Being Home with Dementia

Explorations of the Meaning of Home and Approaches to Care and Support

Stein Erik Fæø

Thesis for the degree of Philosophiae Doctor (PhD)
University of Bergen, Norway
2021

UNIVERSITY OF BERGEN

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Thesis for the degree of Philosophiae Doctor (PhD)
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Date of defense: 21.06.2021

Year: 2021

Title: Being Home with Dementia

Name: Stein Erik Fæø

Print: Skipnes Kommunikasjon / University of Bergen

Scientific environment

This project was carried out at the Center for Elderly and Nursing Home Medicine, at the Department of Global of Global Public Health and Primary Care at the Faculty of Medicine, University of Bergen. The project was funded by the DAM Foundation (Formerly The Norwegian ExtraFoundation for Health and Rehabilitation) [grant number: 2016/FO77186] with The Norwegian Women's Public Health Association as applicant organization. The project is part of the LIVE@Home.Path project, a research project funded by the Norwegian Research Council (sponsors protocol code 273581).

All parts of the project were carried out in collaboration with the municipality of Bergen. Part three of the project was also carried out in collaboration with Haraldsplass Deaconess Hospital; the Center for learning and Coping, Bergen; and Bergen Dementia Association.

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STIFTELSEN
DAM

Norske Kvinners Sanitetsforening

Acknowledgements

First of all, I would like to thank all the wonderful people who have opened up the door to their lives so I could have a look. Thank you for sharing your thoughts, experiences and perspectives. None of this would have been possible without you.

I also want to thank the personnel at the daycare centers who helped us recruit participants and facilitating interviews for study one. Thank you for creating a good room to be in, for me and for the participants. Further, I want to thank our collaborators in the LIVE study: Haraldsplass Deaconess Hospital, the Center for Learning and Coping, volunteer coordinator Eva Steigen and Bergen Dementia Association. Not least, I wish to thank the Resource Center for Dementia. Thank you for your tireless effort to make the study possible and for your genuine care and support for the study participants and eachother.

Thanks to the DAM foundation for funding this project and The Norwegian Women's Public Health Association as applicant organization. Thank you for your trust and support throughout the process.

My supervisors: thank you for your patience, commitment, wisdom, care and inspiration throughout the process. Thank you for constantly pushing me on, step by step, after I thought I had reached my limits. Main supervisor, Bettina Husebø, thank you for your constant support and for teaching me that the proof is in the pudding, it has helped me more than you would know. Co-supervisor, Oscar Tranvåg, thank you for your thoroughness and many good and important talks by the coffee machine. Co-supervisor, Frøydis Bruvik, thank you for all your to-the-point advice and feeback along the way and for always having an open office.

A special thanks to Rune Samdal for contributing with your valuable experience and insight as a co-researcher with user experience throughout the process. Thank you also for being my climbing mate and encouraging me to take risks.

All the great colleagues at SEFAS and FEST, especially the present and former PhD-candidates, thank you for your good humor, your continuous support and many good conversations.

I would also like to thank my new colleagues at VID specialized university for welcoming me into your warm fellowship and for your support and adaptation to help me finish this project. A special thanks to Kjell Arne Aarheim, for following me, step by step, since my surgical practice period in 2007.

Thanks to all my friends and family who have supported me and believed in me along the way. Especially Jonas Svendsen, for reading manuscripts and giving valuable feedback, perspectives and linguistic advice.

None of this would have been possible without my constant, Tone Stokka. Thank you for your patience, your support, your inspiration, your solidity and for being exactly who you are. I cannot imagine how I could have come through this without you. Elisabeth and Jonathan, thank you for always being able to drag me out of the bubble and into your crazy worlds. Thank you all for constantly reminding me of *what matters to me.* I owe you all. Big time.

Introduction

During my last year at high school, I received a part-time job at a dementia ward in a nursing home. In the beginning I did ‘overlap-shifts’ to keep the ward calm in the busy part of the afternoon shift and in the beginning of the night shift, while the night nurse was assisting in other wards. During these late nights, when most patients had gone to bed and I was alone in the ward, I made some experiences – or *‘Erlebnisse’* as Gadamer would have said – about dementia. In the calm of night, persons who in daytime were confused and discarded as ‘being out of their minds’ would come out from their rooms, sit down, take a cup of tea and talk – with me or with eachother – about trivial things, about their lives, their families, where they used to live, sometimes for half an hour, sometimes for ten minutes, sometimes for one minute.

Later, during my nursing education, I had my first practice period in a nursing home. My primary patient had severe dementia, was unable to move by herself, and I was told she had no language except ‘yes’ and ‘no,’ which was used arbitrarily. I made it my mission to prove them wrong. Day by day I used moments of calm and quiet to ask simple questions and establish a relation. Mostly, she replied with the said arbitrary ‘yes’ and ‘no’ until suddenly one day her answers evolved to a simple story about a game she and her friend had used to play as children. In the time following, she would from time to time – not often and not for long – share short stories from her life.

During my years in the homecare services I met many different faces of dementia. I learned, often through failing, the importance of finding time for creating room for small meetings and seeing behind the often chaotic surface of the persons’ lives. Not least, as I received a leading position, I learned to value co-workers who were much better at this than myself.

When entering this project, I was curious, excited, but most of all humble. Humble, because it entailed saying something about a group of persons who have so often been deprived of the possibility to say something about themselves.

In order to see birds it is necessary to become a part of the silence. One has to sit still like a mystic and wait. One soon learns that fussing, instead of achieving things, merely prevents things from happening. To be passive is in some circumstances the most efficient form of activity. You cannot command events: you can only put yourself in the place where events will happen to you. No impatient man has ever seen Nature.

Robert Lynd

Abbreviations

ACP	Advance Care Planning
ADL	Activities of Daily Living
BPSD	Behavioral and Psychological Symptoms in Dementia
GDS	Global Deterioration Scale for Assessment of Primary Degenerative Dementia
GP	General Practitioner
ICD	International Classification of Diseases
MMSE	Mini Mental State Examination
WHO	World Health Organization

Abstract

Background : The coming years will see an increase in the number of persons with dementia, and more persons with dementia will live at home for a longer time. Over time, most home-dwelling persons with dementia will be increasingly in need of individualized, coordinated care and support. A multitude of innovative care and support measures for persons with dementia has been established, and beneficent effects are seen, although with some ambiguity. In addition, coordination and individual adaptation has proved to be challenging. These complex issues have led to a call for developing sustainable care pathways that also are able to maintain the persons' basic rights to autonomy and participation in decision-making processes.

Objectives: Primary objective: To explore the meaning of home and approaches designed to promote and coordinate care for home-dwelling persons with dementia. Secondary objectives: To explore and describe how the home, as described by persons with dementia, can be interpreted and comprehended; to explore and describe how the home may be affected by care and support measures for persons with dementia; to explore the role of a coordinator for persons with dementia and their informal caregivers, and how a coordinator may contribute to support and empower home-dwelling persons with dementia.

Methods: For study one, which resulted in two articles, 12 home-dwelling persons with dementia were interviewed, individually, considering their perceptions on 1) living at home and 2) receiving care and support. In study two, 18 stakeholders in an intervention testing the use of a coordinator for dyads, consisting of persons with dementia and their informal caregivers, were interviewed to explore the role of a coordinator for persons with dementia. In this study we used a combination of focus group-, dyad- and single interviews. A hermeneutical methodology was chosen for the design, application and analysis of both studies. The care philosophy of Kari Martinsen was chosen as a theoretical framework for interpreting the findings.

Results: 1) There is a reciprocal relationship between the life and the home, being held up by certain individual rhythms of life; dementia might disrupt these rhythms.

2) The individual perception of care and support might depend on minor details, often with a thin line between experiencing it as supportive or infringing. 3) As the dyads had differing needs we found that the coordinators took on three roles: being a safety net; being a pathfinder in finding adequate support; and being a source for emotional care and support for persons with dementia and their informal caregivers. Obtaining direct user participation in decision-making processes may, however, be challenging.

Conclusion: The home can be seen as a construction bearing existential meaning beyond its physical function. Its components, in form of habits, things, personal relations, the surrounding environment and so on, may be intricately interrelated and interdependent upon each other. This makes the home flexible, but also fragile, and support measures that are not individually adapted may have unpredicted side effects. A dedicated coordinator, meeting the persons and their informal caregivers with openness, may support the person with dementia in being home, by exploring what matters for the individual; empower them by including them in dialogue about how to make what matters, matter; and by putting adequate care and support into effect in order to actually make it matter. We recommend an open and curious approach in each individual meeting, in the organisation of care and support and in further research upon these issues.

List of Publications

Fæø, S. E., Husebo, B. S., Bruvik, F. K., & Tranvåg, O. (2019). “We live as good a life as we can, in the situation we’re in” – the significance of the home as perceived by persons with dementia. *BMC Geriatrics, 19*(1). https://doi.org/10.1186/s12877-019-1171-6

Fæø, S. E., Bruvik, F. K., Tranvag, O., & Husebo, B. (2020). Home-dwelling persons with dementia’s perception on assistive technology and other care support: A qualitative study. *Nursing Ethics, 27*(4), 991-1002. https://doi.org/10.1177/0969733019893098

Fæø, S. E., Tranvåg, O., Samdal, R., Husebo, B. S., & Bruvik, F. K. (2020). The compound role of a coordinator for home-dwelling persons with dementia and their informal caregivers: qualitative study. *BMC Health Services Research, 20*(1), 1045. https://doi.org/10.1186/s12913-020-05913-z

Related Article:

Husebo B.S., Allore H., Achterberg W., Angeles R.C., Ballard C., Bruvik F.K., **Faeo S.E.**, Gedde M.H., Hillestad E., Jacobsen F.F., Kirkevold, O., Kjerstad, E., Kjome, R.L.S., Mannseth, J. Naik, M., Nouchi, R., Puaschitz, N., Samdal, R., Tranvag, O., Tzoulis, C., Vahia, I.V., Vislapuu, M., Berge, L.I. (2020) LIVE@Home.Path – innovating the clinical pathway for home-dwelling people with dementia and their caregivers: study protocol for a mixed-method, stepped-wedge, randomized controlled trial. *Trials,* 21(1):510. https://doi.org/10.1186/s13063-020-04414-y

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Background

1.1 On dementia

Dementia is a word, consisting of two parts: ‘de’ and ‘mentia’. The ‘de’-prefix is widely used in English, meaning a process of undoing, reversing, removal or going down (Collins Dictionary, 2021). The Proto-Indo-European ‘men’-root has a little more diverse meaning. The first, most commonly ascribed to the word ‘dementia’, is ‘to think’. According to the Online Etymological Dictionary (2020a), the word dementia literally means “being out of one’s mind”. The Collins Dictionary (2020) explaines dementia, besides its meaning as a medical term, as “insanity, madness.” It should be underlined, however, that the ‘de’-prefix often signifies a process and not necessarily an absolute state of being (Collins Dictionary, 2021). The ‘men’-root does have a more diverse meaning than just ‘to think’. It may also mean ‘to project;’ ‘small, isolated;’ or ‘to remain’ (Online Etymology Dictionary, 2020b). In modern English, these derivations of ‘men’ can be found in words such as ‘to mount’, ‘mono’ or ‘permanent’. A radical etymological definition of ‘dementia’ may thus be understood as a process of reversion in the ability to think; to project and initiate; to function as an individual; and to remain, as in being able to settle and dwell. It is however as a medical term that the word is most commonly used, and it is this term that will be in focus in this thesis.

1.1.1 Dementia as a diagnostic category

Dementia as a diagnostic category is a collective term for a number of conditions with coinciding symptoms. According to the criteria of the 11th revision of the International Classification of Diseases (ICD-11) (World Health Organization, 2018), dementia is primarily connected to failure in memory function and at least one other cognitive function in such a degree that function in activities of daily living (ADL) is affected. The Diagnostic and Statistical Manual of Mental Disorders, 5th edition (American Psychiatric Association, 2013), mentions six cognitive functions that may be affected: complex attention; executive ability; learning and memory; language; motor and visual perception; and social cognition. The risk of dementia increases with higher age, making the condition generally related to older age (Prince et al., 2015). With some variance between the different causes of dementia, it may also occur at a younger age. When diagnosed at an age below 65 years, it is defined as early- or younger-onset dementia (Winblad et al., 2016).

Types of dementia

Alzheimers disease and its subgroups are the most common forms of dementia, making up about 60 % of the incidents (Livingston et al., 2017). It is followed by vascular dementia, dementia with Levy Bodies and frontotemporal dementia. In addition, there are a number of other, rare causes of dementia. Apart from vascular dementia, the common forms of dementia are caused by a condition of degenerative structural and/or neurochemical brain damage. These changes may start to occur as much as twenty years before the first symptoms appear. Vascular dementia stands out from the other common types as it is caused by underlying cardiovascular conditions (Engedal & Haugen, 2018a, 2018b). It is, however, not uncommon that Alzheimers disease coincides with vascular incidents, making the pathological picture complex (Livingston et al., 2017).

Behavioral and psychological symptoms

In addition to the cognitive symptoms, behavioral and psychological symptoms in dementia (BPSD) are also common. These ranges from emotional symptoms, such as apathy – which is most common – depression or irritability; delusional symptoms, ranging from delusional ideas to hallucinations; disturbances in motor function, including agitation; various changes in circadian rhythm and sleep patterns; or changes in appetite and eating patterns and preferences (Cerejeira et al., 2012). When assessing BPSD, it is crucial to be aware of possible underlying conditions, such as unmet needs, environmental triggers or underlying medical conditions (Kales et al., 2015). In addition to being burdensome in themselves and impacting function in everyday life, symptoms of dementia may also represent a safety risk for the persons living with the condition, such as by wandering, faults in self-administration of medications or fire hazards (Douglas et al., 2011).

Diagnosing dementia

In general, a dementia condition is characterized by an increase of symptoms and a progressive decline in cognitive and ADL-functions. The symptoms, especially in an early phase, vary both between the various underlying conditions and between individuals. After a diagnosis is set, median survival is 3-9 years for people aged 65 years and above, although it may be as long as twenty years, indicating a large degree of variety (Winblad et al., 2016). Still, we have seen that many may live with a dementia condition for a long time before a diagnosis is set, and an estimate of 20-50 % are not diagnosed (Prince et al., 2015). A Norwegian study among 1000 homecare receivers, aged 70 years and above, found that 41.5 % fulfilled the diagnostic criteria for a dementia diagnosis. Of these, only 19.5 % had a registered or known diagnosis (Wergeland et al., 2014). Diagnosing dementia is a complex task, involving blood tests and brain scans. It is also reliant on an examination of the persons medical history, and the exclusion of other underlying conditions that may cause the symptoms is crucial. The primary diagnostic tools are cognitive tests and questionnaires both for the person and for proxyrating by informal caregivers (Engedal & Haugen, 2018c, 2018d). In a systematic review, Velayudhan et al. (2014) identified 22 validated cognitive tests for use in diagnosing dementia. In Norway, the Norwegian National Advisory Unit on Ageing and Health (Ageing and Health) has developed a comprehensive collection of pre-diagnostic assessment tools for use in the primary healthcare (Ageing and Health, 2019). This also includes interview guides for conversations with the person with probable dementia and their informal caregivers, an assessment of everyday technology use and a scale to assess caregivers' relative stress (Greene et al., 1982). Table 1 provides an overview of the assessment tools that are recommended by Ageing and Health in addition to two commonly used scales used to determine the degree of decline in cognitive and ADL-function.

Table 1. Pre-diagnostic assessment tools in dementia

Name	**Assessing**	**Short description**
Mini Mental State Examination (MMSE) (Folstein et al. 1975; Strobel & Engedal, 2016)*	Cognitive function	30 item cognitive test within the following domains: orientation; registration; attention and calculation; recall; language.
Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS) (Reisberg et al. 1982)	Cognitive function	7 points scale assessment: 1 signifies no cognitive decline, 2-3 signifies degree of cognitive decline without dementia, 4-7 signifies degrees of dementia.
Informant Questionnaire on cognitive declining in the Elderly (IQ-CODE) (Jorm & Jacomb, 1989)*	Cognitive function	16 item questionnaire on change in function over the last 10 years including: memory, learning, handling equipment, learning, decision-making, calculation, resonating– proxy rated – Score 1-5 on each item – 3 indicates no change.
The Lawton Instrumental Activities of Daily Living Scale (IADL) (Lawton & Brody, 1969)*	Instrumental ADL-function	8 item questionnaire: using the telephone; shopping; preparing food; housekeeping; doing laundry; using transportation; handling medications; handling finances – 3-5 point score on each item – proxy rated.
The Physical Self-Maintenance Scale (PSMS) (Lawton & Brody, 1969)*	Physical ADL-function	6 item questionnaire: toilet; feeding; dressing; grooming; physical ambulation; bathing – 1-5 point score on each item – proxy rated.
Functional assessment staging (FAST) (Reisberg, 1988)	ADL-function	7 points scale assessment: 1 signifies no difficulties in ADL-function, 2-4 signifies increasing challenges in ADL-function without need of support, 5-7 signifies increasing need of support in maintaining ADL-function.
Neuropsychiatric Inventory-Questionnaire (NPI-Q) (Kaufer et al., 2000)*	Neuropsychiatric symptoms (BPSD)	12 item questionnaire: delusions, hallucinations, agitation/aggression, depression, anxiety, elation, disinhibition, irritability, motor disturbance, nightime behaviors, appetite/eating – each item scored according to severity (1-3) and experienced distress (1-5) – proxy rated.
Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos et al. 1988)*	Depressive symptoms	19 item questionnaire within 5 domain: mood related signs, behavioral disturbance, physical signs, cyclic functions, ideational disturbance - proxy rated.

