and the parent:

Our problem was that she refused to receive healthcare services. When we siblings saw what condition her house was in, we called the district nursing service, but they came no further than the doorstep, and there they were totally rejected by our mum. This happened twice and we met 'a wall' that was terribly difficult to overcome. So particularly that process of getting her the help she needed, that was heavy.

(Son M)

A parent rejecting to receive healthcare services also included refusing to take the dementia diagnostic tests, refusing to go to the day-care centre or refusing to apply for short-term respite stays at a nursing home. Healthcare professionals often fell short in helping these parents, so the adult children had to take on those tasks

themselves. Most of the adult children had been struggling to cover their parents' need for the right healthcare services and others had received services too late. It was discouraging not feeling able to accomplish anything because their parents did not receive the healthcare services they needed. In the words of Daughter R, 'It was like banging my head against the wall ... I just wanted to give up'. In these situations, some adult children found it hard to remain motivated as caregivers. Daughter U described it this way:

It was very frustrating, I felt like living in a 'vacuum' without 'getting off the spot'.

Homecare nursing services were rarely described as optimal in cases where the parent was dismissive of the services or for other reasons did not receive help. The children linked the parent's resistance to receive healthcare services to the substandard quality of the services and the fact that too many different healthcare professionals visited their parent's home, something that felt unsafe. Most caregivers opined that homecare nursing should focus more on improving the quality of their services related to dementia competence and on workforce stability. A few of the parents had been offered homecare nursing from a smaller dementia team consisting of specially trained nurses, which worked out much better. Here, caregivers found that the assistance provided was targeted, useful and ensured continuity of services and safety for both the parents and the caregivers:

They were amazing people working in that team. I noticed that they had a tremendous level of calmness, they were not quarrelsome or too rapid in their visits and they did not ask a lot of questions that she couldn't answer. If people came in and asked lots of questions in a rapid manner, then they could just leave, because she wouldn't let them past the door. So, there were differences in appearance, those who had worked with persons with dementia were incredibly caring and got the right contact with her.

(Daughter V)

Even though the adult-child caregivers had experienced variability in the quality of services, most of them had also experienced 'backing' from healthcare professionals. They gave examples of receiving advice and having supportive conversations with healthcare professionals working at their parent's day-care centre. At the same time, they knew that their parent had a good time with others and had eaten two meals that day. This gave the caregivers a sense of relief and respite. The day-care centre thus met the interconnected needs of both the adult-child caregiver and the parent. Others mentioned an alliance with the primary nurse in the homecare services where they had enjoyed dialogue and exchange of information. Daughter R gave an example:

We rapidly got quite a common understanding of what my father was struggling with. That was perhaps the best support for me

Although the adult children saw their own needs as interconnected with those of the parent and were not concerned with support structures for their own role, they still had needs of their own as presented below.

3.2 | Caregivers need acknowledgement through respect and involvement

Some of the adult-child caregivers described not having been seen, heard or respected by healthcare personnel in the community. They found it demotivating to have their knowledge or opinions disregarded, or when their consistent care for their parents seemed to have been taken for granted:

I think it would be much better if we as caregivers received some understanding for the situation we are in. I specifically think about a situation when the care coordinator in the community said that it didn't matter if I was there for my mother or not, that was one of the most painful experiences... that's what I mean when I say acknowledgement, I don't need to receive money or a diploma or anything like that, but when I was met with the very opposite attitude, that was shocking.

(Daughter C)

All the adult children insisted that they did not need praise or compensation for having done healthcare professionals' tasks. They all had good relationships with their parents, and it was natural to help them. As Son E declared, 'I don't need a pat on the back. I really don't appreciate that, because that is *not* what this is all about'. Instead, caregivers wanted healthcare professionals to value their voice, appreciate their expertise and acknowledge them as members of the care team. As Son D put it, 'mutual respect is fundamental'. The adult children accepted that the healthcare professionals were experts on dementia, but that they knew their parents better and had the best sense of the measures that would be most helpful in difficult situations. To feel motivated, the caregivers wanted a place in the care team alongside healthcare professionals. They wanted to contribute, but not with everything all the time. The adult children understood that their mother or father could not receive unlimited healthcare services, but they sought more dialogue and interaction with the healthcare services. Son E reflected on this issue:

I want healthcare professionals to acknowledge my experience, keeping in mind that we caregivers are normally well-versed people observing and experiencing vital issues for our parents. Even if we can't express them using the correct 'doctor words', what we say is fundamentally true, an experience that is not incorrect. Then I really expect them to take notice of it and do something about it. Sometimes the response might be: 'Yes, we see that your father needs this type of service,

but we just can't deliver it right now.' I would accept that ... If those working in the community healthcare services are reminded that it is in fact caregivers who often make observations that matter in this context. Then I feel that I would be recognised, and that is probably the acknowledgement that I am looking for ... Actually, I want that recognition to permeate the entire range of healthcare professionals I meet, from the general practitioner, to the homecare nurse and everywhere.

3.3 | Caregivers need timely information and competence as the dementia progresses

One of the main reasons for the adult-child caregivers' motivation was to ensure that their parent could have the best possible life and to receive the help he or she needed. To provide such help, caregivers required more information and advice about dementia. Some caregivers had been invited to attend a 'caregiver school', but only a few had participated. Some had not been aware of the services and other did not have the time or energy. Most caregivers had seen it as essential to search information online themselves or talk to people in their private network who had competence in dementia and/or how to navigate in the healthcare system. Daughter N explained how she missed information:

I didn't know how to deal with her irregular symptoms, and I've been annoyed at her because she didn't want professional help and she was delusional and difficult. I didn't know better and then I provoked her and she yelled at me many times. But I've kind of thought, 'Okay, that's the way it is'... If I had gotten the right information and advice up front, maybe I wouldn't have been that frustrated and I would have avoided the scolding from her. Maybe it would have been easier for the both of us.

All of the adult children wanted to get the accurate and timely information, and to ensure their parent's access to needed services. Caregivers also wanted specific information such as what to expect with their parent's type of dementia, disease development, and functional ability in order to make informed decisions:

After all, the GP has a huge opportunity to provide us with information, or those at the Memory Clinic at the hospital or the care coordinator in the community. What if they could just give us an envelope the first time around with info on 'This is dementia. Check out this website. Here is where you can get help. Call this number if you need to talk to someone. These are your legal rights as caregivers and so on ...'. Information to caregivers at an early phase is very important because you do not always know what

to ask for, what information you need, and then you could call someone as the questions come up.

(Son I)

The adult children wanted to be considered as capable partners in their parent's healthcare services. Several of them understood that this would require a better knowledge of dementia. A daughter explained that she had learned an incredible amount about dementia and how it affected her mother. As a result, she remained motivated, involved and engaged in the healthcare services. It was also clear that the caregivers expected healthcare professionals to have expertise on dementia when working with their parents:

So, I'm thinking of further developing the healthcare services in the community with improved expertise in dementia and how to involve caregivers. With more specialised knowledge among professionals, the caregivers also become more active since you are recognised because you are in a dialogue and collaborate with professionals about someone you really care for, right. This doesn't mean there will be less things to do for the caregivers, but they will experience better quality of the total amount of care work. I just think it becomes more meaningful and rewarding for everyone. I think even the professionals will feel better because they work with something that they really have skills in. It will be a richer experience for everyone, rather than everyone being dissatisfied.

(Daughter V)

The adult-child caregivers agreed that such competence among caregivers and healthcare personnel would constitute a win-win situation for everyone involved in caring for the parent with dementia.

4 | DISCUSSION

Our study of adult-child caregivers' experiences with community healthcare services for their home-dwelling parents with dementia found that the caregivers stayed motivated if their parent's needs for healthcare services were sufficiently met. The caregivers saw their own needs as interconnected with those of the parent placing their parents' needs first. Furthermore, they wanted to be involved as respected and competent members of the community healthcare team.

The adult-child caregivers in our study were motivated by healthcare professionals' respect and wanted to be involved partners in the community healthcare team. They also wanted their specific competence on the needs and possible measures for their parent to be acknowledged. According to the relationship-centred care framework (Nolan et al., 2003), this is in line with the sense of *significance*, a feeling of being recognised and heard. The emphasis on involvement and being part of the parent's healthcare team is also indicative of the sense of *belonging*. This implies a feeling of being part of

something, to be able to maintain relationships, and not being 'in this alone' (Nolan et al., 2003). The adult children in our study wanted professionals to have expertise on the dementia of their parent and also in how to collaborate with caregivers. Lapidou et al. (2018) found that lack of training of healthcare professionals led to absence of information for caregivers and thus did not fully support the caregivers as part of the services. Hengelaar et al. (2018) described professionals who were not confident or qualified to support informal caregivers in a partnership. The caregivers in our study appreciated their own and professionals' competence in dementia as contributing for better help for their parent. Such a sense of *achievement* implies a feeling of 'getting somewhere', to meet challenges and competing demands, and to develop new skills (Nolan et al., 2003).

Even if the adult children in our study wanted to be partners in the community healthcare services, not all caregivers do. Spouses and others who cohabit with the persons with dementia might need other forms of support to reduce the demands on caregiving (Moholt et al., 2020). The sample in our study mainly consisted of highly educated women between the age of 50 and 59 and working full-time. They should be considered as resourceful caregivers and their motivation might differ from caregivers less likely to speak up for themselves and their parents with dementia. Many of the participants had university education, with assumably higher levels of health literacy and thus higher level of satisfaction in the caregiver role (Yuen et al., 2018). Häikiö et al. (2020) therefore recommend targeted support taking caregivers' health literacy into account increasing the potential to enhance their ability to provide sustainable care over time.

Regardless of the adult children's competence, access to timely and appropriate services for their parent was essential to keep caregivers motivated. In situations where the adult children struggled obtaining access to services, they compared it to 'banging their head against a wall'. They emphasised the value of being secured that their parent's needs were met at an early stage. This sense of *security* makes caregivers feel confident, able to provide good care, having adequate support networks, and timely healthcare services when required (Nolan et al., 2003). Security was achieved through receiving high-quality services at the right time from the dementia team. Variability in the quality of services is nevertheless confirmed by the caregivers of our study, as well as in other studies (Tretteteig et al., 2019). High-quality services also produced a sense of *continuity* through the use of a limited number of professionals working in the healthcare team and collaborating closely with the adult-child caregivers. Continuity implies the provision of competent and consistent standards of care (Nolan et al., 2003). Professionals can thus provide security and continuity by clarifying goals, consequences of actions, expectations, providing feedback, and supporting caregivers' control, provide an overview of the situation, and plans for future tasks (Pierce et al., 2001; Tretteteig et al., 2017). The adult children in our study were more concerned with the quality of their parents' healthcare services than their own need for support. It was hard for them to differentiate their own needs from those of their parent. The caregivers' motive for providing care was encompassed by an overarching *purpose* where their parent should do as well as possible while living at home. This sense of purpose implies having goals, feeling capable of making a

difference, and striking a balance between caregiving and other parts of life (Nolan et al., 2003). Community healthcare services should thus work with caregivers in a way that recognises their expertise, not supporting caregivers beyond a point at which their health suffers (Quinn et al., 2015; Nolan et al., 2003).