*Part of recommended examination from the Norwegian National Advisory Unit on Ageing and Health

Degrees of dementia

As a rough gradation of the severity of dementia, according to the degree of how the condition affects the individuals ability to cope in everyday life, dementia is often graded in mild, moderate and severe degrees (World Health Organization, 1993). In mild dementia the symptoms influence the ability to cope in everyday life. In moderate dementia, the symptoms make the patient dependent on support from others to manage everyday life and BPSD. When the dementia condition has progressed to the severe stage, the ability to manage is severly reduced, and most are in need of continuous care. Using the Mini Mental State Examination scale (MMSE), a commonly used diagnostic tool, in general, a score of 30 suggests no dementia, 26-29 suggests questionable dementia, 21-25 suggests mild dementia, 11-20 indicates moderate dementia and less than 11 is counted as severe dementia (Perneczky et al., 2006). This classification should, however, be treated with precaution. For example, higher cut-offs should be used if the person has higher education (O'Bryant et al., 2008). In the seven point Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS) (Reisberg et al., 1982) the first three stages are defined as pre-dementia with cognitive impairment, while the last four stages define degrees of dementia.

Dementia in nursing homes

Due to the increase in BPSD combined with an incresing need for care and support, dementia is recognized as the most important reason for nursing home admission (Gaugler et al., 2009). In Norway, an estimated 85-90 % of all persons with dementia will at some point be admitted to a nursing home (Vossius et al., 2015), and a study from 2007 found dementia in 80.5 % of a sample of 1163 Norwegian nursing home residents (Selbæk et al., 2007).

1.1.2 Prevalence and risk factors

Due to the assumption of a high number of undiagnosed persons with dementia, it is challenging to establish certainty on the prevalence of dementia. A 2015 report suggested an estimate of 46.8 million people living with dementia across the globe (Prince et al., 2015). As the risk of developing dementia increases with higher age, and the world's population is rapidly getting older, the prevalence of dementia is expected to rise accordingly, with a doubling every 20 years (Prince et al., 2015). In Norway, the estimated number of persons with dementia, per 2020, is 101 000 with an expected increase to 235 000 in 2050 (Gjøra et al., 2020). There is yet no known cure for dementia, and the World Health Organisation (WHO) (2012) has labelled dementia a global public health priority. However, there is growing evidence of risk factors for developing dementia related to socio-economical lifestyle factors such as nutrition, use of alchol and tobacco, social isolation and low education as well as other health issues such as diabetes mellitus and hypertension, which suggests that some forms of dementia might be prevented (Livingston et al., 2017; Norton et al., 2014). A British study comparing a large scale study carried out from 1989-1994 with a similar study from 2008-2011 suggest a 20 % drop in dementia incidence (Matthews et al., 2016). This change is attributed to a fundamental change in brain health, due to reduced exposure to risk factors and lifestyle changes. Interventions to help prevent or delay the onset of dementia has shown promising results (Livingston et al., 2017; Ngandu et al., 2015; Winblad et al., 2016).

There has also been an increased focus on optimalizing care structures and improving quality of life for persons with dementia and their informal caregivers. Many countries have formulated dedicated, governmental dementia plans on how to provide adequate support for this group (Dementia Policy Team, 2016; Ministry of Health and Care Services, 2015). A need for clinical pathways for persons with dementia has been addressed, and guidelines for such pathways have been formed (National Institute for Health and Care Excellence, 2018; Winblad et al., 2016; World Health Organisation, 2018).

1.1.3 Living with dementia

Living with a dementia condition will, for most persons, lead to an experience of gradually losing functions over a wide spectre of areas. The exploration of how persons living with dementia experience and perceive their own life situation has been a growing field of research. In a systematic review on 'suffering' from dementia, de Boer et al. (2007) states that the literature in this field *'gives no solid* *support to the widespread assumption that dementia is necessarily a state of dreadful suffering'* (p.1033). Instead, these kinds of studies provide valuable insight into the complexity and heterogeneity in experiences of living with dementia, stretching beyond assessments of what the persons can or cannot do.

Table 2 is a survey of meta-syntheses based on articles where qualitative interviews with persons with dementia is used as the main empirical data. The literature reveals a large degree of heterogeneity in the experiences, but some common aspects can be identified. Living with and adapting to change is a common focus in studies exploring aspects concerning life with dementia (Bjorklof et al., 2019; Conway et al., 2018; Eriksen et al., 2016; Gorska et al., 2018; Hennelly et al., 2019). Wogn-Henriksen (2012) revealed how persons with dementia use a wide register of individual, dynamic and flexible strategies to cope with dementia related challenges. It has also been shown how persons with dementia, despite severe losses in life, express feelings of happiness, love and warm relationships (von Kutzleben et al., 2012). O'Rourke et al. (2015) illustrates this double-sidedness by dividing the concepts they identify into positive and negative aspects, such as experiencing purpose versus aimlessness or being well versus being ill. As an example, participating in social activities and being part of a fellowship, might be a source for experiencing community and being confirmed as a person. On the other hand, it might be an arena where cognitive impairment becomes pronounced, strengthening the sensation of being 'demented' and different from the others (Bjorklof et al., 2019; Daly et al., 2019; O'Rourke et al., 2015).

Table 2 – Metasyntheses exploring experiences of living with dementia

Author/Year/ Country	**Theme**	**Inclusion/exclusion criteria**	**No. of articles**	**Main findings**
(Bjorklof et al., 2019) Norway	Coping in dementia	Incl: Only persons with dementia included, clearly described voice of person with dementia, experiences of coping Excl.: Uncertainty in diagnose, mixed sample with other diagnoses, studies of specific interventions	74	• The persons experience a threat towards their identity, due to stigma, loss of social contact etc. • They use humor and social and emotional support to cope as well as strategies to holding on to life as usual; o adapting and adjusting; o accepting the situation; o and avoiding the situation. • Latent theme: *balancing the struggle of living with dementia*
(Daly et al. 2019) Ireland	Experience of spirituality in dementia	Incl.: Participants with a diagnosis of dementia, exploring spirituality in dementia Excl.: Other diagnoses, other persons included (relatives, professionals, etc.)	8	• Maintaining spiritual practices, either through religious activities, arts, music, nature or social interaction might serve as a resource to maintain personhood, meaning and hope. • Challenges in social interaction within a community might prevent this resource.
(Eriksen et al., 2016) Norway	Experience of relations in dementia	Incl.: sample of persons with dementia only, persons' with dementia voice made explicit, describing relations with other persons Excl.: Mixed sample, uncertainty due to dementia, studies of a certain intervention	63	The persons experience a change in relations in terms of: • being disconnected, • being dependent, • being a burden, • being treated in paternalistic ways. • They find meaning through supportive relations with meaningful others. Being with other persons with dementia is also found to be supportive
(Forsund et al., 2018) Norway	Experience of lived space in dementia	Incl.: only persons with dementia, explicit voice of persons with dementia, experiences of lived space Excl.: Mixed sample, uncertainty on diagnose, studies of specific interventions	45	• Latent theme: *"Living with dementia is similar to living in a space where the walls keep closing in."* • The lived experience was related to the four categories: *belonging; meaningfulness; safety and security; and autonomy.* • Living at home might both be supportive towards these categories, or lead to decline. • Nursing home admission might strengthen the experience of these categories or lead to further loss.

(Gorska et al. 2018) Scotland	Lived experience in dementia	Incl.: Majority of participants living in community – ≥ 65 years, dementia diagnosis, living with dementia as main focus Excl.: Participants <65 years, inclusion of other diagnostic groups, majority living in residential care	34	• Changes in awareness and memory function impactful on lived experience. • Conflicting emotions, reduced participation, loss of social contact and loss of autonomy were also frequent. • Losses poses a threat to identity. The persons' strive for continuity by using emotional strategies, adapt to new situations and compensate for lost functions. • The environment has a double-edged role in this regard, as it can strengthen or weaken the persons' coping strategies.
(O'Rourke et al. 2015) Canada	Factors that affect quality of life in dementia	Incl.: primary purpose to identify factors affecting quality of life in dementia Excl.: persons with dementia not included, perspective of persons with dementia not differentiated from that of family members	11	Six concepts were identified. The first was represented also in number 2-5. Concepts 2-6 all represent a dichotomy that may affect quality of life positively or negatively: • 1) Connectedness • 2) Relationships (together vs alone) • 3) Agency in life today (purposeful vs aimless) • 4) Wellness (well vs ill) • 5) Sense of place (located vs unsettled) • 6) Happiness and sadness
(Wadham et al. 2016) England	Couples shared experience of dementia	Incl.: Persons with dementia and partners as participants, both view synthesised in findings, focus on impact of dementia on couple dynamics Excl.: both parts not active, other dyads than couples or other diagnoses than dementia without being distinguished, studies of specific interventions	10	Four inter-related themes were identified: • Togetherness: continuing as 'we' are – an ideal, under threat from the progression of dementia; • Upsetting and re-defining the balance: a new 'normal' is evolving – shift of balance within the relationship; • Sensitive attunement: shielding one's partner from the effects of dementia – this theme was two-way within the couples; • Resilience: distancing distress while cherishing life and the present moment –continuum from hopelessness to acceptance

In general, the importance of relationships and how relationships may affect the persons' experience of life with dementia, positively or negatively, is a repeated finding within the literature. Other persons, whether it is close relatives or healthcare personnel, might be sources for experiencing belonging, dignity and respect, strengthening what resources the person has left, helping them retain their identity, and give adequate support where function is decreased. Conversely, they might make the person feel like a burden, dependent on help from others, disconnected from society or even life (Eriksen et al., 2016; Gorska et al., 2018; O'Rourke et al., 2015). In the prolongation of this issue, we find a repeated emphasis on the importance of being respected as a human being and of retaining autonomy and independence, aspects that are repeatedly found to be important for this group, but also, repeatedly found to be violated (Cahill, 2018; Gorska et al., 2018; Hedman et al., 2016; Smebye et al., 2016; Tranvag et al., 2016).

1.1.4 Persons with dementia as 'other'

Due to the complex symptomatic picture with impairment of cognitive function and the high burden of care related to dementia, it is widely recognized that persons with dementia have fallen victim to a high degree of stigmatization, discrimination and loss of basic human rights (Cahill, 2018). In an article on health priorities, Brock (1993) claims that persons with severe dementia are '*worse off than animals such as dogs and horses who have a capacity for integrated and goal directed behavior that the severely demented substantially lack'* (p.373). Behuniak (2010) describes an analogy between the discourse on dementia, both in academia, media and society in general, and the portrayal of zombies in popular culture. Through seven points she describes how this happens either throught direct comparisons of persons with dementia as *'zombies'* or *'living dead'*, or through analogous descriptions. Examples are descriptions of how persons with dementia are losing 'self'; how their need for care and support consume the persons caring for them in cannibalistic manners; or how death may be described as preferable to living with dementia. These discourses, she claims, contribute to a dehumanization of persons with dementia and a categorizing of these persons as '*other*'. In turn, this paves the way for further discrimination and denial of basic rights (Behuniak, 2010). Kristiansen et al. (2017)

show how similar metaphors are used by persons with dementia in an early stage, when exploring their perceptions of their own future.

1.1.5 Dementia and personhood

Starting in the late 1980s and through the 1990s, British psychologist Tom Kitwood published a series of articles where he fronted a break with what he called the 'neuropathic ideology,' calling for a recognition of persons with dementia as equal persons (Kitwood, 1997). In short, he described an ideology where dementia is viewed solely as a neurological disease, requiring little attention as long as no cure is available. This view, he claimed, involved a dehumanization of the persons with dementia, depriving them of personhood. Kitwood describes personhood in three main types of discourse. First, as transcendental, with reference to how the human being is considered sacred across religions. Second, he refers to respect for the individual human being as an ethical imperative. Third, he describes personhood as a category within social psychology, with reference to human beings as interdependent and interconnected to each other. Focusing on the third category, Kitwood systematically and empirically illustrates how personhood persists through severe dementia. Further, he shows how healthcare personnel can support personhood for, or deprive it from, the individual through their attitudes and actions. Although Kitwood died in 1998, the year after publishing his influential book *Dementia Reconsidered – the person comes first*, the emphasis on personhood and person-centered care has gained a strong foothold within dementia care. As a result, there today exist a variety of conceptualizations and care models for persons dementia, building on the person-centered care philosophy (Fazio et al., 2018; McCance & McCormack, 2017). Among these conceptualizations, the VIPS model has gained a strong foothold. VIPS is an acronym for **V**aluing the persons with dementia and their carers, treating the persons as **I**ndividuals, looking at the world from their **P**erspective, and enriching their **S**ocial environment (Brooker & Latham, 2015).

The focus on reducing stigma and strengthening the status of persons with dementia as equal human beings has also been illustrated through other concepts. In 1992, American psychologists Steven Sabat and Rom Harré (1992) published an article where they used case studies to illustrate how the person's 'self' and use of 'self'-representations' persist through late stage dementia. Sabat has followed this line with a number of publications and books on these issues. Among his suggestions we find a claim that persons with dementia experience an environment focusing mainly on their reduced function, ignoring their remaining strengths and resources. This, in turn, leads to self-reinforcing psychological mechanisms where the person with dementia starts to identify as being "demented," leading to a further decrease in function and negligence of the remaining resources (Scholl & Sabat, 2008). His latest contribution to date is an easy-to-read-book on dementia for the general public (Sabat, 2018). Through a variety of cases, he illustrates how persons with dementia, also in late stage, are able to make self-representations, establish new compassionate friendships, show and receive empathy or learn new tasks (Sabat, 2018). British psychiatrist Julian Hughes (Hughes, 2014) illustrates how personhood is related to the body-subject, drawing on the phenomenology of Merleau-Ponty. This entails a break with Cartesian dualism, where the mind and body are seen as separate entities. Merleau-Ponty's philosophy is characterized by an emphasis on our senses as bodily, the body as our access to perceiving the world, and the body as intentional in itself (Leder, 1992). Based on these assumptions, Hughes (2001) introduces the concept of human beings as situated embodied agents, meaning that despite cognitive decline persons with dementia, through their embodiment, are embedded within a cultural and historical narrative.

1.1.6 Exclusion from participation in decision-making processes

Basic human and patient rights involve the rights to receive relevant information and participate in decision-making processes concerning one's own health and care. In Norway, this is regulated through the Patient Rights Act (1999). This act explicitly states that information and participation shall be given to and adapted to the individual. Similar regulations are adopted by most western countries (Cahill, 2018). However, special terms arise when the person in question is deemed unable to provide informed consent, for example because of cognitive impairment, such as dementia. The law is clear that such conditions just *may* affect the persons ability to consent, wholly or partly, and that healthcare personnel should do their best to enable the person to make informed consent (Patient Rights Act, 1999). It is, however, vague concerning how to apply these complex judgments in clinical practice. Cahill (2018) describes how persons with dementia's difficulties in understanding and resonating, or simply having a dementia related diagnosis in the journal, repeatedly leads to healthcare personnel and others taking for granted that the person is unable to understand information and consent to decisions considering their own care and treatment. This leads to the holding back of information and exclusion of the persons from decision-making processes.