The relationship-centred care framework implies that good care of high quality can only be delivered when all the 'senses' are experienced by the persons with dementia, by the caregivers, and by the healthcare professionals. Nolan et al. (2003) acknowledge that this might be an idealistic goal in contexts where lack of resources is a reality (Hengelaar et al., 2018; Lapidou et al., 2018). Challenging relations between the person with dementia and their caregivers can also thwart caregivers' motivation making them act out of duty (Greenwood & Smith, 2019). From the perspective of adult-child caregivers, our study results still point towards the need for continuing to strive for the senses included in relationship-centred care to support caregivers' sustained motivation.

4.1 | Limitations

We conducted three focus group interviews with 15 participants. A larger sample could have generated more information. A small sample from the Norwegian context may also affect transferability to countries dominated by private healthcare. The need for support to parents with dementia and their caregivers was reported by adult children. Asking spouses the same questions might lead to different answers. The similarity in caregiver experiences reported by the participants in the study might be caused by homogeneity in the sample, meaning that caregivers who were struggling probably declined to participate. Still, we suggest that our findings might be transferable to settings such as adult children caring for home-dwelling parents with other long-term illnesses.

4.2 | Implications

Community healthcare services can optimise the positive aspects of caregiving for adult-child caregivers to persons with dementia by implementing the relationship-centred care framework that emphasises significance, belonging, achievement, security, continuity, and purpose. More research can form the basis for finding better ways of giving support tailored to the three categories that influence caregivers' motivation.

5 | CONCLUSION

The study results reveal three categories supporting adult children's sustained motivation in their caregiver role: (a) prioritization of parents' need for healthcare services over caregivers' own need for support; (b) acknowledgement of caregivers through respect and involvement; and (c) timely information and competence as the

dementia progresses. From the perspective of the adult-child caregivers, respected involvement (significance, belonging, achievement) and access to healthcare services for their parent (security, continuity, purpose) influenced their sustained motivation in the caregiver role. We claim that a relationship-centred care framework could be emphasised as a way of supporting sustained motivation among caregivers to parents with dementia as part of community healthcare services.

ACKNOWLEDGEMENTS

We thank the project nurse for recruiting the caregivers who participated in the study. We also thank Kristin Humerfelt, associate professor at the University of Stavanger, for being a part of the initial research group, contributing to the development of the interview guide and for moderating one of the focus groups.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Heidi Dombestein  <https://orcid.org/0000-0001-7478-2429>

Karina Aase  <https://orcid.org/0000-0002-5363-5152>

REFERENCES

- Alzheimer's Disease International. (2018). *From plan to impact: Progress towards targets of the Global action plan on dementia*. Retrieved from <https://www.alz.co.uk/adi/pdf/from-plan-to-impact-2018.pdf?2>
- Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review. *International Nursing Review*, 62, 340–350. <https://doi.org/10.1111/inr.12194>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative & mixed methods approaches* (5th ed.). Sage.
- Dombestein, H., Norheim, A., & Aase, K. (2020). Caring for home-dwelling parents with dementia: A qualitative study of adult-child caregivers' motivation. *Nursing Open*, 7(6), 1954–1965. <https://doi.org/10.1002/nop2.587>
- Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatrics*, 19, 169. <https://doi.org/10.1186/s12877-019-1185-0>
- Häikiö, K., Cloutier, D., & Rugkåsa, J. (2020). Is health literacy of family carers associated with carer burden, quality of life, and time spent on informal care for older persons living with dementia? *PLoS One*, 15(11), e0241982. <https://doi.org/10.1371/journal.pone.0241982>
- Health Personnel Act. (1999). *Act of 2 July 1999 No. 64 relating to Health Personnel etc.* In Norwegian: Lov 2, juli 1999 nr. 64 Lov om helsepersonell m.v. (helsepersonelloven). Retrieved from <https://lovdata.no/dokument/NL/lov/1999-07-02-64?q=helsepersonell%20loven>
- Hengelaar, A. H., van Hartingsveldt, M., Wittenberg, Y., van Etten-Jamaludin, F., Kwekkeboom, R., & Satink, T. (2018). Exploring the collaboration between formal and informal care from the professional perspective—A thematic synthesis. *Health & Social Care in the Community*, 26, 474–485. <https://doi.org/10.1111/hsc.12503>