In a multi-case study of ten cases, Smebye et al. (2012) examined persons with dementia's participation in decision-making processes. They described several cases where healthcare personnel and informal caregivers adapted everyday choices to enable the person with dementia to take active part in decision-making. This could, for example, be to decide what activities to attend in a daycare center, what groceries the homecare should order or when to receive help to take a shower (Smebye et al., 2012). They also described instances where the person with dementia delegated responsibility of specific decision-making to others. On the other hand, they also described instances of no or pseudo-autonomous decision-making, the latter described as instances where the persons with dementia are not adequately informed or decisions are made based on mere presumptions of the persons' values and preferences. Taghizadeh Larsson and Österholm (2014) conducted a qualitative synthesis on decision-making in care services for home-dwelling persons with dementia, including 24 articles. They also found examples of persons with dementia taking active part in these processes, or had their prior wishes respected. However, exclusion of persons with dementia from decision-making processes considering their own care and support was reported as the most frequent finding in their study. Similar experiences were found by Miller et al. (2016) in their review on shared decision-making in dementia, including 36 studies.

1.2 The home in a care context

Traditionally, the home has been the main locus for the care and support of those who are in need of care. In Norway, we have laws going back to the 10th century imposing relatives and neighbors to care for the sick and poor in turns (Moseng, 2003). From the late 19th century, this basic responsibility for health and care was handed over to the municipalities with large contributions from religious and ideological organisations, especially in terms of providing care at home or establishing nursing homes for those in need (Schiøtz, 2003). Starting in the late 1950s the municipalities gradually took over the running of the homecare, and from 1983 municipal homecare services in the municipalities became mandatory by law. Simultaneously, the arguments for having homecare gradually shifted from economic beneficence to a claim of the home being the best place for the patient to be. In accordance, the principles of keeping care at the 'lowest efficient care level', later replaced by 'best efficient care level' has guided the policy of health prioritization in Norway since the 1970s. In 2012, the so-called Coordination Reform came into effect, introducing stronger economic incentives to reduce hospital admissions and length of stay (Meld. St. 47., 2008-2009). On the one hand, the governmental health budget transferred a far larger share to the municipalities; on the other hand, the municipalities were obliged to co-finance hospital admissions and pay day fines if they were unable to receive patients from the hospital after final treatment. Thus, in addition to the narrative of the home as the 'best' place to be, also in ageing and decreasing health, there are strong political and economical incentives to encourage life at home as long as possible (Fæø, 2016).

1.2.1 The home as a physical space

In a large systematic review, including 210 articles, Gomes et al. (2013) found that a majority (60 %) of the population in western countries has a wish to die at home and that this wish persists through serious illness. However, they refer to a large heterogeneity in the data material, and qualitative research revealed a conceptual distinction between being cared for at home and dying at home. In addition, despite the heavy emphasis on 'the home' as the preferred locus of care, there seems to be a lacking consensus of what a home actually is, and what constitutes 'living at home.' This ambiguity is further complicated in the varieties of assisted living facilities, where the limits between home and institution might be blurred (Han et al., 2017). For example in such facilities where each person has their own apartment with their own bathroom and kitchen, but there are healthcare personnel available in the building and public rooms for social activities and common meals. Is the person still living 'at home'? If so, how about persons selling their house and moving to a more convenient apartment? There is also the issue when a high amount of medical-technical equipment and many visits from healthcare personnel gives the home an institutional character (Alvsvåg, 2008; Milligan, 2009) .

1.2.2 The home as a philosophical concept

The concept of *'home'* has been extensively investigated within the health and care sciences, but although increasingly nuanced, a clear definition of the concept is long in coming. The Proto-Indo-European root of *'home'*, *'*tkei'* means *"to settle, dwell, be home,"* (Online Etymology Dictionary, 2020c), that is, it is derived from a verb, indicating that '*home*' is not so much about a place but about an activity or a state of being. Perhaps its different translations, *'to settle, dwell, be home,'* also may be indicative of '*home*' as procedural, that the act or state of being home consists of two parts: settling and dwelling – both composing the act or state of being at home, or perhaps, being home. With care philosopher Kari Martinsen's (2006) writings on '*the home'* and '*dwelling'* as a starting point, I will, in the following, make an account for some of the extensive research on '*the home'* within the health and care sciences. In addition, I have brought in some perspectives from anthropologist Mary Douglas (1991) and psychologist Judith Sixsmith (1986).

The relationship between building or settling, and dwelling, is central in Martinsens writings on this topic. One builds a home to acquire a foothold in life, a place to belong and feel secure. When this feeling is established, one dwells, that is, one is at peace; one is free and one cares for the home and its surroundings (Martinsen, 2006). Zingmark et al. (1995) interviewed 150 people aged 2 to 102 years old exploring various aspects of 'home.' They describe how a process of creating a home begins already in childhood by creating a personal corner in the parents' home. This aspect of creating a home becomes increasingly important through adolescence and into adulthood, and returns after changes in life, such as after children moving out or the death of a spouse. Young (1998) interviewed 21 persons between 72 and 96 years after they had moved into congregate housing. She uses the term *'nesting'* as a metaphor to describe the initial process of settling in for this group. Martinsen (2006) claims that to dwell is to care for the home and points to an ongoing process of sparing and preserving the home '*so that man may thrive and grow'* (p.20) – indicating that the creational part of being home is continuous. It also shows how the home stretches beyond the boundaries of the house and involves the environment where one works to preserve life. It also involves the relations to those one are at home with, care with and care for. Zingmark et al. (1995) also emphasise the relational aspects of home and describe '*sharing a home'* and *'offering a home'* as part of the experience of being home. They also show how the relational aspect of home is not limited to significant others but also involves the relation to significant things, places, activities, oneself, and to God or other spiritual concepts. This last aspect, termed transcendence, may also include the hope of a future 'real home' beyond earth in the afterlife. The aspect of being related to oneself is also emphasized by Hilli and Eriksson (2017) in a concept determination of '*home as ethos of caring.*' They further claim that being at home is about being, not only in the world as such, but in one's own world, that is in one's self. Thus, they draw a line between the home and the self in an ontological perspective. Molony (2010) draws this into the psychological sphere by pointing to the home as a place of empowerment, mastery and being in control over ones own life.

The significant things that make out a home, according to Zingmark et al. (1995), are described as identity markers that serve as tools, memories or bearers of beauty. Martinsen (2006) describes how we cooperate with the things, and become intimate with them, understood as *'a friendship relation between the thing and the relation the thing gathers through its use'* (p.24). Within this quote we also find indications of an internal relation between the thing, the activitiy of using the thing, the place where the thing is used, and the overarching purpose of this enterprise as an endeavor to uphold life and create meaning. Sixsmith (1986) describes three different experiential modes of being home, namely a personal, social and physical experiential mode. This reflects descriptions of Zingmark et al. (1995) and Martinsen (2006) in that the home serves as a base for being oneself, for meaningful relations and for doing meaningful everyday activities. In line with Martinsen's (2006) emphasis on the internal relation between the different aspects of home, Sixsmith (1986) states that *'The division of home into these modes of experience exists only in an analytical sense, the three being indivisible in the man-environment unity'* (p.293).

The relational aspects of home are also described by Douglas (1991). She focuses on the social interaction and need for cooperation and coordination between the inhabitants of the home in order to keep and uphold the home in all its facets. Thus, she describe the home as an organizational unit. As such, she claims that the home has memory in that it is built and equipped to be prepared for the shifting cycles of life and the world. These are cycles of different sizes and shapes, such as day and night, the shifting seasons or the cycle of life and death. These cycles provide the home rhythms to be adapted to and followed. Martinsen (2006) also draws on the metaphor of rhythms and how these are manifested through habits in the home one inhabits. In this way, the demands and possibilities of the home, situated in the world, are incorporated in the persons dwelling there. In this way, one takes the home along when transitioning to another space, as the rhythms created by the demands and possibilities of former homes have become part of oneself. Thus, a home is not necessarily fixed to a specific space, but may be transitory, a view that is also shared by Sixsmith (1986) and Douglas (1991). Transferring this view to a healthcare context, there is not necessarily any hindrance for a nursing home to be called a home within these definitions.

Finally, Martinsen (2006) draws the metaphor of rhythms one step further, claiming that every house and every room has a tone and a song. This tone may be harmonious or it may be screaming. On the one hand, it may be a connecting and caring tone that leads to a sense of belonging, dignity and room for growth. On the other hand, it may be a tone that separates, that urges to battle and diminishes the home's function as a foothold in the world, leaving its inhabitants homeless. Similarly, Douglas (1991) describes the non-home, a place of confusion, without rhythms. Molony (2010) shows how a house may serve as a refuge or a confinement, or both at the same time. According to Martinsen (2006), these distinctions become apparent when the inhabitant meets sickness and disease, with disrupted rhythms and reduced ability to uphold the rhythms themselves. These are the times when healthcare personnel enter the home. Martinsen refers to Florence Nightingale's practical prescriptions of keeping the wards clean and neat, with access to clean air and daylight; providing meaningful activities for the patients; and arranging for visitors. By such means, Martinsen (2006) urges healthcare personnel to uphold a harmonious tone that matches the patients' incorporated rhythms in the sickroom – whether the sickroom is situated in the patients' own home or in an institution. Indeed, deaconess Rikke Nissen (2000), in the first Norwegian nursing textbook from 1877 urges the nurses to particular caution when adapting the sickroom to be more functional for providing care at home. These kinds of recommendations illustrate how the abstract metaphor of a home's tone and rhythms can be interpreted into concrete nursing practice.

1.2.3 Living at home with dementia

Førsund et al. (2018) sum up their metasynthesis on the experience of lived space in dementia with the sentence '*living with dementia is similar to living in a space where the walls keep closing in.*' This metaphor is ascribed to the experience of reduced social interaction and reduced activity out of doors, and indoors, either because of insecurity, inability or worried family members. In line with the double-sidedness of living with dementia in general, increasing anxiety of going out may further contribute to giving the home a Janus-face: on the one hand, it may represent safety and comfort; on the other hand, it may become a place of isolation, frustration and anger – or both at the same time. Increasing dependence of others was also emphasized as a factor contributing to this reduction of lived space (Forsund et al., 2018). According to the previous exploration of 'home,' it may be appropriate to suggest that this decline in function that follows living with a dementia condition also affects the persons' *'home'* or the persons' *'being home'*. That is, depending on what symptoms they experience and to what degree they experience their symptoms, they will gradually experience a change in relations: to others, to things, to the environment, to activities (Han et al., 2016). This, in turn implies a disturbance in their rhythms, and over time a need for care and support to be able to withhold a rhythm. Aminzadeh et al. (2010) describe how dementia may lead to a disruption in the persons' emotional home. Fitting to this, and the above description of the home as an existential aspect, McCabe et al. (2018) suggest 'scaffolding' as a metaphor to describe how the network of formal and informal caregivers around the person with dementia work together to support the person. This metaphor describes the need to cooperate and build structures that are able to uphold and maintain, metaphorically, the person's home. On the other hand, they also use the metaphor to describe the risk of such structures to collapse, as the person's condition progresses, and the burden of care increases.

1.3 Care for persons with dementia

The often complex symptomatic picture of dementia, the longevity of the condition, along with the complex legal and ethical issues as described above, makes caring for persons with dementia often complex and burdensome. Although there has been a substantial growth in formal care solutions for persons with dementia, informal caregivers, such as family members or close friends, still represent the majority of care for this group.

1.3.1 Informal care

According to a Norwegian report, persons with dementia receive an average of 60 to 80 hours of informal care each month, at the time of diagnosis. In the time before nursing home admission, this has increased to 160 hours (Vossius et al., 2015). The combination of increasing care needs, impaired cognitive functioning and the longevity of the condition makes these informal caregivers subject to a high risk of stress related health issues (Bremer et al., 2015; Etters et al., 2008). In a systematic review with 25 articles, Feast et al. (2016) discuss challenges for family members related to behavioural and psychological symptoms. They present descriptions by informal caregivers that are fitting to the analogy presented by Behuniak (2010) as described above – of persons with dementia being described as ‘living dead’ (Feast et al., 2016). Thus, they discuss how social constructs and stereotypic images of persons with dementia are being adopted by informal caregivers leading to a pattern of coping with behavioral symptoms with emotional distancing and a further depersonalization of the person. Similarly, Smebye and Kirkevold (2013) found that reluctance or task-orientation from informal caregivers might diminish personhood for persons with dementia. With Scholl and Sabats (2008) theory of self-realising psychological mechanisms in mind, we may see the contours of a negative spiral for both the person with dementia and their informal caregiver.

In a thematic review on the lived experience of informal caregivers, Hooper and Collins (2019) present a wide specter of experiences. At the one end are feelings of being ‘confined’ or ‘imprisoned’ or an experience of identity change, both for oneself and the person with dementia and a sense of disconnection from the family member with dementia. A feeling of losing someone to communicate and converse with is a common theme in explorations of spouses’ experiences of living with a partner with dementia (Feast et al., 2016; Pozzebon et al., 2016). At the other end, however, there are examples of informal caregivers who manage by focusing on satisfactory elements in their lives and by hanging on to moments were they feel connected to the persons with dementia (Hooper & Collins, 2019). The descriptions of living as an informal caregiver for a person with dementia does, nevertheless, in sum, draw a more bleak picture compared to that of living with dementia. In a synthesis of the literature on spouses’ experience of living with a partner with dementia, Pozzebon et al. (2016) present ‘loss of a partner’ as the central theme. Still, they also highlight how some manage to cope and accept the situation by holding on to memories and finding satisfaction by giving care and accepting their partner unconditionally. Similarly, Tranvåg et al. (2019) found that caring for a husband might be seen as ‘dignity-work’ for wives of persons with dementia. Stensletten et al. (2016) found that a high sense of coherence and a high degree of social support might reduce the burden of care for persons with dementia. Accordingly, formal support for persons with dementia aims to a high degree at supporting their informal caregivers as well as the persons themselves.

1.3.2 Formal care for persons with dementia in Norway

Due to the complex needs of persons with dementia and their informal caregivers, an extensive amount of care and support measures has been initiated. As an example, Table 3 is a survey of available support measures for persons with dementia living in the municipality of Bergen. Most of these services are exclusively for persons with dementia, or suspected dementia, and their caregivers. Other general support measures, such as care payment (NO: omsorgsstønad), an accompanying certificate, a taxi free-card, assistive technology and the like are not included in the table. Until 2019, of the measures in the table, only nursing homes and homecare were legally required, with daycare being added from January 2020 (Health and Care Services Act, 2011).

In general, daycare centers for persons with dementia are well established in Norwegian municipalities. Studies of their effect are few, but qualitative evaluations have shown that they provide meaningful activities, a sense of belonging and improved quality of life for the persons with dementia as well as respite for their informal caregivers (Soderhamn et al., 2014; Strandenæset al., 2018; Tretteteig et al., 2017). In addition to traditional daycare, alternative variants, such as daycare on farms, where farmwork is integrated in the activities, has become popular and has shown promising results (de Bruin et al., 2010; Ibsen et al., 2020).

Table 3. Measures for persons with dementia and their formal and informal caregivers in the municipality of Bergen.

	Support measure	Description	Provider
Pre-diagnostic	Memory teams	Interdisciplinary team –home visits for health interviews, initial testing of cognitive- and ADL-function. Reports to GP for further follow-up.	Municipality
Daycare	Traditional daycare centers for persons with dementia	From around 9 PM to 2 AM. 1-5 days a week. Participants receive breakfast and dinner and take part in activities.	Municipality
	Daycare center for younger persons with dementia	As traditional daycare center, but with extended activities based on cooperation with local cultural institutions, a gym, etc. Extended opening hours. Mainly for persons aged 70 years and below.	Municipality
	"Inn på tunet" (Daycare on farm)	As traditional daycare, but situated on a farm. Participants take part in daily work at the farm. In general for persons below 70 years old.	Private, municipally financed
Volunteerism	Activity friends	One-to-one volunteerism based on "pair-matching" to maintain meaningful activities.	Municipality, in cooperation with dementia organisation
	Peer persons	Persons with experience as informal caregivers with training as peer persons. May be called for counselling or just to talk.	Municipality
	Experience group for persons with dementia	Meeting place for persons with dementia to share experiences. Arranged by volunteers from the dementia organization.	Municipality
	Dementia Café and music groups	Meeting places for persons with dementia and their informal caregivers, facilitated by volunteers. Social gathering combined with various activities.	Dementia organisation with municipal support
	Dialogue groups for informal caregivers	Monthly gatherings for sharing experiences or discussing relevant themes. Led by experienced healthcare personnel. Varies if leader is volunteer or paid.	Dementia organisation or Municipality
Homecare	Traditional homecare*	Homecare to help maintain ADL-functions, provide medical treatment, etc.	Municipality
	Home help*	Practical help to maintain household activities.	Municipality or private with partly municipal financing
	Dementia Work Team	For the time being only in selected areas. As traditional homecare but with fewer personnel with higher competence in order to provide individualized follow-up.	Municipality

Learning activities	Courses for informal caregivers	10-12 hours courses on various relevant topics.	Municipality, outpatient geriatric clinic
	Courses for persons with dementia	Provided by outpatient geriatric clinic – three gatherings of three hours each. Planned composition of groups and adapted education. Informal caregivers may accompany.	Outpatient geriatric clinic
	Dementia care ABC	Two one-year courses with monthly gatherings for healthcare personnel at all levels of competency.	Municipality
Nursing homes	Respite care*	Generally up to three weeks nursing home admission – can be occasional or by regular intervals.	Municipality
	Short term examination stay	On specialised units. The person is observed over time as part of examintation and identifying care needs.	Municipality
	Long term care*	When it is no longer advisable for the person to live home.	Municipality
Other	Resource center for dementia	Advisory unit for persons with dementia, informal caregivers and healthcare services, in groups or individual, on dementia in general as well as in specific challenges.	Municipality
	Care payment - “Omsorgsstønad”*	Minor economic compensation for informal caregivers with a high burden of care.	Municipality
	Contact person*	Person paid by municipality to maintain meaningful activities – a limited hours every 1 or 2 weeks.	Municipality

*Not limited to persons with dementia or suspected dementia.
References: (Bergen demensforening [Bergen Dementia Association], 2020; Resource Center for Dementia, 2020)

Learning activities for persons with dementia and their informal caregivers, aiming to increase competence on dementia and what it entails, is a defined objective within the Norwegian governmental dementia plan (Ministry of Health and Care Services, 2015). Such activities for informal caregivers have existed for a while, but there is limited evidence as to the effect of these programs (Bruvik et al., 2013; Jensen et al., 2015). Still, qualitative explorations of participants' experiences with such interventions has shown that the intervention might be perceived as useful, despite a lack of effect in predetermined outcome measures (Johannessen et al., 2015). Read et al. (2017) described how the lack of knowledge of possible future trajectory makes it challenging for persons with dementia at an early stage to plan ahead and leaves them in a sense of losing control. Accordingly, initiatives of adapted educational programs for persons with dementia have also grown forth.

Various forms of assistive technology have seen a massive growth the last few years. The stove guard, to prevent a fire hazard, has been common for a long time (Nygård, 2009). Now, the market is abundant, with solutions ranging from electronic pill dispensers and robots, to advanced monitoring and positioning systems (D'Onofrio et al., 2017; Karlsen et al., 2017). It has, however, been challenging to implement technology that supports persons with dementia directly (Van der Roest et al., 2017) There is also limited knowledge as to what and how the end-users, that is persons with dementia and their informal caregivers, perceive these approaches and the relevance of such approaches in their everyday life (Husebo et al., 2019). Currently, the use of technology for home-dwelling persons with dementia is scarce and, during the Covid-19 pandemic, the interest for new technology increased by only 17% (Gedde et al., 2021).

Volunteerism has a strong tradition in Norway and is a defined area of priority in order to provide meaningful activities for the elderly population in general and for persons with dementia especially (Dementia Policy Team, 2016; Meld. St. 29., 2017-2018; Ministry of Health and Care Services, 2015). Being engaged in volunteerism has been shown to have a beneficial effect on both mental and physical health (Anderson & Bernstein, 2014; Pilkington et al., 2012). Thus, the arrangement of organized one-to-one volunteer support is considered a win-win-situation – for the person with dementia, for the persons' informal caregivers, for the volunteer helper, and for society as a whole. Although there is sparse research on volunteerism for persons with dementia, we aslo find indications of these benefits here, along with descriptions of how these arrangements may help to break down some of the stigma when considering dementia (Greenwood et al., 2018). However, there are also challenges related to issues such as organizing, building relationships, communicating with caregivers or adjusting to increasing demands for support (Greenwood et al., 2018; Herron et al., 2016).

Despite the massive growth in care solutions, the evidence that has been presented in this field does, however, reveal an ambiguity concerning what actually works – and what and who it works for. A large systematic review of 'what works' for home-dwelling persons with dementia refers to limited and low-quality evidence, and a general lack of effect on most outcomes (Dawson et al., 2015). In addition, there is a large degree of heterogeneity both in study design and outcome measures between studies of similar interventions. This is supported by a synthesis of systematic reviews on psychosocial interventions (McDermott et al., 2019). Although beneficent effects are found, it is challenging to generalize and point to 'best practice.' This is partly attributed to the heterogeneity between individuals living with dementia. Findings of perceived usefulness among the participants in qualitative follow-up studies should also be considered in this concern (Johannessen et al., 2015). Consequently, Dawson et al. (2015) point towards individual, flexible and compound solutions as potential success factors.

1.3.3 Coordinating care

To meet the requirements for individualized, flexible and compound care solutions, various concepts of coordinating individualized care for home-dwelling persons with dementia has grown forth. Advance Care Planning (ACP) is described as an ongoing process, with repeated meeting points, where involved healthcare personnel, informal caregivers and persons with dementia plan ahead and discuss the persons' values considering future decision-making (Flo et al., 2016). This concept has been increasingly implemented within nursing homes and has shown promising results, both to increase patient participation and document their wishes, and in terms of increased staff and family satisfaction (Aasmul et al., 2018; Saevareid et al., 2019). Although most common in nursing home settings, ACP for home-dwelling persons with dementia has also shown satisfying results (Kelly et al., 2019). It varies, however, to what degree the person with dementia is actuallty involved in the process. A reluctance to initiate the ACP-process has also been reported (Ryan et al., 2017). One of the issues addressed in this case is the gap between the persons' and caregivers' wishes and available services or challenges in prognosticating possible scenarios. Another issue is a reluctance to initiate conversations about end-of-life-care, and timing for these conversations to be held, as this has been seen as the main focus of ACP (Ryan et al., 2017). Flo et al. (2016) do, however, suggest that the concept should not be limited to end-of-life issues but should be applied when considering decision-making in general.

For home-dwelling persons with dementia, various concepts of care coordination or case management has been increasingly utilised and tested. In the United Kingdom, the 'Admiral nurses' has been a charity funded concept for specialized follow up of persons with dementia and their informal caregivers. The concept is based on relational follow-up and tailormade support with a high focus on supporting the informal caregivers. As such, the concept achieves a high degree of satisfaction from the carers, although with no significant findings considering caregiver psychological or somatical health (Bunn et al., 2016). The concept is also critised for long wait times, large caseloads for the nurses and a lack of clarity considering the Admiral nurses' role.

Norwegian law instruct municipalities to offer a coordinator and an individual plan for persons in need of long-lasting services and coordinated services and the governmental dementia plan emphasize this as crucial in the care for persons with dementia (Health and Care Services Act, 2011; Ministry of Health and Care Services, 2015). It does however exist an uncertainty about how to implement this for this group and Larsen et al. (2019) describes how healthcare personnel describes this as irrelevant for this group, despite an expressed need from informal caregivers. Still, to comply to this need the ‘Tiltakspakke demens’ has been adopted by several municipalities (Nærdal, 2017). In short, the persons with dementia will be provided a primary contact, mostly based in the homecare services, that follows up the person with monthly, one-hour home visits. The concept has shown several beneficial effects in terms of optimizing person-centered care. The primary contacts base in the homecare services does, however, make follow-up vulnerable as the home visits often have to be deprioritized due to unforeseen events and reduced personnel. The standardization of duration and frequency of the home visits are also perceived as suboptimal as they are administratively inflexible for individual variation in needs (Nærdal, 2017).

Challenges as described above seems to be common for case management concepts in general within dementia care (Khanassov et al., 2014a). Although with many variances, the basic principle within these concepts is that the persons with dementia and their informal caregivers are provided a coordinator or case manager whose tasks are to coordinate care and support from various providers and make sure that the care and support received are in line with the persons’ needs and wishes. In the following I will use the term coordinator for these roles. The level of organization for these coordinators also varies; some work within the care services and are part of the daily care and support for the persons, while others to a higher degree cultivate the coordinator role, leaving the practical care and support to other instances. Khanassov et al. (2014a) performed a mixed studies review, including 11 quantitative and 12 qualitative articles, exploring implementation of case management within primary healthcare. They recommend a limited caseload for the coordinators, with frequent contact with both patients and general practitioners and a proactive approach. Further, they point to the importance of clearly defined roles and coordinator competence, especially in terms of communication and ability to cooperate.

In general, the case management or care coordination intervention designs, within dementia care, are criticized for being highly varied, lacking clear definitions of the coordinators tasks as well as being costly (Backhouse, Richards et al., 2017;

Khanassov et al., 2014b; Reilly et al., 2015). As a result, these conceptualisations generally share the same characteristics as we have seen for the single standing interventions; beneficent effects are seen, but the results are inconsistent and ambiguous. According to a Cochrane review, case management for this group might lead to reduced institutionalization and decreased caregiver burden and depression (Reilly et al., 2015). The article does, however, point at inconsistent results when measurements were repeated over several time points. Likewise, Backhouse, Ukoumunne et al. (2017) refers to a reduction in neuropsychiatric symptoms in the persons with dementia and in the burden for informal caregivers when investigating community based coordinating interventions for this group. Again, the authors refer to weak and inconsistent results. Consequentially, they encourage future research to increase rigor in terms of design and implementation, as well as to provide comprehensive descriptions of the interventions to allow for replication and comparison.

Iliffe et al. (2017) suggests a different approach. They have written a discussion paper to case management based on investigations of different approaches for persons with dementia, across countries. They highlight how adaptation to specific contexts, often on a local level, might determine the initiative’s success. Based on these observations, they suggest ‘fluidity’ as a concept to consider in future research into the field. This means toning down the standardization of approaches and acknowledging the need for local adaptations. They call for research looking into crucial components that ensure case management works and descriptions of how concepts are developed and adapted between places. Thus, they suggest that case management concepts need to be ‘*fluid*,’ that is, they need to be flexible, built on components that are adaptable between contexts.

1.4 The LIVE@Home.Path

The LIVE@Home.Path study (hereafter: LIVE) (Husebo et al., 2020) is a research project at the Center for Elderly and Nursing Home Medicine (SEFAS) at the University of Bergen, financed by the Norwegian Research Council (sponsors protocol code: 273581). This is a complex intervention aiming to improve quality of life among home-dwelling persons with dementia and reduce caregiver burden. As a primary outcome, the trial aims at reducing resource use, both in terms of healthcare utilization and in terms of caregiver burden. The study aims at combining **L**earning activities, **I**nnovative solutions and **V**olunteer support in an effort to **E**mpower the person with dementia and their caregivers to enhance coping and gain a higher degree of patient participation and autonomy in decision-making processes, hence the acronym **LIVE.** An overarching objective is to establish the LIVE framework as an evidence-based clinical pathway for persons with dementia – from the time of diagnosis and throughout the illness progression. Participants in the LIVE trial are defined as dyads, consisting of a person with dementia and their closest informal caregiver. The four LIVE components will be elaborated in the following.

Learning activities on dementia for persons with dementia and their informal caregivers have, as described above, shown ambiguous results in effect studies (Bruvik et al., 2013; Jensen et al., 2015). Accordingly, further research on such activities are needed. In addition, there has been an expressed need of establishing educational programs for persons with dementia and their informal caregivers at an early time (Johannessen et al., 2015). In planning the LIVE study and discussing these issues with our collaborators, we also became aware that when and how persons with dementia and their caregivers are informed of and offered these courses is relatively arbitrary. A main objective of the L-part of the LIVE study is therefore to provide learning activities for the persons with dementia and their caregivers as an integrated part of the initial follow-up after a diagnosis has been set.

Innovative solutions for persons with dementia, in all its forms and definitions, has seen a massive growth the latest few years. As such, the LIVE trial is an example of service innovation (Husebo et al., 2020). When it comes to technological solutions it has, as decribed above, proved challenging to implement for persons with dementia (Van der Roest et al., 2017). A main objective with the I-part of the LIVE trial is to explore how persons with dementia and their caregivers perceive the use of innovative care solutions they already have acquired; strive for tailormade aqcusition of new relevant solutions; and evaluate the use of these solutions.

Volunteer support is, as decribed, a defined area of priority within dementia care (Ministry of Health and Care Services, 2015). Still, we have seen that there are challenges to explore when it comes to successful implementation of such support (Greenwood et al., 2018; Herron et al., 2016). In the LIVE trial, we wish to have experiences with and explore issues related to organization, recruitment and follow-up of volunteer support for persons with dementia.

Empowerment is a concept that is widely used within healthcare, based on a perception of the patient as expert on his or her own condition (Thornquist, 2009). Hennink et al. (2012) presents five domains of empowerment: health, economic, political, resource, and spiritual. Empowerment in these domains may be fostered by six components: knowledge, agency, opportunity, capacity-building, resources, and sustainability (Hennink et al., 2012). For persons with dementia, the concept has been further defined as *"A confidence building process whereby PWD (Persons with demenia, my remark) are respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources"* (McConnell et al., 2019, p.9). Considering these definitions, empowerment may be seen as part of all the LIVE components. To further strengthen empowerment, participants in the LIVE trial will receive a dedicated coordinator who serves as a connection to the various available support measures and helps finding the right measure at the right time. In addition, they will initiate a process of ACP and medication review in collaboration with the person's general practitioner. We hypothesize that a process of ACP, initiated by a dedicated coordinator that is able to build up a relation with the person with dementia and their informal caregivers over time, combined with the other LIVE-components, may have the potential to achieve a high degree of empowerment of persons with dementia.

1.5 The care philosophy of Kari Martinsen

To be able to see a horizon, one needs to be positioned. The position and the perspective the position offers will affect the perception of the horizon (Gadamer, 2013). My supervisors and I, as a research team, have attempted to see our empirical field from a variety of positions. All these views have given new insights and understandings and we have attempted to bring light to some of them in our discussions, in order to illustrate how the field might look from different angles. As an overarching position, to understand the empirical field throughout this project, the writings of Norwegian care philosopher Kari Martinsen provided valuable insights. Martinsen has had a substantial influence on Scandinavian care philosophy and has been appointed Knight 1st class of the Royal Norwegian Order of Saint Olav for her influence on Scandinavian nursing and caring. To give a justified elaboration on her writings is unfortunately beyond the scope of this thesis, but in the following I will give an account of some of her key concepts that will be used in this thesis. Her writings on *'the home'* and *'dwelling'* have been accounted for above.

An important influence on Martinsen's writings is the Danish tradition of philosophy of life, with a special emphasis on the works of theologian Knud E. Løgstrup. A central concept adopted from this tradition is that of '*the ethical demand'* (Martinsen, 2012). This is a complex concept, but in its essence we find the principle that matters of ethics should not be reduced to standardized rules and procedures for how to act in certain situations, neither should it be reduced to informal cultural norms. The ethical demand is bound to every specific meeting between human beings and the appeal to be seen and cared for that might arise throught such meetings (Martinsen, 2012). When applied to a concrete healthcare setting, Martinsen's appeal is for healthcare personnel to be open to the other's appeal for being taken care of, regardless of diagnosis or predetermined needs. As part of her arguments, she has criticized the increasing focus on evidence-based practice within healthcare (Martinsen, 2003, 2005). Not because increased knowledge and evidence is wrong in itself, but because she claims it might lead to an instrumentalistic approach to care. The increase in knowledge about health and illness leads to increasingly specialized health and care services aiming to tailormake care for the individual. Although this may be good in itself, Martinsen claims that it fails to genuinely meet the individual's specific needs and acknowledge the necessity of the open meeting between persons (Martinsen, 2012). The increased mapping out of all aspects of the patients life, in order to provide individualised care and treatment, instead leads to what she calls a dissection of the patient as a person, putting all aspects of the patient's life into predetermined categories of challenges, needs and resources – to be met with predetermined solutions of care and support. Thus, the open meeting between nurse and patient, where the patient is allowed to come forth as a whole person with individual needs, is replaced by sessions of filling out forms. In the process of mapping out the patients' individidual traits, Martinsen claims that the patient as an individual is lost. Within this system, neither nurse nor patient are allowed to be persons; they are only fulfilling their roles as mechanistic nurse and obedient patient. Martinsen's claim is that instead of searching for individual traits in the other, the nurse, through an open, trusting meeting, should aim to relate to the other (Martinsen, 2006, 2012). Recognizing similarities between oneself, as a person, and the other as an equal person, in turn opens up for an acknowledgement of spotting the dissimilarities – the things that do not fit into predetermined categories and truly define the other as an individual. Then, if opening up to the ethical demand to come forth, the patient's true care needs, regardless of diagnosis, may be exposed within a trusting relationship. Within this trusting relationship there should also be room for sensibility to what Martinsen calls the others' *'zone of untouchability.'* That is, areas in life that are not to be explored or touched, at least not at the time being, before sufficient trust has been built (Martinsen, 2012).