- Karlsson, S., Bleijlevens, M., Roe, B., Saks, K., Martin, M. S., Stephan, A., Suhonen, R., Zabalegui, A., & Hallberg, I. R.; on behalf of the RightTimeCarePlace Consortium. (2015). Dementia care in European countries, from the perspective of people with dementia and their caregivers. *Journal of Advanced Nursing*, 71, 1405–1416. <https://doi.org/10.1111/jan.12581>
- Laparidou, D., Middlemass, J., Karran, T., & Siriwardena, A. N. (2018). Caregivers' interactions with health care services – Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia – A qualitative study. *Dementia*, 18, 2526–2542. <https://doi.org/10.1177/1471301217751226>
- Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*, 15, 1534–1561. <https://doi.org/10.1177/1471301214564792>
- Malterud, K. (2012a). *Fokusgrupper som forskningsmetode for medisin og helsefag*. (Focus groups as a research method for medicine and health sciences). Universitetsforl.
- Malterud, K. (2012b). Systematic text condensation: A strategy for qualitative analysis. *Scandinavian Journal of Public Health*, 40, 795–805. <https://doi.org/10.1177/1403494812465030>
- Moholt, J.-M., Friberg, O., Henriksen, N., Hamran, T., & Blix, B. H. (2020). Non-use of community health-care services – An exploratory cross-sectional study among family care-givers for older, home-dwelling persons with dementia. *Ageing and Society*, 1–25. <https://doi.org/10.1017/S0144686X2000015X>
- Morgan, D. (1997). *Focus groups as qualitative research* (Vol. 2). SAGE Publications.
- Morrisby, C., Joosten, A., & Ciccarelli, M. (2018). Do services meet the needs of people with dementia and carers living in the community? A scoping review of the international literature. *International Psychogeriatrics*, 30, 5–14. <https://doi.org/10.1017/S1041610217001491>
- Municipal Health Services Act. (2011). *Act of 24 June 2011 No. 30 relating to Municipal Health and Care Services*. In Norwegian: Lov 24. juni 2011 nr. 64. Lov om kommunale helse- og omsorgstjenester m.m. (helse- og omsorgstjenesteloven). Retrieved from <https://lovdata.no/dokument/NL/lov/2011-06-24-30?q=lov%20om%20kommunale%20helse%20og>
- Nolan, M., Davies, N., & Grant, G. (2001). *Working with older people and their families*. Open University Press.
- Nolan, M., Grant, G., & Keady, J. (2003). *Partnerships in family care*. McGraw-Hill Education.
- Norwegian Directorate of Health. (2018). *Nasjonal faglig retningslinje om demens* (The Norwegian national guidelines for dementia care). Retrieved from <https://www.helsedirektoratet.no/retningslinjer/demens>
- Norwegian Ministry of Health and Care Services. (2015). *Dementia plan 2020 – A more dementiafriendly society*. Retrieved from https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/dementia_plan_2020_long.pdf
- Norwegian Ministry of Health and Care Services. (2018). Meld. St. 15 (2017–2018) *Leve hele livet – En kvalitetsreform for eldre*. (Report no.15 (2017-2018). To live the whole life, a quality reform for people of old age). Retrieved from <https://www.regjeringen.no/no/dokument/enter/meld.-st.-15-20172018/id2599850/>
- OECD (Organization for Economic Cooperation and Development). (2018). *Care needed – Improving the lives of people with dementia*. Retrieved from <http://www.oecd.org/health/care-needed-9789264085107-en.htm>
- Pierce, T., Lydon, J. E., & Yang, S. (2001). Enthusiasm and moral commitment: What sustains family caregivers of those with dementia. *Basic & Applied Social Psychology*, 23, 29–41. https://doi.org/10.1207/S15324834BASP2301_3
- Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, 26, 1–14. <https://doi.org/10.1037/a0021863>
- Polit, D. F., & Beck, C. T. (2018). *Essentials of nursing research: Appraising evidence for nursing practice* (9th ed.). Wolters Kluwer.
- QSR International. (2019). NVIVO 12 for Windows. NVIVO Web Page. Retrieved from <https://qsrinternational.com/nvivo/home>
- Quinn, C., Clare, L., & Woods, R. T. (2012). What predicts whether caregivers of people with dementia find meaning in their role? *International Journal of Geriatric Psychiatry*, 27, 1195–1202. <https://doi.org/10.1002/gps.3773>
- Quinn, C., Clare, L., & Woods, R. T. (2015). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia*, 14, 220–237. <https://doi.org/10.1177/1471301213495863>
- Ryan, R. M., & Deci, E. L. (2017). *Self-determination theory: Basic psychological needs in motivation, development, and wellness*. Guilford Press.
- Tatangelo, G., McCabe, M., Macleod, A., & You, E. (2018). "I just don't focus on my needs". The unmet health needs of partner and offspring caregivers of people with dementia: A qualitative study. *International Journal of Nursing Studies*, 77, 8–14. <https://doi.org/10.1016/j.ijnurstu.2017.09.011>
- Tong, A., Craig, J., & Sainsbury, P. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19, 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Tretteteig, S., Thorsen, K., & Rokstad, A. M. M. (2019). Pårørendes Erfaringer Av Kvalitet I Helse- Og Omsorgstjenester Til Personer Med Demens Og Pårørende. En Longitudinell Narrativ Studie. (Family caregivers experiences of quality in health and care services for people with dementia and their caregivers. A longitudinal narrative study). *Tidsskriftet Aldring Og Helse*, 23(4), 56–64.
- Tretteteig, S., Vatne, S., & Rokstad, A. M. M. (2017). The influence of day care centres designed for people with dementia on family caregivers – A qualitative study. *BMC Geriatrics*, 17(5), 1–11. <https://doi.org/10.1186/s12877-016-0403-2>
- Weinstein, N., & DeHaan, C. R. (2014). On the mutuality of human motivation and relationships. In N. Weinstein (Ed.), *Human motivation and interpersonal relationships: Theory, research, and applications* (pp. 3–26). Springer Netherlands: Imprint: Springer.
- WHO (World Health Organization). (2020). *Dementia – Key facts*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/dementia>
- Wilson-Brown, C., Swarbrick, C., Pilling, M., & Keady, J. (2013). The senses in practice: Enhancing the quality of care for residents with dementia in care homes. *Journal of Advanced Nursing*, 69, 77–90. <https://doi.org/10.1111/j.1365-2648.2012.05992.x>
- World Medical Association. (2008). Ethical principles for medical research involving human subjects. In Declaration of Helsinki, Seoul. Retrieved from <https://www.wma.net/what-we-do/medical-ethics/declaration-of-helsinki/>
- Yu, D. S. F., Cheng, S.-T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies*, 79, 1–26. <https://doi.org/10.1016/j.ijnurstu.2017.10.008>
- Yuen, E. Y. N., Knight, T., Ricciardelli, L. A., & Burney, S. (2018). Health literacy of caregivers of adult care recipients: A systematic scoping review. *Health & Social Care in the Community*, 26(2), 191–206. <https://doi.org/10.1111/hsc.12368>