It is when such a relation is established that the nurse, through professional judgment, should use professional knowledge in order to care for the other (Martinsen, 2006). This is in line with a well-known quote on the art of helping by Kierkegaard, recognized as a predecessor of the Danish tradition of life philosophy, that in order to help the other one must *"first and foremost understand what he understands. If I do not do that, then my greater understanding does not help him at all*" (Kierkegaard, 1998, p.45). As a healthcare professional, one has knowledge and skills that the other may and should benefit from. It is, however, crucial to gain an understanding of how the other perceives her's or his situation and needs in order to use such knowledge and skills adequately (Martinsen, 2012).

Another aspect of this instrumentalization of nursing criticized by Martinsen is that it makes the nurse create distance from personal emotions (Martinsen, 2006, 2012). She acclaims this to be a misunderstanding of professionalism, where one thinks that in order to be professional one must act objective and rational and not involve one's emotions. Martinsen claims that this locking up of emotions will inevitably lead to emotions being expressed in one way or another, e.g. through self-reproach, anger or sentimentality. Rather, she encourages the nurse to use oneself as a professional person, involving one's emotions in the meeting, again allowing the nurse-patient meeting to be a meeting between two equal persons. In sum, Martinsen encourages the nurse to meet the other with openness, using oneself as a whole person and one's preunderstanding in order to let the other come forth as an equal and whole person and be aware of the ethical demand in the meeting. Then, one should use one's judgment and knowledge as a professional person in order to meet the other person's needs.

1.6 Study rationale

To sum up, and push towards the extremes, we have a situation where a heterogeneous group of persons, living with a condition that has a high variety of symptoms, are in need of individualized support with ambiguous effects, from a multitude of uncoordinated providers, within a space that lacks a clear definition – often with limited or no possibilities to influence the decisions being made. As said, this is to push the issues towards the extremes, and research aiming to comply with these challenges continuously provides new insights and enhanced solutions. Still, the complexities within this field require an ever expanding horizon of understanding so that we to a greater degree might be able to grasp the nature of the present challenges in order to meet them.

As described, the LIVE research project aims at meeting these challenges as a sustainable care pathway that empowers the persons with dementia and their informal caregivers, and aids them to live safer, longer and more independently at home. Given the ambiguity of the home as such, and the common care and support measures that are provided to persons with dementia, we identified a need for more insights into 1) how persons with dementia's perceive living at home, and how they describe the meaning of home and 2) their experience and attitudes towards care and support, with an emphasis on assistive technology, volunteer support, homecare and daycare. These issues constitute the study rationale for the first study in this project, which resulted in the two first articles in this thesis.

As the LIVE study developed, with the central role of the coordinators to implement the intervention, and our knowledge of the complexities of this task, we wished to make some initial experiences with the coordinator role within the LIVE framework. Here we wished to explore how the coordinator role evolved in interaction with the dyads, consisting of a person with dementia and their informal caregiver, and further explore issues related to our aim of empowering the persons with dementia in decision-making processes. These issues constitute the study rationale for the second study of this project, which resulted in the third article in this thesis.

1.6.1 Study objectives

The primary objective of this project is as follows:

- To explore the meaning of home and approaches designed to promote and coordinate care for home-dwelling persons with dementia.

Given the complexities of the field considering living at home with dementia, and the ambiguity of providing adequate care and support, the following secondary objectives are defined:

- To explore and describe how the home, as described by persons with dementia, can be interpreted and comprehended.
- To explore and describe how the home may be affected by care and support measures for persons with dementia.

- To explore how a coordinator may contribute to support and empower home-dwelling persons with dementia.

Table 4 gives an account of the two studies in this project and the research questions for each of the three articles.

Table 4. Account of studies

Study	***Article***	***Research questions***
I	1	1) How do persons with dementia describe the meaning of home? 2) How do persons with dementia describe their perceptions of living at home – in the present, and in the future?
	2	1) How do persons with dementia describe their present and past experiences related to assistive technology, volunteer support, homecare services, and daycare centers? 2) How do persons with dementia describe their attitudes toward receiving these support measures in the time to come?
II	3	1) How do the participating dyads and the coordinators describe the coordinator role and functions? 2) How can a coordinator contribute to the empowering of the person with dementia in decision-making processes – in everyday life and in planning present and future care and support?

Methods

As the main objective of this PhD-project is to explore people's experiences with and perceptions of various phenomena, conversations in various forms of research interviews were chosen as an appropriate data collection tool for both studies. For the first study, we conducted single in-depth interviews with home-dwelling persons with dementia considering their perceptions on the themes of inquiry. For the second study, we conducted single, dyad and focus group interviews with stakeholders in a small scale intervention based on the LIVE framework. The hermeneutic methodology based on the works of Hans-Georg Gadamer (2013) was chosen as an epistemological framework for interpreting and understanding the empirical data collected throughout the studies.

2.1 Epistemological framework

Hermeneutics has lent its name from Hermes, notorious trickster and messenger of the Greek Gods. Gonzales (2015) points to the use of the word's origins in Plato and Aristotle and claims that an original understanding of the word would be the act or art of expressing and communicating a message verbally and in a clear manner. Since the word gained its renaissance in a newer age it has been in the form of being a theory of interpretation. The hermeneutic tradition is mostly applied in the interpretation of texts, mainly within theology, law and prose. It is, however, not a uniform methodology and the discourse on how to interpret a text 'correctly' or in a 'scientifically objective' manner has run strong over the years (Grondin, 1994). In his magnum opus, 'Truth and Method', German philosopher Hans-Georg Gadamer (2013) refined the hermeneutical thought, putting an emphasis on the interpreter rather than on the original authors' intentions or the text to interpret. Starting by referring to the act of judgement of aesthetics, he illustrates how taste and judgment will always rely on the pre-understanding of the one who is judging. Likewise, a text has no right or wrong interpretation; rather, the interpretation relies on the pre-understanding of the reader. This pre-understanding is also in constant change as the person in question continuously gains new experiences, leading to new perspectives and new understanding. Gadamer draws this principle further, involving interpretation of the world as such. Instead of dismissing the interpreters' pre-understanding and pre-judgment of a phenomenon as subjective distractions, he claims that the pre-understanding is a prerequisite for experience and understanding as such. As the interpretor gains new experiences and knowledge, the interpretations of similar experiences or even of a singular text will always change by repetition – as the pre-understanding is in constant change.

Gadamer does not present a method of interpretation, rather he claims to describe what happens in the act of interpretation, when new understanding is allowed to occur. Knowledge, he claims, does not occur as a result of rigid methodology, but as a result of a fusion of horizons between the interpreter and the object of interpretation. He argues that it is not the methods as such that lead to new discoveries, but the ability to be prepared and open for what can be found in the empirical data. For this, the various methods may serve as excellent tools, given an acknowledgement of their essential hermeneutic nature; all science and gaining of knowledge relies on subjective judgments and interpretations, otherwise it could not be thought of, planned, carried out, or reported. Although Gadamer illustrates that there can be no strict method of hermeneutics, he does not invite arbitrary interpretations based solely on the interpreters' pre-understanding. Rather, he invites the interpretor to open up his horizon of understanding for new perspectives and allow new horizons of understanding to come forth. As a hermeneutical researcher, the task is then to describe this process, and the new horizon one has explored, as accurately as possible. Thus, allowing the critical reader to judge whether the interpretive process holds water – based on their pre-understanding of what characterizes an adequate interpretation.

A last point from Gadamer's thinking is an emphasis on the relation between understanding and application. That is, he explains the hermeneutic process as an experience that leaves a trace on the person making this experience. If a new horizon of understanding truly has been brought forth, it implicates that one's view of the world in some way has been changed. In turn, if one's view of the world changes, it should lead to a change in the way one relates to the world, and thus a change in one's attitudes and actions when acting in the world. Hence, cognitive and normative understanding cannot be distinct. The answer to the above question on how to 'correctly' interpret a text, a set of data, or the world as such, in a Gadamerian way, will neither be by asking for an objective truth behind what we observe nor attempting to understand what we observe in light of all possible contexts. Rather, it means to open oneself up for a dialogue with the empirical data, asking what they can add to one's own understanding of the world, then, to ask how this new knowledge can or should affect the way one understands the world and how this experience of understanding should affect the way one relates to the world in terms of attitudes and actions.

These premises match the pragmatic aim of both studies in this thesis, which is to expand the horizon of understanding and explore how this new horizon may be applied into improved clinical practice and to then, again, explore how this application works and how it affects those involved, so that the horizon of understanding may be further expanded, in a spiraling hermeneutical movement. Thus, this opens up for further refined application when conducting the LIVE-study on a larger scale.

2.1.1 On my pre-understanding in this project

My own pre-understanding founds on clinical experience as a nurse and leading nurse within the homecare services. I also worked as an assistant in dementia wards in nursing homes before entering nursing studies. While working as a nurse I took further training in health administration and in municipal healthcare. I then earned a master's degree in nursing science where I wrote my master thesis about the political development of the homecare services in Norway, using a structuralist approach. In this PhD project, my supervisors are a medical doctor, a geriatric nurse, and a psychiatric nurse. They have considerable clinical experience from palliative, psychogeriatric and psychiatric care from hospitals, nursing homes and homecare. In research, they have experience ranging from large scale randomized controlled trials to qualitative studies in the hermeneutic tradition. Empirically, their academic interests are primarily focused on dementia, with research ranging from pain assessment and treatment, through psychosocial interventions, to dignity preservation. This variety in clinical and academical experience revolving around issues related to living with dementia brought forth fruitful dialogues concerning our pre-understandings, as well as in our later interpretation of the empirical data in both studies.

Based on previous research on the themes of inquiry, my clinical experience, and the clinical and scientific experience of my supervisors, we did not, as a research team expect to find uniform answers to the research questions in study one. Rather, we expected to find it challenging to draw general conclusions. When reflecting on this before starting the data collection process, we found this openness to variety to correspond well to the hermeneutical approach (Gadamer, 2013). On the other hand, it made us aware that such a view might hinder us from identifying and observing substantial, general features within the individual variety. We were also curious about what the expected variety might consist of and what the basis for the study participants perceptions might be. Especially, in dialogue with study participants who had relatively recently moved to smaller apartments, we were curious about how they would describe the meaning of their present home.

We also reflected on the possibility that although open for variance between individuals, our former experience might lead us to categorize the individuals, as such, to fit into predetermined categories. Especially on questions about experiences with and attitudes towards care and support, we were aware that our former experience might lead us to draw premature conclusions upon these matters. Underway in the process, we therefore took time to read transcripts of completed interviews and reflect upon this matter within the research team.

For study two, we, as a research team had designed and organised the intervention and we were naturally inclined to hope for its success. Still, we had theoretical knowledge on the complexity of such interventions as well as of the importance of identifying crucial factors to consider when implementing the LIVE study in a large scale. In the interview settings I as an interviewer therefore paid careful attention to follow up critical remarks on aspects of the intervention, regarding this as valuable information. In the interpretive phase, we paid caution to avoid using the data material to evaluate the intervention in terms of whether it was successful, that is whether it had effect, or not. Rather, we focused on using the data material to answer the research questions, searching for success factors, potential weaknesses and what effect the intervention had for the individual participating dyads.

2.2 User involvement in the studies

Involving representatives from the end-users in research on health and care services are recommended as it brings the users' unique knowledge and experiences into the research process (Morrow et al., 2011; Staats et al., 2020). This principle is specifically recommended by the WHO when it comes to research considering persons with dementia (World Health Organisation, 2018). We were not able to engage a person with dementia to contribute in these studies. However, a co-researcher with user experience as an informal caregiver for a person with dementia contributed with valuable insights throughout both studies. In study two, he took active part from planning and designing the intervention, throughout the process of evaluating the intervention and in writing article 3.

2.3 Study 1 – Articles 1 and 2

2.3.1 Participants

Participants were recruited through four municipal daycare centers for persons with dementia after the following inclusion criteria: age above 67 years; having a dementia diagnosis according to the ICD-10-criteria (World Health Organization, 1993); able and willing to consent to and participate in an interview conversation. Healthcare personnel at the daycare centers assessed the participants' ability to consent and participate based on clinical observation and a close relation to the eligible participants. Their assessment also considered the individual's risk of anxiety that might follow taking part in an interview conversation. Over an approximately six-months period, 13 eligible persons accepted to participate. One participant did however withdraw on the day of the interview due to an acute incident in the family. Thus, twelve persons took part in the interviews, see Table 5 for participant characteristics.

Table 5. Interview participant characteristics

ID	**Gender**	**Age**	**Marital status**	**Cohabitant/ Living alone**	**Living arrangement**	**Place for interview**	**Formal support**
A	Female	87	Widowed	Alone	Apartment	DCC	HC, HH, DCC
B	Male	83	Married	With spouse	Apartment	At home	DCC
C	Female	82	Married	Alone	Apartment	DCC	HC, HH
D	Male	86	Married	With spouse	Apartment	DCC	DCC
E	Male	74	Married	With spouse	House	At home	DCC
F	Male	87	Married	With spouse	Apartment	DCC	HC, DCC
G	Female	86	Widowed	Alone	Apartment	DCC	DCC
H	Female	82	Divorced	Alone	Apartment	DCC	HC, HH, DCC
I	Male	87	Separated	Alone	House	DCC	HC, HH, DCC
J	Male	69	Married	With spouse	House	At home	DCC
K	Female	89	Widowed	Alone	Apartment	DCC	HC, HH, DCC
L	Female	75	Married	With spouse	Apartment	At home	DCC

HC= Homecare: medicinal, nutritional and/or personal hygienical aid; HH= Home help: house cleaning, laundry; DCC= Daycare centre

2.3.2 Data Collection

Gadamer (2013) claims that *"a genuine conversation is never the one that we wanted to conduct"* (p.401). Rather, he describes a genuine conversation as something we fall into or become involved in, an event with a spirit of its own that we are more being led by, than leading. The result of taking part in such a conversation is "*that it allows something to emerge, which henceforth exists*" (p.401). As a hermeneutical-oriented researcher, it is this 'something' that is the object of desire. Still, there is the need to recieve an answer to the research questions. Thus, the hermeneutical interviews entail a balancing act. On the one hand it involves falling into a genuine conversation, allowing the conversations' 'spirit' to take the lead. On the other hand, it involves keeping a hand on the ‘steering wheel’, so that the conversation is not led astray.

A thematic interview guide (Appendix 1) was developed with ten main questions, each with several possible follow-up questions. After memorizing the interview guide, it was broken down to a shortform list of keywords on each main theme and its follow-up questions. This was done to adapt the interviews to, as far as possible, take the form of genuine conversations, rather than as session of questions and answers. In addition, the shortform was adapted to a little piece of paper to bring to the interview situation in order so as to reduce possible distractions.

The interviews were carried out either at the participants’ home or at the daycare centre, at the participants convenience. I started the interviews by asking the participants to tell about themselves and their lives. This was followed by an inquiry about their homes: how they would describe their homes and how they experienced living at home. Then, as the conversations evolved I tried to touch into the themes of inquiry as naturally as possible. For example if a participant described difficulties and anxiety related to going to the store, the possibility of a volunteer aide for this particular issue could be proposed, leading to a dialogue on the subject of volunteer support, opening up for other possibilities. During the interview process, I would also return to previous questions where this was natural and allowed for putting the question in context. I experienced early that it become far easier for the participants to reflect on the issues of inquiry when this principle was followed.

Two participants had a family member present during the whole interview. In one interview, the participant’s spouse passed through the room on some occasions and gave small contributions to the conversation in doing so. In another interview, the participant’s spouse joined the conversation as we were about to finish, thus extending the interview into another almost half hour.

2.3.3 Data interpretation

I transcribed all interviews verbatim within one week. Within 1-3 weeks after transcription I made an initial analysis mainly based on the themes of the interview guide, but also with the intention of finding new and unexpected themes, which might prove useful to explore more in later interviews. After the two first interviews, one of my co-supervisors (OT) and myself went thoroughly through the first two interviews to refine the interview guide, work on challenges connected with phrasing, and follow up themes that proved unclear to participants, especially considering volunteer support and assistive technology. Here we also discussed how my pre-understanding might affect the interview situation, how situations might be understood otherwise and how to bring these perspectives along to future interviews (Gadamer, 2013). As an example, I discovered that, although I had an initial open approach to the themes of inquiry, I at times made premature conclusions based on the participants' initial answers and followed up with close-ended questions. This acknowledgement was useful in the following interviews. After five interviews, the whole research team read these transcribed interviews and discussed important themes and findings so far. Based on these discussions, we also made new adjustments to the interview guide. After all interviews were transcribed, the interviews were distributed among all authors. My co-supervisor (OT) and I performed in-depth interpretations of each interview, first separately and then discussing our findings interview by interview. This was done with each interview by itself, all interviews as a whole and each interview in relation to all the interviews. This followed a circular interpretive movement between the transcribed interviews as individual texts, as parts of a whole text and as one text as a whole (Gadamer, 2013). Throughout this process, we discussed various theoretical perspectives that might open up new horizons of understanding. These conversations were supplied by repeated meetings with the rest of the team who shared their perspectives and discussed these in deeper interpretations. Here we also discussed how our individual pre-understanding might affect our understanding of the empirical data. In some of these meetings, we were also accompanied by our co-researcher with user experience who gave feedback on our findings and shared his thoughts on how our findings corresponded with his own experiences.