How to cite this article: Dombestein H, Norheim A, Aase K. How to stay motivated: A focus group study of Norwegian caregivers' experiences with community healthcare services to their parents with dementia. *Health Soc Care Community*. 2021;00:1–9. <https://doi.org/10.1111/hsc.13396>



Appendices



Appendix A

Participant information letter and consent form



FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

MOTIVASJON OG UTHOLDENHET I PÅRØRENDEROLLEN - når foreldre med demens bor hjemme

Dette er et spørsmål til deg om å delta i forskningsprosjektet *MOTIVASJON OG UTHOLDENHET I PÅRØRENDEROLLEN - når foreldre med demens bor hjemme*. Prosjektet er delt i to delprosjekter. Formålet i delprosjekt 1 er å få dypere innsikt i voksne døtre og sønner sine opplevelser og erfaringer med det å være pårørende til foreldre med demens som nylig har bodd hjemme. Ved økt forståelse og kunnskap om denne gruppen pårørende og deres situasjon kan helse-, omsorg- og velferdstjenestene bidra til å lette pårørendes utfordringer i hverdagen og forebygge overbelastning og helsesvikt. Formålet i delprosjekt 2 er å få fram pårørendes erfaringer og meninger om hva som er og kan oppfattes som god støtte for å opprettholde motivasjon og utholdenhet i pårørenderollen. Denne kunnskapen kan i fremtiden bidra til videreutvikling av offentlige tjenester rettet mot pårørende til personer med demens. Eksempel på støtteordninger kan være informasjon, kurs, veiledning, dialog med helsepersonell og ulike typer avlastning. Dette doktorgradsprosjektet er tidsaktuelt fordi nyere nasjonale føringer setter fokus på pårørendes rolle som ressurspersoner, og det kreves en ny pårørendepolitikk som anerkjenner pårørendes kompetanse og innsats.

Du får denne forespørselen fordi du er registrert som pårørende til din mor/ far, og du har erfaringer med hvordan det var å være pårørende da din mor/ far bodde hjemme. Sentral koordinator i Stavanger kommune har valgt ut pasienter med demensdiagnose som har flyttet til sykehjem for mellom 2 og 12 måneder siden. Du har sagt deg villige til å motta dette uforpliktende informasjonsskrivet og bli kontaktet av doktorgradskandidat Heidi Dombestein for eventuell avtale om tid og sted for et individuelt intervju.

HVA INNEBÆRER PROSJEKTET?

Deltagelse i delprosjekt 1 innebærer et individuelt intervju der du deler dine erfaringer og synspunkter på ulike aspekter ved det å være pårørende. Fokuset under intervjuet vil være på deg og hvordan du opplevde å være pårørende da din mor/ far bodde hjemme i egen bolig. Det vil ikke bli registrert helseopplysninger og det dreier seg ikke om intime opplysninger om din mor/ far. Det vil bare være deg og undertegnede tilstede, og intervjuet vil ta omtrent en time. Det er ønskelig å gjøre lydopptak av intervjuet, slik at dine formuleringer bevares og man får nøyaktig oversikt over hva du forteller.

Delprosjekt 2 innebærer deltagelse i et fokusgruppeintervju som planlegges å ta omtrent 1,5 timer. Her legges det opp til en gruppesamtale mellom 5-6 pårørende der hensikten er erfaringsutveksling, diskusjon og idemyldring. Her er man ute etter informasjon om hvilke støttetiltak pårørende savnet da forelderen med demens bodde hjemme, og nytenking og forslag til forbedring av støtteordninger som kan bidra til å utvikle fremtidens offentlige tjenester rettet mot pårørende til personer med demens.

MULIGE FORDELER OG ULEMPER

Din deltagelse er et viktig bidrag til forskningen, fordi dette prosjektet vil fremme kunnskap som kan bedre hverdagen for andre pårørende som kommer i din situasjon i fremtiden. Du får ingen direkte personlige fordeler ved å delta, og ulempen for deg er at du må sette av tid til deltagelse.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Du har sagt deg villige til å motta dette uforpliktende informasjonsskrivet, og du vil dermed bli kontaktet av Heidi Dombestein per telefon med forespørsel om avtale av tid og sted for et individuelt intervju. Det er frivillig å delta i prosjektet. Dersom du velger å delta i et individuelt intervju, tas samtykkeskjemaet med til intervjuet. På slutten av det individuelle intervjuet vil du bli spurt om du ønsker å delta i et fokusgruppeintervju på et senere tidspunkt. Du står her fritt til å velge om du vil være med i gruppeintervjuet eller ikke.

Du kan når som helst og uten å oppgi årsak trekke ditt samtykke. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte doktorgradskandidat og prosjektleder Heidi Dombestein, telefon nummer 51 83 42 89, E-post adresse: heidi.dombestein@uis.no Hovedveileder og førsteamanuensis ved Universitetet i Stavanger kan også kontaktes på tlf.nr: 51 83 42 83 eller E-post: kristin.humerfelt@uis.no

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert.

Lydopptakene fra intervjuene vil bli nedskrevet, anonymisert og analysert for å bli benyttet i forskningsprosjektet. Alle opplysningene vil bli behandlet uten navn og telefonnummer eller andre direkte gjenkjenner opplysninger. Dine personopplysninger blir gitt en kode for å sikre konfidensialitet. Denne kodenøkkelen og lydopptak blir lagret i et låst skap. Kun undertegnede og veiledere ved Universitetet i Stavanger har tilgang til dette. Hovedveileder er førsteamanuensis Kristin Humerfelt og medveileder er dosent Anne Norheim. Når studien avsluttes 14.06.2019, vil lydopptakene bli slettet, avskriften fra intervjuene og kodenøkkelen vil bli makulert. Ved publikasjon av doktorgradsavhandlingen vil ikke deltagerne kunne gjenkjennes, og det vil heller ikke bli gjort kjent hvilken kommune deltagerne tilhører.

Prosjektleder Heidi Dombestein har ansvar for den daglige driften av forskningsprosjektet og at opplysninger om deg blir behandlet på en sikker måte.

GODKJENNING

Prosjektet anbefales gjennomført av Norsk senter for forskningsdata (NSD) sak nr. 48276.

Med vennlig hilsen

Heidi Dombestein
Sykepleier og doktorgradskandidat ved Universitetet i Stavanger

INFORMERT SAMTYKKESett kryss
for JA

Jeg bekrefter at jeg har lest og forstått informasjonsbrev.

Jeg ønsker å delta i et individuelt intervju. (delprosjekt 1)

Jeg ønsker å delta i et fokusgruppeintervju, og jeg forstår at jeg blir kontaktet på et senere tidspunkt for avtale om tid og sted. (delprosjekt 2)

Jeg forstår at min deltagelse er frivillig, og jeg kan trekke meg når som helst uten begrunnelse.

Jeg gir tillatelse til at det gjøres digitale lydopptak under intervjuene.

Jeg forstår at materialet fra intervjuet anonymiseres og behandles konfidensielt. Både lydopptak og transkribert materiale oppbevares nedlåst og slettes/makuleres når doktorgradsavhandlingen er ferdig.

Jeg forstår at dersom jeg har kommentarer i etterkant av intervjuet kan doktorgradskandidat Heidi Dombestein kontaktes.

Med min underskrift ønsker jeg å delta i studien:

«MOTIVASJON OG UTHOLDENHET I PÅRØRENDEROLLEN - når foreldre med demens bor hjemme»

Navn på informant

dato

signatur

Heidi Dombestein

Navn på doktorgradsstudent

dato

signatur

Samtykkeskjemaet tas med til intervjuet og leveres til Heidi Dombestein



Appendix B

Interview guide, individual interviews

Interview guide (Sub-study 2)

(Published as online supplementary material in Article II, except question nr.6
6)

At the beginning of the interview, I will remind the participant that it is the caregiver who is the focus of the interview and not the patient. I will also like to mention that I have not received consent from the parent to obtain information about them. Therefore, third part information should be minimised.

1. Can you tell me about your everyday life and how it was for you when your mother/father lived at home with dementia?

Possible follow-up questions:

- What practical tasks and how often did you help your mother/father in everyday life?
- Did you do something social or other things together with your mother/father, can you tell me about it?
- Did your mother/father have other persons than you to help her/him, if so, who?

2. What made you help your mother/father while she/he lived at home?

Reformulation if necessary:

- What were your drivers to help your parent with dementia?

Possible follow-up questions:

- Did you experience something positive for yourself by caring for your mother/ father, can you tell about it?
- Did you get any positive feedback and appreciation from other persons for your efforts? If so, how and from whom?
- Did you see your caregiving as meaningful? If so, can you give examples? Did you find that you made a difference to your mother/father when she/he lived at home? If so, in what way?
- Have you ever felt pressured to take care of your mother/father? If so, can you tell about it and from whom you felt pressure?
- Has your relationship with your mother/ father changed after she became ill? How do you think your relationship with your mother/ father has affected your efforts in the caregiver role?

3. What helped you endure and stay in the role of caregiving during the years when your mother/father lived at home with dementia?

Possible follow-up questions:

- From where did you get information about dementia? Have you attended a dementia course for caregivers or similar? If so, can you tell me about it?
- If you experienced support from (possible) workplace, your private network or health professionals, can you tell me about it?
- Did you get any kind of relief, e.g. daycare centre or respite services in nursing homes for your mother/father?
- Did you receive any kind of financial compensation for the caregiver work, for example in the form of care pay, leave with pay, pension points or the like?

4. Think about the challenges you have described. What made you still go on?

Reformulation if necessary:

- Adult children have no legal duty to take care of old parents in Norway, what made you continue to help your mother/father despite the challenges?

5. Are there any other needs or associations about being a caregiver that you think is important to mention?

6. Additional question

As next part of this PhD-project I will conduct focus group interviews, where we gather adult-child caregivers and discuss how motivation in the dementia caregiver role can be better supported. For you, what is the most important thing to discuss in this context?

Additional question asked in sub-study 2 was not published online as this was preparations for the interview guide developed for focus group interviews in sub-study 3.