2.3.4 Ethical considerations

Healthcare personnel at the daycare centers assessed the participants' ability to consent to participation according to the definition of ability to consent as described in the Norwegian Patients Rights' Act (1999) and the Helsinki Declaration (WMA Declaration of Helsinki, 1964/2013). The healthcare personnel informed eligible participants of details concerning the study and handed out forms for written consent, which included information about the study and the ten main questions from the interview guide, see Appendix 2. Signed forms of consent were sent to the research group. Healthcare personnel at the daycare centers or myself contacted informal caregivers, where available, and informed them about the study and got their oral consent for the person to participate. On two occasions, we were unable to inform the informal caregivers prior to the interviews. Personnel at the daycare centers had a conversation with the informal caregivers afterwards where the situation was clarified. Before each interview, I informed each participant about the purpose of the interview, data treatment procedures, anonymization procedures related to publication of result, and their right to withdraw at any time or request deletion of all data. Gadamer (2013) emphasized the importance of *tact* when meeting the other, understood as the ability to be sensitive towards the other in order to avoid intrusion. Similarly, Heggestad et al. (2013) encourages moral sensitivity when persons with dementia are included in qualitative research. In the interview situations, I paid particular attention to the participants' response and reactions to questions and formulation and adjusted the interview according to this. The study was approved by the Regional Committee for Medical and Health Research Ethics, Region West (Project number 2016/1630). See Appendix 3 for approval.

2.4 Study 2 – Article 3

The second study is based on the evaluation of a six-month intervention, where we wished to make initial experiences with the LIVE framework, with a main focus on the coordinator role and function, before carrying out the large scale LIVE intervention study. The project was a collaboration between a municipal resource center for dementia, a geriatric outpatient clinic, a center for learning and coping and a municipal coordinator for volunteers. During the project period the leader of the local dementia association took regular part in our project meetings, representing user participation on a systemic level. In addition, our co-researcher with user experience as an informal caregiver for a person with dementia was part of the research group from an early stage, as described above. In the following I will account for the different aspects of the intervention as such, based on the components of the LIVE framework.

Learning

Both the resource center for dementia and the geriatric outpatient clinic, the latter in collaboration with the center for learning and coping, arranged courses for informal caregivers for persons with dementia. Both courses for informal caregivers were based on a framework recommended by the the Norwegian National Advisory Unit on Ageing and Health (Hotvedt, 2019), a framework that is also integrated in the Norwegian governmental dementia plan (Ministry of Health and Care Services, 2015). This includes group sessions where the participants have the opportunity to discuss challenges from their own life situation. The two courses were also coordinated in that the municipal resource center arranged their courses over three evenings, and the geriatric outpatient clinic arranged their courses over two days at daytime, to adapt to persons in different life situations. Both courses were arranged twice a year, and the arrangers took care to keep some time between their own and the others' course, so that it should not go too long between available courses.

The geriatric outpatient clinic in collaboration with the center for learning and coping had also recently started arranging patient courses for persons with dementia. These were arranged during the daytime with three sessions of two and a half hours each. Informal caregivers were invited to join and they kept the number of participants small. The courses focused on the themes: "living with dementia, challenges and possibilities," "dementia, causes and treatment," and "available support within the healthcare services" (Haraldsplass Deaconess Hospital, 2018). The teaching sessions were flexible and opened up for dialogue and general adaptations according to the participants' needs and abilities. These courses were generally arranged twice a year and as patient courses, they required a referral from the patients' general practitioner. For the intervention, we used these existing structures without any modifications, besides arranging an extra course for persons with dementia to match the timing of the study.

Innovation

During the project period, the project-municipality had an ongoing project of implementing ICT-solutions to their elderly population. The coordinators registered the solutions that the participants used on inclusion and refered to possible solutions when this was relevant for the participants. Otherwise, we did not focus on this aspect in this intervention.

Volunteers

For the volunteer-component we identified a municipal volunteer coordinator responsible for organizing volunteerism within healthcare in general in the municipality. Here the organisation of 'activity friends', that is one-to-one volunteer support for persons with dementia, was an important priority (Resource Center for Dementia, 2020). This included recruitment, training, pairing the "right" volunteer to a person with dementia with similar interests, and continuous supervision and follow-up. Also in volunteerism, we built on these existing structures, adding extra courses for volunteer training during the project period. We encouraged the coordinators to suggest 'activity friends' as a possibility for the participating dyads. In addition, the members of the research team marketed the concept within their networks in an effort to increase recruitment.

Empowerment

For this project, procedures for ACP, medication review and general involvement of the persons' general practitioners (GP) was not yet fully developed or implemented in the intervention. The specific empowerment part was based on the coordinators' contact with the dyads. They were, however, encouraged to initiate contact with the GPs to inform them of the persons' participation in the study and arrange meetings with the GPs if this was perceived appropriate. The basic structure for contact with the dyads was defined as one initial home visit by both coordinators together, to be able to have individual conversations with both the person with dementia and the informal caregiver. For these meetings the coordinator who was to follow up the specific dyad was encouraged to have the individual conversation with the person with dementia. The focus for this meeting was mostly for formal information regarding the study, signing consent forms and filling in questionaires, but also for getting to know the dyad, gaining an impression of their situation and if needed, complying with the immediate needs for care and support. This first home visit was followed by a second home visit after one month, by the dedicated coordinator alone. For this visit, the focus was on '*what matters to you?'* Based on this question, in dialogue with the dyads, the coordinator set the course for the time to come as well as helped with relevant applications and continued the building of a relation with the dyad. These second visits were then followed by monthly phone calls for continuous evaluation of the implemented measures and follow-up of relevant issues. After six months, the dyads were offered a third home visit. In between these contact points, the participants were encouraged to contact the coordinators when needed. Moreover, the coordinators were encouraged to initiate meetings with other family members or friends to inform and encourage cooperation.

Table 6. Summary of standardized follow up in the intervention

Time	**Intervention**	**Focus**
Baseline	First home visit	Initiate contact, formal inclusion, data gathering, inform on learning courses and other relevant support.
Month 1	Second home visit	Build relation, *"what matters to you?",* further conversations on relevant support with a focus on the LIVE components, help with applications, etc.
From month 2	Monthly phone calls	Continuous evaluation of initiated support, follow-up topics from earlier contact points, listening and counseeling.
Month 6	Third home visit	Evaluate the follow up so far, discuss the way forward.
From month 7	Various	Continued follow up according to the dyads needs and wishes.

Table 6 is a short summary of the standardized follow up in the intervention. The coordinators were, however, given flexibility and encouraged to adjust further follow up according to the dyad's needs.

2.4.1 Other aspects explored

As a large scale randomized trial, the main LIVE trial will use a variety of quantifiable data to measure effect. As part of study two, we focused on experiences with different means to collect questionnaire data from the persons with dementia and the informal caregivers. Thus, we collected questionnaire data by telephone, at their home, in meeting the persons with dementia at their daycare centers and by following the coordinators on their home visits. These experiences were valuable, not only to gain experiences on how to organize this in the main study, but also for us as a research team to get to know some of the participating dyads. In addition, the coordinators registered resource use, in terms of time spent on follow-up of each of the participating dyad. That included home visits and phone calls with the dyads, as well as documentation and communication with other instances, such as GPs, health administration, homecare, daycare or nursing homes. These registrations were used to calculate approximate need for personnel to implement the main LIVE study. We have, however not used any of these quantitative data in the article.

2.4.2 Study participants

Participants in the intervention, as such, were recruited through the resource center for dementia and the geriatric outpatient clinic at Haraldsplass Deaconess hospital. Some of the participants from the outpatient clinic were also connected to the resource center, and there was therefore some overlap as to where the participants were recruited. Participants were recruited successively up to a target number of sixteen dyads. Eligible participating dyads were contacted by the coordinators from the resource center which informed about the study. If interested, a first home visit, as described, was planned for formal inclusion and gathering of baseline data. Only one eligible dyad rejected participation.

Througout the intervention, I had regular contact with the coordinators, both to aid in issues that arose and to keep updated on how the intervention progressed. Based on these conversations and experiences of gathering questionnaire data, as described earlier, we combined principles of opportunity and maximum variation sampling (Patton, 2015) to recruit a sample of participants for qualitative interviews considering their experiences with the intervention. After approximately 6-9 months after the intervention started, we conducted qualitative interviews with six of the participating dyads, three informal caregivers, and the two coordinators and their leader in order to evaluate the intervention. Table 7 gives an account of the participants in these interviews.

Table 7. Interview participant characteristics

ID	*Role*	*Gender*	*Age*	*Interview type*
A	Informal Caregiver	Female	68	Focus group
B	Person w/dementia	Male	67	Focus group
C	Informal Caregiver	Female	69	Focus group
D	Person w/dementia	Male	83	Focus group
E	Informal Caregiver	Female	65	Focus group
F	Person w/dementia	Male	65	Focus group
G	Informal Caregiver	Male	69	Dyad Interview
H	Person w/dementia	Female	75	Dyad Interview
I	Informal Caregiver	Female	75	Dyad Interview
J	Person w/dementia	Male	78	Dyad Interview
K	Informal Caregiver	Female	57	Dyad Interview
L	Person w/dementia	Male	69	Dyad Interview
M	Informal Caregiver	Female	71	Single Interview
N	Informal Caregiver	Female	59	Single Interview
O	Informal Caregiver	Female	57	Single Interview
P	Coordinator			Focus group
Q	Coordinator			Focus group
R	Coordinator leader			Focus group

2.4.3 Data gathering

Three dyads, all married couples, participated in a focus group interview, immediately after attending one of the patient learning courses for persons with dementia mentioned above. In this way, we received an opportunity to explore the persons' fresh experiences with participating in these courses. In addition, we had an opportunity to initiate a conversation between the participants concerning their experiences with participating in the study as a whole. Further, three dyads participated in in-depth interviews with both the person with dementia and informal caregiver present. Three informal caregivers also participated alone in in-depth single interviews. After all interviews with dyads and informal caregivers alone were completed, we conducted a combined evaluation meeting and focus group interview with the two coordinators and their leader.

Based on our initial research questions and experiences made throughout the project period, we developed a semi-structured interview guide for the interviews with the dyads and informal caregivers, see Appendix 4. For the focus group interview with the dyads participating in the patient learning course for persons with dementia we started with some additional questions concerning the course to gain insight into experiences considering this. In this focus group interview, one of my co-supervisors (OT) participated as a co-moderator. For the focus group interview with the coordinators and their leader, a new, semi-structured interview guide, see Appendix 5, was designed, based on the initial research questions, experiences throughout the project, and experiences from the interviews with participating persons with dementia and their caregivers. Also in this focus group interview, one of my supervisors (OT), participated as a co-moderator. In addition, our co-researcher with user-experience as an informal caregiver for a person with dementia, participated as a second co-moderator. In this way, we were able to draw on experiences from the interviews with the participating persons with dementia and their informal caregivers when planning the final interview-evaluation with the coordinators and their leader.

2.4.4 Data interpretation

All interviews were audio recorded and transcribed successively. After transcription, each interview was examined in an initial analysis in order to search for aspects to pursue in the further interviews. Before the final focus group interview with the coordinators and their leader, I discussed the findings so far with the two co-moderators, in order to establish congruency in what themes to focus on in this final interview. When all interviews were completed and transcribed, the transcripts were shared within the research group for individual analysis, followed by shared discussions within the research group as a whole. Similar to the analytical process for study one, the interviews were analyzed as single texts, as a whole body of texts and each text in relation to the whole body of texts (Gadamer, 2013). Then, our findings were brought into dialogue with relevant theory. As we had found the care philosophy of Kari Martinsen (2006) to be well responding to our findings in study one, we wished to follow this up in this study as well. We found that her writings brought interesting new horizons of understanding that responded well to our findings in this study.

2.4.5 Ethical considerations

The main informal caregivers in eligible dyads were first contacted by their contact person from the site of recruitment. They were informed about the purpose and entails of participating in the study and asked to discuss participation with their families or others involved in the care for the person with dementia. If interested, they were contacted by one of the coordinators and the first home visit was planned, as described above. Here the information about the study was repeated along with detailed information on data gathering, both in terms of questionnaire data and that they might be asked to participate in a single or focus group interview at the end of the intervention period. They were also informed about their right to withdraw from the whole study, or parts of it, at any time without any consequences for their follow up. Both the persons with dementia and their informal caregivers signed written forms of consent to participate. This also included written consent to participate in qualitative interviews as part of the evaluation of the study, see Appendix 6.

Participants in the focus group interview from the patient course were informed and asked about participation beforehand by the course leader. For the single and dyad interviews, the informal caregivers were contacted by myself and asked about participation along with repeated information that participation was voluntary, that they might withdraw at any time without consequence as well as information about data gathering and treatment. This information was repeated before starting the interviews. For the focus group interview with the coordinators and their leader, this same information was repeated along with information that they should be cautious about their duty of confidentialty towards the dyads and that they should strive to preserve anonymity when describing experiences. The coordinators continued to follow up the dyads after the study intervention period was over, according to the needs and wishes of each dyad. As there was only one female and one male coordinator, we have referred to them as female, that is *she/her,* in order to preserve their anonymity as well as possible.

The study was approved by the Regional Committee for Medical and Health research Ethics, Northern Norway (2017/1519 REK Nord), see Appendix 7.

Results

3.1 Article 1

In article 1 we explored the persons with dementia's descriptions of their homes and how they perceived living at home at the present time and in the future. Considering their despcriptions of the meaning of home, we identified two complementary themes.

Home as a foundation for lived life

The first, we called *Home as a foundation for lived life.* This interpretation was founded on how the participants described their homes as a base for them to be able to live their lives. This were expressed in descriptions of how the familiarity of the home and its interior made the activities of daily living go *'sort of automatically,'* and how these small parts of everyday life were highly appreciated. Further, this was seen in descriptions of how the participants' would strive to sustain habits and hobbies from earlier, such as tending the garden or going fishing, even though the circumstances had changed. Here we also found how *'home'* was not necessarily synonymous with the participants' formal address. One participant had little to say about his present apartment, but gave rich descriptions of the family country house, the activities he enjoyed pursuing there, and how he would visit as often as possible.

Persistent love – lived life as a foundation for being home

On the other hand, we found the theme *Persistent love – lived life as a foundation for being home.* In the empirical data, we found several examples of how the participants' lived lives were in many ways imprinted in the walls of their home. This was particularly described in stories of their home as a base for meaningful relations, especially to their spouses. Those who were still living with their spouses emphasized the comfort and safety in being taken care of by a loving partner. Participants who lived alone shared stories of how the memories of a loving spouse lingered in their present home, and how this created a sensation of still being together. Finally, there was the description of how the hope of getting a spouse back home from a nursing home represented a motivation for preserving the routines of everyday life. These two first themes, *Home as a foundation for lived life* and *Persistent love – lived life as a foundation for being home* complemented each other and illustrate how '*the home'* and lived life may be seen as intertwined and interdependent of each other.

Disturbed rhythms in life at home

The participants further described how the symptoms of progressing dementia brought *Disturbed rhythms in life at home*, in terms of practical problems in everyday life. Examples include trouble finding things, handling equipment, taking part in and following conversations, orienting outside, and disturbed circadian rhythms. Thus, they were forced to continuously adapt their habits and rhythms in their home and in their life in general. We also found how the complex total situation made the home ambiguous in that it might serve as a shelter and confinement at the same time.

Hopes for a future home

Finally, the participants described their *Hopes for a future home*. However strong their attachment to their present homes, all participants shared an acceptance that nursing home admission might be necessary at some point. For some, this acceptance relied on a trust that their family would be able to decide in this matter, should they not be able to understand the necessity themselves if the time should come. Still, most also shared a hope of being 'spared' such a fate. Participants with experience of short term stays in nursing homes mostly agreed that, although necessary at the time, they preferred to be home, referring to a lack of homeliness in the nursing home.

Overall, we found that the participants described their homes as quite complex constructions where the different components were intricately interwoven.

3.2 Article 2

In article 2, we explored the participants' experiences with and attitudes towards assistive technology, volunteer support, homecare services and daycare centers. Concerning assistive technology and volunteer support, these themes were chosen as they were intended as crucial components of the LIVE study. Thus, experiences and attitudes on these aspects were considered important to explore with a pragmatic view on the further development of the LIVE study. Homecare was explored due to the simple fact that it is considered the baseline of care, and it was expected that some might have had experiences with, directly or indirectly through family or friends, and so hence certain attitudes towards it. Daycare was not initially part of the inquiry, but as all participants were recruited through such centers, they all shared experiences with this as part of the conversation. During the interviews, we also touched on other means of care and support, such as patient and caregiver courses and general practitioners. Although we had some interesting conversations on these themes, the findings were not found to be substantial enough for further pursuit.

Assistive technology – safety with side effects

The participants shared various experiences and attitudes towards the care and support measures in question. Only a few had direct experience with assistive technology, limited to safety alarm and stove guard. Although these measures were perceived as providers of safety, one participant emphasized that there are also side effects. For her, her inability to handle the stove guard had *"ruined the whole stove"* and she was not able to use this at all anymore. Potential side effects were also remarked by those who had no previous experience with assistive technology. Fear of not being able to handle equipment, or reluctance towards 'beeping' made many participants hesitant, although not rejective, towards this kind of support.

Volunteer support – the complexity of preferences

A hesitation was also found in the participants' views on volunteer support. They were concerned about how this could be personally adapted, and had quite specific preferences for the prerequisites for such an arrangement to work. The only participant who had direct experience with a volunteer explained how she had been disappointed as the volunteer only '*talked and talked and talked*' instead of joining her for a walk.

Homecare services – the diversity of care experience

Considering homecare, most of those living alone had daily visits, mostly to receive medication and prepare meals. All described satisfaction with this arrangement, although they emphasized different aspects when describing what they were satisfied with. Those who did not receive homecare were open for this as something that might be necessary in the future, but tried not to think about it.

Daycare centers – it's all in the details

Finally, almost all of the participants described how the daycare centers played an essential part in enriching their everyday lives. Again, they ascribed their satisfaction to varying parts, so it was not necessarily the daycare centers as such that were important, but parts of it, such as the personnel, the activities or simply the minibus ride back and forth. There was however one participant who was not as enthused about this arrangement. Being reluctant towards some of the activities, she pulled away from the rest of the group, feeling outside.

The common theme in their responses was a high degree of individual preferences which were crucial for whether a support measure was assessed as beneficial. The participants further described a fine line between support perceived as a beneficiary or experienced as an infringement. These differences were not necessarily attributed to the support measures as such, but to specific aspects of these measures.

3.3 Article 3

The second study was an exploration of the coordinator role for the LIVE trial and had thus a pragmatic aim, besides the pure scientifical. The main objective was to explore how the participating dyads and coordinators described the coordinator function and role. The second objective was to explore how the coordinator could contribute to empower the persons with dementia in decision-making processes.

The coordinator as a safety net

We found that three coordinator functions emerged in the dyad-coordinator relation as a reply to the dyads' needs. First, the coordinators functioned as a safety net. This function was most clearly expressed by dyads where the dementia progress and life situation were relatively stable and necessary support was in place and functioned according to the dyads' needs. These dyads expressed that there was little the coordinator could do for them at the moment, but that the regular contact with the coordinator made them feel safe; if the situation should change, they knew who to contact, and they knew that this person would know them and their situation.

The coordinator as a pathfinder

The second function was that of being a pathfinder. Some dyads described the terrain of available care and support as a confusing landscape, with many different providers and a complex administrative system. In these instances the coordinators helped the dyads find their way in the often confusing terrain of support, applications and administration in order to access necessary support. This involved helping the dyads to find support measures that were purposeful in their current situation. Related to this issue, we also found that slight differences in the coordinators' approaches to issues that arose throughout the intervention, such as their level of support concerning applications, had an impact on how the participating dyads valued the follow up they received.

The coordinator as a source for emotional care and support

The third function was that of providing emotional care and support for the informal caregivers. This function ranged from simply listening to the informal caregivers concerns, through acknowledging their efforts, to counselling in challenging situations.

Thus, although participants in all interviews expressed that they were satisfied with the intervention, they were satisfied to varying degrees and by varying aspects of the intervention – namely, according to how it fitted their individual life situation and shifting needs throughout the intervention period.

Emphasis on trust-based working conditions for the coordinators

We also found that the coordinators and their leader emphasized the importance of trust-based working conditions for the coordinators to be able to follow up the dyads adequately. This involved having a flexible work situation, as well as being trusted and enabled to prioritize according to the dyads' shifting needs. Further, it was described as important to have trusting relations with co-workers and leaders with room to discuss challenging situations and receive acknowledgement for challenging emotions related to the close follow up of the participating dyads.

Empowering the person with dementia in decision-making processes

Finally, we found that the objective of empowering the persons with dementia was challenging to pursue. This perception was based on the number of home visits as too sparse to be able to build a trusting relationship to the persons with dementia, and the challenges associated with maintaining contact by telephone with persons with dementia, especially without a trusting relationship having been established.

Discussion

Throughout these studies we have explored the meaning of the home and some of the complexities in providing care and support for home-dwelling persons with dementia. First, we explored the existential interconnection between a person's home and life and how this complexion grows when living with a progressing dementia condition. Second, we found how the appraisal of care and support often depends on details – marking a thin line between support experienced as supportive versus offensive, diginity preserving versus dignity violating. Third, we investigated the role and function of a coordinator for persons with dementia and their informal caregivers, and how challenging it might be to genuinely empower the person with dementia to take part in continuous decision-making processes.

4.1 Methodological considerations

The Gadamerian hermeneutical approach turned out to be useful as an approach through all stages of the research process in both studies. When designing the studies, I found the open approach, combined with a reflexivity of my own and my supervisors' pre-understanding, useful throughout the research process. The methodological approach combined with qualitative interviews as a data gathering tool has proved useful in gaining insights into complex phenomena and mechanisms. In line with the Gadamerian hermeneutical tradition, this approach has not allowed me to draw general conclusions upon the themes of inquiry or about the groups whose experiences and perspectives we have explored (Gadamer, 2013).

Hence, all three articles are based on data materials achieved through qualitative interviews with a relatively limited number of participants, recruited from within a limited geographical area in western Norway, making the groups of participants relatively homogenous. Recruiting more participants with more socio-demographic variety might have led to a richer data material, opening up for other interpretations. Fleming et al. (2003) recommend repeated interviews, based on the understanding that the pre-understanding of both the interview participants and the interviewer is in constant change and repeated interviews would thus lead to new understanding. For study one, this was discussed, but based on an intention to minimize strain on the participants, we did not go through with this. In retrospect, I believe repeated interviews could have been fruitful, at least with some of the participants. When talking with personnel at the daycare centers after all interviews were conducted, they also said that several of the participants had asked if I would come back, indicating that our considerations in this regard were perhaps a bit exaggerated. If we had conducted repeated interviews, this might have brought forth new and deeper perspectives on the themes of inquiry. For study 2, we experienced that it was challenging to appoint time for interviews with several of the participants. Many of the caregivers had challenging life situations, balancing care for the person with dementia with work, other family members, and their own health, all while also trying to preserve a social life. I was in contact with more dyads who were willing to participate in interviews, but as weeks became months without any possibility for them as caregivers to find time in their busy schedule, we decided to cancel. Interviews with these persons could have given substantial insight into other and perhaps more complex aspects of living with dementia and on being an informal caregiver for a person with dementia. In study two, we also discussed arranging interviews at baseline to be able to explore the process of having a coordinator. As the dyads received two home visits from the coordinators in around a month, where they also went through comprehensive questionnaires, we decided to avoid this, again to reduce strain.

Unfortunately, I was not aware of the book of Moules et al. (2015) on '*Conducting hermeneutic research*,' before I was far into the interpretive phase of article 3. In line with the Gadamerian hermeneutical principles (Gadamer, 2013), the book does not provide a method of hermeneutic research; instead, it provides reflections alongside practical examples of possibilities. This has been very helpful when working with this thesis. First, it has given me the necessary courage to interpret my findings in metaphors. Second, it has encouraged my reflections on how my findings can be interpreted in terms of '*Bildung,'* that is, how my experiences throughout this work have cultivated my horizon of understanding, but also my horizon of possibilities within the field. Third, it has helped me identify the analogies of Gadamers (2013) hermeneutic thinking and Kari Martinsens (2006) care philosophy and thus how the hermeneutic perspectives may be applied in concrete nursing practice – a possibility that has also been suggested by Rolfe (2015). Lastly, Moules et al. (2015) provided novel terms and novel understandings of terms to assess study validity, or trustworthiness (Lincoln & Guba, 1985), which I experienced resonated well with the hermeneutical approach. Moules et al. (2015) used the term *rigor* as an overarching term in this regard.

4.1.1 Study rigor

According to Moules et al. (2015), study *rigor* in hermeneutic research should be understood in terms of paying careful attention when treating the topics in question in order to extend the horizon of understanding. Within this term, we find the terms *validity* and *veracity*. *Validity* in this context may be understood in terms of *rhetoric* and *critic*. This means that findings are presented convincingly and credibly, while at the same time keeping a critical attitude towards the interpretations. In addition, Moules et al. (2015) suggest assesing ethical validation, that is, whether the research may lead to a change in practice; and substantive validation, that is, if prior research and context are accounted for. Throughout the studies we have endeavored to pay careful attention to the variety of perspectives that came forth through our interviews and have attempted to elucidate this variance at the same time as we have investigated the inner convergence within this variance. Further, we have dicussed our findings in light of relevant research, theory and policies, and proposed ways to apply the new understanding in concrete nursing practice. As we discussed the data material in light of differing theoretical perspectives in the interpretive processes, we saw how different perspectives led to different interpretations. Although we have tried to elucidate some of the variance in the data material, in light of some different perspectives, we are aware that other perspectives and focuses might have led to other interpretations. Similarly, we are aware that the pre-understanding of each member of the research team, and our interaction, have also affected the interpretations. In this case, we have experienced that the contributions from the co-researcher with user-experience have been very beneficial in order to bring in other perspectives.

Related to *validity* is *veracity.* The objective of hermeneutic research is not to present truth, but to explore and illuminate possible interpretations and horizons of understanding. According to Moules et al. (2015), there are several criteria to assess veracity. In our studies, we have worked to achieve *coherence* and *agreement* by considering contradictions in our findings and making sense of these contradictions in our presentations. We have sought *comprehensiveness* and *thoroughness* by providing rich examples of direct quotes from the data material, exploring the topics of inquiry from various perspectives and addressing relevant questions within these perspectives. *Contextuality* has been attempted through careful descriptions of the context of our studies and how this has affected the studies. As described, in study one, family members of some of the study participants were present and took part in the interviews and it can be argued that these interferences can threat the study's validity. From a hermeneutical point of view, I would argue that they might bring forth perspectives other than those originally pursued, but the perspectives, as such, cannot be made more or less valid. The interviews would have been different if the informal caregivers had not been present. The interviews would also have been different if I had been a woman, had been another age, had spoken another dialect or had used other words during the interviews (Brinkmann & Kvale, 2015). I will therefore argue that even though the family members' contributions may have affected the interview situations, they do not necessarily compromise the studies' veracity. Finally we have attempted to achieve *suggestiveness* and *potential* by raising new questions and suggesting new approaches to the field both for research and clinical practice. We acknowledge that the hermeneutical circle of understanding is an infinite process in nature. It will always be possible to identify new ways of interpreting data: seemingly accordances may be interpreted as contradictions and vice versa, and what is perceived as strengths might also hide limitations.

In many ways, hermeneutic research operates in the borderland between giving consistent, convincing and coherent interpretations and emphasizing contradictions and the particular. In light of this, Moules et al. (2015) suggests that a study's *integrity* lies in the ability to hold this tension and be humble towards the possibility of other interpretations. Throughout the studies we have paid careful attention to how we use language when presenting and discussing our findings and interpretations. We have argued for the premises of our interpretations but at the same time attempted to present them in terms of suggestions and possibilities, keeping the doors open for other perspectives, opening up for other horizons of understanding.

Ethical conduct

As a final point of study rigor, Moules et al. (2015) emphasize the importance of rigor in *ethical conduct.* This concept entails that ethical considerations in research involving human beings should be considered in all decisions and in all meetings throughout the research process. Equal to Martinsen's (2006) focus on *the ethical demand,* they warn against limiting ethical judgments to what has been permitted by ethical commitees or through formal regulations (Moules et al., 2015). Especially when involving persons with dementia in research this principle becomes apparent, underlining the importance of conducting moral sensitivity through the process (Heggestad et al., 2013). Ethical considerations related to the two studies has been accounted for in the methods section.

4.2 The home – when living with dementia

In article 1 (Fæø et al., 2019), we interpreted the interview participants' descriptions of '*home'* as existentially founded constructions consisting of a variety of components. Primarily, this was found in terms of habits and routines, understood as rhythms in how they acted and structured their lives. This could be seen both in the basic activitities of daily living, such as cooking and cleaning, but also in terms of rhythms based on wider cycles, such as the seasonal tending of the garden. In this holding on to rhythms, we can see parallels to how persons with dementia strive to sustain personhood (Hughes, 2014; Kitwood, 1997). Traces of these rhythms can also be found in article 2 in the participants' descriptions of meaningful activities, such as hunting or taking walks (Fæø, Bruvik et al., 2020). This brings us over to the participants' relation to the outside environment, such as nature, the sea or the once familiar streets, and how this was part of their experience of being home (Fæø et al., 2019). Here we also find the internal relation between the environment and the activities. Although not explicitly stated, these descriptions also involved material things: the homes' inferior, equipment needed to perform activities, items that triggered memories, and so on. We also found how relations to others were described as essential in how they experienced being home. In this case, we primarily emphasized the participants' descriptions of their strong relationship to their spouses, whether they still lived together or not. One of these descriptions also bordered a transcendental sphere, in the experience of feeling the presence of a deceased spouse (Fæø et al., 2019). Although not described in the article, the participants also shared stories of their children, their parents and siblings, and how these important persons in various ways had influenced their homes and their views of what a home ought to be like. In sum, these findings match the views of Martinsen (2006) and Zingmark et al. (1995) concerning how the home consists of a multitude of relations between the home, the person(s) inhabiting and guesting it, its surroundings, the things it contains and the activities it houses.

Figure 1 is an illustration of how some of these components may together constitute the construction of a home that situates the person in the world and the interdependence between *'the home'* and lived life. These components must be understood as overarching. As we have seen, the composition of these components vary from person to person, as do their size, their internal relations and their importance in holding up the structure as a whole.

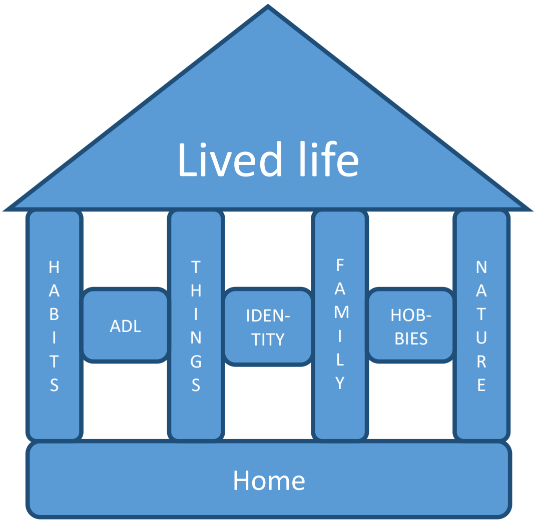

Figure 1. Illustration of *'the home'*

Central in the figure, we find the component *'identity'* signifying how the relation to oneself and creating an identity is central in the experience of being home (Hilli & Eriksson, 2017; Molony, 2010; Sixsmith, 1986). Kitwood (1997) describes how a person's identity creates a sense of continuation from the past into the present and consistency across the roles and contexts one are, or have been, part of.

4.2.1 The complexity of '*home*'

Further, in article 1, we argued that the components of '*home*' must be understood as intricately interwoven and interdependent on each other, constructed as a complex network of structures, carefully placed and adapted to create a place to dwell (Fæø et al., 2019). This became even clearer in descriptions of how the progression of dementia, or other changes in life, had disrupted some of these components of *'home,'* and how these disruptions spread like ripples of water to other components of *'home.'* The once familiar streets had become unknown, affecting the participants' confidence in going out on their own; they had trouble following conversations, which affected their relation to others; they could no longer handle once familiar equipment, affecting their ability to manage on their own (Fæø et al., 2019). The participants also described how they continuously strove to adapt to these changes.