THANK YOU for participating in this study!

Appendix C

Interview guide, focus group interviews



Interview guide Sub-Study 3. (Only in Norwegian)

FOKUSGRUPPE intervju

Velkommen og introduksjon

Presentasjonsrunde rundt bordet

Tema 1: Erfaringer med foreldrenes kommunale helse- og omsorgstjenester og støtte til pårørende

Eventuelt:

-Hvilke støtteordninger til pårørende har dere erfart som virkningsfulle slik at motivasjon og utholdenhet i pårønderollen bevares/styrkes?

-Er det noe form for støtte du savnet da din mor/far bodde hjemme?

-Hvilke forslag har dere til hvordan helsetjenesten kan støtte dere pårørende bedre?

Tema 2: Anerkjennelse av pårørendes innsats.

Eventuelt:

-Kan dere fortelle om situasjoner der dere har følt at innsatsen deres ble verdsatt?

-Basert på erfaringene deres, hvilke forslag har dere til hvordan pårørendes innsats kan bli synliggjort og anerkjent på en bedre måte?

Tema 3: Prioriteringer for å bevare pårørendes motivasjon

Eventuelt:

-Dere har nå snakket om tiltak som kan støtte pårørende slik at de bevarer sin motivasjon i pårønderollen. Hva er det viktigste for dere å prioritere?

-Kan dere tenke spesielt på voksne sønner og døtre som er pårørende til hjemmeboende foreldre med demens. Slik dere ser det, hva er det aller viktigste som må skje i den nærmeste fremtid for pårørende på feltet?

Takke for deltagelsen i studien



Appendix D

Western Regional Ethics Committee, response letters

Svar på framleggingsvurdering mottatt 04.01.16 fra
post@helseforskning.etikkom.no
REK vest 2016/2 – Fremleggingspliktig

Vår ref. nr.: 2016/2

Prosjekttittel: "Motivasjon og utholdenhet i pårønderollen når foreldre med demens bor hjemme i egen bolig."

Prosjektleder: Heidi Dombestein

Heidi Dombestein.

Jeg viser til framleggingsvurdering innsendt 22.12.2015.

Min forståelse av prosjektet

Problemstillingen i prosjektet er definert som: "Hvordan opplever voksne barn motivasjon og utholdenhet i pårønderollen, og hvordan kan offentlige støttetiltak styrkes slik at pårørende kan bidra uten selv å ta skade når foreldre med demens bor hjemme i egen bolig?" Prosjektet er planlagt som en doktorgradsavhandling, der resultatene skal søkes publisert i tre artikler. Hensikten i delstudie 1 beskrives som: "...å komme i dybden og studere fenomenene motivasjon og utholdenhet i pårønderollen, og det er ikke helseopplysninger om pasienten som er i fokus."

Vurdering

Helseforskningsloven (jf. §§ 2, 4) gjelder for medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger. Medisinsk og helsefaglig forskning defineres som virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom. Det er altså formålet med prosjektet som er avgjørende for hvorvidt søknad til REK skal sendes eller ikke.

Jeg er enig med prosjektleder i at dette prosjektet havner i gråsonen, og at det prosjektet ikke åpenbart kan gi ny kunnskap om helse og sykdom. Helsebegrepet skal tolkes vidt, og kunnskap om "opplevelse av motivasjon og utholdenhet" kan sees på som ny kunnskap om helse og sykdom. Ved tvil skal full søknad sendes til REK, og jeg basert på denne vurderingen vil jeg derfor be deg sende en prosjektsøknad til REK. Vennligst bruk skjemaet "prosjektsøknad" i saksportalen til REK.

Jeg gjør oppmerksom på at neste søknadsfrist er 12.01.2015.

Med vennlig hilsen
Øyvind Straume
sekretariatsleder
post@helseforskning.etikkom.no
T: 55978496

**Regional komité for medisinsk og helsefaglig
forskningsetikk REK vest-Norge (REK vest)**
<http://helseforskning.etikkom.no>



Region: REK vest	Saksbehandler: Camilla Gjerstad	Telefon: 55978499	Vår dato: 04.04.2016	Vår referanse: 2016/262/REK vest
			Deres dato: 16.02.2016	
Vår referanse må oppgis ved alle henvendelser				

Heidi Dombestein
Institutt for Helsefag

2016/262 Motivasjon og utholdenhet i pårønderollen når foreldre med demens bor hjemme i egen bolig

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 10.03.2016. Vurderingen er gjort med hjemmel i helseforskningsloven § 10, jf. forskningsetikkloven § 4.

Forskningsansvarlig: Universitetet i Stavanger
Prosjektleder: Heidi Dombestein

Prosjektomtale

Prosjektet søker ny kunnskap om pårørendes opplevelse av motivasjon og utholdenhet i pårønderollen. Man vil videre undersøke deres meninger om betydningen av offentlige støttetiltak, samt deres forslag til forbedring av offentlige tjenester rettet mot pårørende. Datainnsamlingen vil forgå ved individuelle intervju og fokusgruppeintervjuer. 1 delprosjekt 1 intervjues 20-25 personer. Delprosjekt 2 består av to fokusgrupper med tilsammen 16 deltakere.

Vurdering

Fremleggingsvurdering

Helseforskningsloven gjelder for medisinsk og helsefaglig forskning på mennesker, humant biologisk materiale eller helseopplysninger, jf. § 2. Medisinsk og helsefaglig forskning defineres som «*virksomhet som utføres med vitenskapelig metodikk for å skaffe til veie ny kunnskap om helse og sykdom*», jf. § 4 bokstav a. Slike prosjekter må søke REK. Formålet med studien er å undersøke motivasjon og utholdenhet i pårønderollen når foreldre med demens bor hjemme i egen bolig. Komiteen oppfatter at formålet med undersøkelsen ikke er å skaffe til veie ny kunnskap om helse og sykdom som sådan, slik dette skal forstås i helseforskningsloven § 4. Studien omfattes dermed ikke av helseforskningsloven, og søknaden skal ikke vurderes av REK.

REK gjør oppmerksom på at forskningsprosjekter som ikke omfattes av helseforskningsloven, men som innebærer behandling av personopplysninger skal fremlegges for personvernombudet.

Vedtak

Prosjektet faller utenfor helseforskningslovens virkeområde og søknaden skal derfor ikke behandles av REK.

Klageadgang

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

Besøksadresse:
Armauer Hansens Hus (AHH),
Tverrfløy Nord, 2 etasje, Rom
281, Haukelandsveien 28

Telefon: 55975000
E-post: rek-vest@uib.no
Web: <http://helseforskning.etikk.com.no/>

All post og e-post som inngår i saksbehandlingen, bes adressert til REK vest og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK vest, not to individual staff

Med vennlig hilsen

Ansgar Berg
Prof. Dr.med
Komitéleder

Kopi til: post@uis.no

Camilla Gjerstad
rådgiver



Appendix E

Norwegian Centre for Research Data, response letters



Heidi Dombestein
Institutt for helsefag Universitetet i Stavanger
Ullandhaug
4036 STAVANGER

Vår dato: 06.05.2016

Vår ref: 48276 / 3 / HIT

Deres dato:

Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 08.04.2016. Meldingen gjelder prosjektet:

48276 *Motivasjon og utholdenhet i pårønderollen når foreldre med demens bor hjemme i egen bolig*
Behandlingsansvarlig Universitetet i Stavanger, ved institusjonens øverste leder
Daglig ansvarlig Heidi Dombestein

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, 01.06.2019, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Hildur Thorarensen

Kontaktperson: Hildur Thorarensen tlf: 55 58 26 54

Vedlegg: Prosjektvurdering

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



Prosjektet har vært vurdert av REK vest (ref. 2016/262) som ikke fremleggespliktig etter helseforskningsloven.

Utvalget informeres skriftlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er i utgangspunktet godt utformet, men setningen "Prosjektet er godkjent av Norsk samfunnsvitenskapelige datatjeneste (...)" må omformuleres, da vi ikke gir formelle godkjenninger. Det kan heller stå at prosjektet er meldt til oss. For øvrig har vi nylig byttet navn til NSD - Norsk senter for forskningsdata.

Det tas høyde for at datamaterialet vil kunne inneholde til dels sensitive opplysninger om identifiserbare tredjepersoner (foreldre). Behandlingen anses nødvendig for formålet, da det i mange tilfeller vil kunne være vanskelig for informanten å gi beskrivelser uten å identifisere involverte tredjepersoner. Vi forstår det slik at fokus vil være på informanten og dennes opplevelser. Personvernombudet legger til grunn at tredjeperson, så langt det lar seg gjøre, får informasjon om prosjektet via deltaker. Dersom det i noen tilfeller skulle vise seg uforholdsmessig vanskelig å informere tredjeperson, kan prosjektleder unntas fra informasjonsplikten. Alternativt må opplysninger om tredjeperson anonymiseres fortløpende. Personvernombudet foreslår at prosjektleder oppfordrer informanten til å omtale andre i så lite identifiserende grad som mulig/nødvendig.

Personvernombudet legger til grunn at forsker etterfølger Universitetet i Stavanger sine interne rutiner for datasikkerhet.

Forventet prosjektslutt er 01.06.2019. 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)
- slette digitale lydopptak

-----Opprinnelig melding-----

Fra: Lasse Andre Raa <Lasse.Raa@nsd.no>

Sendt: onsdag 10. juli 2019 14.14

Til: Heidi Janne Dombestein <heidi.dombestein@uis.no>

Emne: Prosjektnr: 48276. Motivasjon og utholdenhet i pårørenderollen når foreldre med demens bor hjemme i egen bolig

BEKREFTELSE PÅ ENDRING

Hei

Viser til statusrapport registrert hos NSD 3.7.2019.

Vi har nå registrert at ny prosjektslutt er 31.12.2019 (tidligere 1.6.2019).

Ved behov for ytterligere forlengelse, må prosjektet meldes på nytt meldeskjema og vurderes etter nytt personvernlovverk som trådte i kraft i fjor.

Prosjektperioden forlenges med dette fra rundt tre år til rundt 3,5 år. Forlengelsen anses i liten grad å øke personvernulempen, og behandlingen har derfor fortsatt lovlig grunnlag i samtykke.

NSD forutsetter at prosjektopplegget for øvrig gjennomføres i tråd med det som tidligere er innmeldt samt våre tilbakemeldinger. Vi vil ta ny kontakt ved prosjektslutt.

Med vennlig hilsen

Lasse Raa
Seniørrådgiver | Senior Adviser
Seksjon for personverntjenester | Data Protection Services
T: (+47) 55 58 20 59

NSD - Norsk senter for forskningsdata AS | NSD - Norwegian Centre for Research Data Harald
Hårfagres gate 29, NO-5007 Bergen
T: (+47) 55 58 21 17
postmottak@nsd.no www.nsd.no