Challenges like these, and the effort to adapt have been widely explored in research on the experience of living with dementia (Bjorklof et al., 2019; Eriksen et al., 2016; Gorska et al., 2018). With Førsund et al. (2018), we can say that the participants strove to maintain an experience of space while *'living in a space where the walls keep closing in.'* Here we are at the core of our findings presented in article 1; in the reciprocal relationship between '*home'* and *'lived life.'* On the one hand the home is continuously adapted to fit the person(s) inhabiting it; its form and content are adjusted according to the persons rhythms and changes of rhythms. On the other hand, the home forms the person, forcing the person to adjust her or his rhythms in harmony with the possibilities afforded by the home. This implies that the *'home,'* in addition to being a complex construction, also can be seen as organic in nature, continuously in change through a formative, creational process. This matches the descriptions of being home as a continuous process, as described by Douglas (1991), Martinsen (2006) and Zingmark et al. (1995). A process that is perpetual and immediate, and that may, in itself, be seen as part of what makes the home, as a physical space, into a home in an existential manner. Without this effort, the home would be a '*non-home'* (Douglas, 1991) and simply a place to reside. Thus, the home and the effort of a continuous creation of the home are also conjointed. This effort is not necessarily pleasant; it may be painful and demanding. Hellström et al. (2013) describe how women with dementia strive to hold on to their chores, although increasingly strenuous, to hold on to the feeling of being home and keeping the core of self. Some participants portrayed in article 1 described how they strove to keep up their routines, to keep their homes, practically and existentially (Fæø et al., 2019). One described times of hardship on his childhood farm during the Second World War as '*splendid times*' due to the family's collaborative effort to utilize all available resources to care for themselves and support their neighbors. Perhaps we can say that not only despite of, but also because of, the hard work and need for well-functioning relations between all components of the home – people, things, nature, activities – the home as an existential fundament, was strengthened.

4.2.2 The nest-home – a metaphorical interpretation

Although Figure 1 may serve as an illustration to describe the overarching components that constitutes *'home,'* I will here present a more complex metaphorical interpretation in order to increase the understanding of the complexity of the home. Unlike the strictly planned constructions of human houses, I will argue that the way the birds build their nests may be an enlightening perspective, enhancing our understanding of the complex constructions of the home as a vital, existential *'home.'* Indeed, Young (1998) uses nesting as a metaphor of how older persons adapt and settle when moving to congregate housing. French author Jules Michelet (1868) portrays the bird's house as follows:

> *Thus, then, his house is his very person, his form, and his immediate effort—I would say, his suffering. The result is only obtained by a constantly repeated pressure of his breast. There is not one of these blades of grass but which, to take and retain the form of a curve, has been a thousand and a thousand times pressed against his bosom, his heart, certainly with much disturbance of the respiration, perhaps with much palpitation* (p.249).

In many ways, I will argue that this poetic description sums up the essence of the home in its existential meaning, as described above. Transferring the descriptions of *'home'* to the metaphor of the nest, it illustrates not only the creational aspects of being home, but also the effort, and the importance of the effort, put into this process, and not least, the complexity of the home as a structure. Again, we can refer to the example of the participant describing times of hardship as *'splendid times'* (Fæø et al., 2019). This was ascribed to a complex interaction between various components of his home. We can only imagine how slight differences in the composition of these components might have given quite another comprehension of the situation. In line with Sixsmith's (1986) remarks that the experiential modes of home only exist in an analytical sense, Michelet (1868) observes that the nest should be regarded more as a condensation than a weaving. The various components of the home may be seen as entwined and entangled in each other, so that even though they to a certain degree might be distinguishable, they are also, to a certain degree, indivisible, making life go on '*sort of automatically'* – as one participant described it (Fæø et al., 2019). Although we can observe a variety of composite parts making out the construction that is home, we cannot subtract them, draw them out one by one and attempt to treat each part individually. The home cannot be decomposed, or, to use the words of Martinsen (2006), dissected, without at the same time being damaged. Likewise, a bird may, perhaps, be able to rebuild a damaged nest, but only by taking into account the construction of the nest as a whole. The dilemma then arises when persons with dementia are in need of care and support in order to maintain their homes and when their own efforts are not enough to adapt to the continuous disruptions of rhythms they are experiencing. How can formal or informal caregivers help maintain or repair the home, or build sustainable scaffolds to support the home (McCabe et al., 2018), without at the same time causing damage to the home, and harm to the person?

4.3 The *'home'* and support for persons with dementia

In article 2, we found how details regarding the way support was arranged could make a difference in how the participating persons living with dementia experienced the support they were provided (Fæø, Bruvik, et al., 2020). Seen in relation to our experiences from article 1, we can say that these details affected the persons' experience of being home. One woman described that she was no longer able to handle her stove because of her inability to handle the stove guard, a device that prevents fire hazard. With Martinsen (2006), we might say that the stove guard affected her relation to the stove – a relationship that had formerly been intimate had now become estranged. As a result of her inability to handle the stove, she could no longer bake, an activity she perceived as meaningful. Thus, her relation to this activity was also affected. An aspect that was not described in the article, was how she formerly had baked and shared cookies with her neighbor. As this was no longer possible, her relation to her neighbor was also affected by her inability to handle her stove, because of the impact the stove guard had on her life. Here we can see clearly how an intention to support and maintain safety in one area of the person's life, her home, spreads like ripples of water with unexpected side effects that affected quite different areas of her life. Similarly, in a study based on focus group interviews with eleven healthcare professionals, Nygard (2009) found that stove guards might have unwanted consequences for the persons using it. Furthermore, she described how the stove guard was a common safety measure for persons with dementia, even though those providing it were aware that the person often was unable to use it and might perceive it as stigmatizing. Another example is the woman who felt that the activities at the daycare centers did not appeal to her, causing her to choose to sit down outside of the group. In this way, we might wonder if the support affected her relation to herself, as it caused her to look at herself in a new light, stating; *'perhaps I'm a bit weird'* (Fæø, Bruvik, et al., 2020). In light of this example, Strøm and Engedal (2020) emphasize an increased attention to ethical dilemmas related to psychosocial interventions in care for persons with dementia and how these might affect the individual. They describe how such interventions may have unpredicted consequences if they are not individually adapted, an aspect which is central in the philosophy of person-centered care (Brooker & Latham, 2015; Kitwood, 1997). The examples described may, however, illustrate how complex it might be to fulfill this ideal. To summarize, we can see how support measures that are intended to support the persons in living at home, may turn out to harm their 'being home'. However, we also found how the participants through dialogue and reflection, when given time and space, turned initial reluctance towards certain support measures into possibilities for how it might fit them (Fæø, Bruvik, et al., 2020).

4.3.1 The ability to adapt

Despite these unwanted side effects, most participants who received various means of support mostly expressed satisfaction with the support they received (Fæø, Bruvik, et al., 2020). However, they ascribed their satisfaction to different aspects. For example, two women, both living alone, received mostly the same care from the homecare service, and both were mostly equally happy with this. One because it made her feel safe to know that she would recieve her pills at the right time, and the other, because she found it nice to have visits, and found comfort in the personnels' concern. Concerning the daycare centers, the participants attributed their satisfaction to everything from the minibus drive, through the meals or activities, to their relations to the personnel. Thus, they were able to adapt these new elements in their lives to their existing rhythms, integrating them as new components in their being at home. In a synthesis of articles on meaningful activities for persons with dementia, Han et al. (2016) found that different people can perceive different activities as meaningful in different ways, based on their preferences. Further, they describe how taking part in meaningful activities can contribute to a strengthened sense of being connected, to one's self, to others, and to the environment. Here we can see how taking part in such activities can contribute to strengthening or rebuilding the relations that constitutes '*home.'* Accordingly, in article 1, we saw how a participant described her daycare center as crucial for her to be able to continue living at home (Fæø et al., 2019). We also found that the participants, when given time and space, were able to reflect on how unfamiliar support might be adapted to fit them (Fæø, Bruvik, et al., 2020). Although they were facing challenges and were met with support that might be unfamiliar, the participants described how they mostly were able to make good use of these measures. Likewise, when given time and place, they were able to reflect on how unknown measures might be of help in the future, despite initial reluctance. Perhaps we can see this in light of what has been shown above of persons with dementia's ability to adapt in general (Bjorklof et al., 2019; Eriksen et al., 2016; Gorska et al., 2018). Even though many might require support from others to be able to adapt to the continuous changes caused by dementia, their own effort and participation is a basic premiss for adaptation to take place.

4.3.2 Seeing the other

Now let us return to the metaphor of the nest: We can imagine how the bird is presented with materials to repair a damaged nest. The bird might not be able itself to gather the materials; it might not know what materials are available or the nature of the available materials. It might also be unaware of parts of the damage to the nest. Still, it is only the bird itself who may be able to integrate the materials in its nest through 'repeated pressure of his breast' (Michelet, 1868). If care is not taken, the material might damage more than it repairs. We can see how this applies to the thoughts of Martinsen (2006). Healthcare personnel have knowledge the person with dementia does not. Their task is to use this knowledge in order to inform and support the person with dementia. To be able to provide information and support that is actually supportive, Martinsen claims that it is necessary to see the other detached from a diagnosis and any presumed needs based on predetermined categories. Likewise, Smebye and Kirkevold (2013) emphasize the importance of contextualizing knowledge about dementia to each specific situation. Similarly, Brooker and Latham (2015) emphasize looking at the world from the perspective of each individual person with dementia. In article 3, we saw how some of the informal caregivers described how they experienced the coordinators as being one step ahead. The coordinators used their knowledge and experience to see challenges before they arrived and were able to help the dyads prepare and receive the right support in the right place and time (Fæø, Tranvåg, et al., 2020). However, we found it challenging to include the persons with dementia in these processes as the communication turned out to be mainly between coordinator and informal caregiver. This leads us to the complex issue of user participation within dementia care.

4.4 The issue of user participation

User participation in dementia care is a complex issue. Above, we saw how persons with dementia too often are excluded from participation in decision-making processes concerning their own care (Cahill, 2018; Smebye et al., 2012; Taghizadeh Larsson & Osterholm, 2014). Based on the participants’ descriptions of the complexity of the home and how details in support might have unforeseen consequences, we emphasized in article 1 and 2 the importance of increased user participation in dementia care (Fæø, Bruvik, et al., 2020; Fæø et al., 2019). This view is also in line with extensive research emphasizing autonomy, independence and agency as crucial for persons with dementia in order to experience dignity, quality of life and sustained personhood (Bosco et al., 2018; Gorska et al., 2018; Hedman et al., 2016; Kitwood, 1997; O'Rourke et al., 2015; Tranvag et al., 2016). The interpretations of our findings concerning this issue can, however, be questioned. Indeed, one of the participants in article 1 described how she hoped her family would be able to take action if they should see that it is no longer safe for her to remain at home, in case she is unable to judge this by herself (Fæø et al., 2019). The descriptions of participants being able to turn initial reluctance towards support into possibilities can also be interpreted otherwise (Fæø, Bruvik, et al., 2020). What if they had not been able to see these possibilities? What if a representative from the municipality does not have the needed time, patience and skills to engage the persons in reflecting on these possibilities? Should the persons' reluctance be accepted and the support not given based on a principle of user participation and autonomy?

Through interviews with seven persons with dementia, Haugen, Ytrehus and Slettebø (2018) describes a high degree of individual variations among the participants' views on this topic. These ranged from feelings of lost independence and frustration over others making decisions, to being content by leaving decisions to others for fear of making mistakes. In a systematic review on shared decision-making, Daly et al. (2018) found that for some, taking part in the process may be as important as making the decisions themselves. This matches the findings of Smebye et al. (2012) on how persons with dementia might leave decisions to others, whom they trust. An arrangement that is also regulated by legal arrangements (Guardianship Act, 2010).

4.4.1 Legal regulations and human rights concerns

In line with these views, it is possible to transfer legal authority on certain issues, such as personal economy, to others. An expanded legal authority can also be delegated by legal authorities, or the person with dementia to a certain person, giving expanded economical rights and the right to apply for or formally complain about services, formal resolutions and so on (Guardianship Act, 2010; Norwegian Civil Affair Authority, 2020). Similar regulations, although with some variety, are common in most western countries (Cahill, 2018; Gallagher et al., 2012). In line with the regulations of exception from the laws regarding consent, the purpose with these regulations is to safeguard that persons with challenges related to understanding information, making informed decisions or administering economical and legal issues, are not subject to harm or maleficent incidents because of reduced functioning. An issue does however arise when compliance to these regulations excludes persons with dementia from information and taking part in decision-making processes (Cahill, 2018; Smebye et al., 2012; Taghizadeh Larsson & Osterholm, 2014). Practices that are further held up by the still widespread stigmatization of persons with dementia (Behuniak, 2010; Haugen, Slettebø et al., 2018).

The United Nations Committee on the rights of persons with disabilities signals contempt towards practices of holding back information or denying opportunities of participation in decision-making processes (Committee on the Rights of Persons with Disabilites, 2014). A major contribution to enlighten these issues is the inclusion of dementia as category of 'disability.' This entails that dementia should be treated as equal to any other disability. Meaning, for example, that although dementia can lead to challenges in participating in decision-making processes, these are challenges to be overcome; the person should not be automatically excluded (Cahill, 2018). Generalized tests, scores or conceptions to assess a person's ability to consent is deemed as contributing to '*lowering his or her status as a person before the law*' (Committee on the Rights of Persons with Disabilites, 2014 para.15). In situations where participation is challenging, healthcare personnel have a duty to support and empower the person to become able to participate as far as possible. Violation of this principle is considered a breach of human rights. Accordingly, Smebye et al. (2012) claims that the question on this issue should not be *if* the person is able to participate and consent, but *how* to make the person able. When aiming to empower persons with dementia in decision-making processes, this question is essential.

4.4.2 Empowerment and the ethical demand

Human rights defines the right to participate as an absolute right (Committee on the Rights of Persons with Disabilites, 2014), and a starting point should be in treating it as such. I will, however, argue that applying this principle without question will be a serious sin of omission. A central point of criticism of the empowerment concept in its wider use within healthcare is the risk of an abrogation of responsibility: as the patient is deemed the expert, the healthcare personnel should not impose their views on the other. This may in turn lead to the healthcare personnel refraining from recommending adequate care or treatment, or warning against potentially inexpedient choices, based on a misunderstood respect for the others autonomy (Thornquist, 2009). When applying the concept to dementia care, where the persons may have challenges understanding and resonating, I will argue that the concept should be handled with care. As the term user participation implies, it is relational in nature; it is about taking part in the processes. Hence, McConnell et al. (2019) emphasize respecting the persons, giving them a voice and involving them, in their definition of empowerment for persons with dementia. Similarly, Groen-van de Ven et al. (2018) suggests a gradual accommodation in the involvement of the persons with dementia, allowing them to participate according to their strengths and remaining resources.

According to the views of Martinsen (2006) and the tradition she represents, healthcare personnel have a responsibility to use their knowledge to care for the other as an answer to the ethical demand that comes forth in the singular situation. The care and support should, however, not be enforced on the other, but offered and explained through an open dialogue. This view may be helpful in meeting some of the dilemmas concerning consent as described earlier. Justifying forced treatment based on a superficial assessment of ability to consent should be avoided. Conversely, not giving necessary healthcare because the patient opposes, does not understand or simply does not ask is an abrogation of responsibility. There are many ways to involve persons with dementia in decision-making processes – and many different processes that require decision-making – and the persons themselves may have differing wishes and expectations when it comes to this (Haugen, Slettebø, et al., 2018; Smebye et al., 2012; Taghizadeh Larsson & Osterholm, 2014). Thus, providing care and support to persons with dementia is a task that requires openness, judgment and the ability to grasp and explore the complex ethical demands that arise in the meetings with these persons (Martinsen, 2006, 2012). In many ways, the coordinators' leader sums up these views, in article 3, when she described how she would like to hand-pick coordinators, because they '*have so much impact on people's lives'* (Fæø, Tranvåg, et al., 2020). With Gadamer (2013), we might say that going into this kind of work requires tact.

4.4.3 On finding the other

As a measure to involve and empower the persons with dementia, a central question in the LIVE framework is *'what's important to you?'* (Husebo et al., 2020). In article 3 we found how the coordinators found that the answer to this question was not necessarily found in the participants' answers to the question (Fæø, Tranvåg, et al., 2020). Rather, the coordinators described how they found an answer to this question in the stories the participants told about their lives. Within the tradition of person-centered care, focus on the person's life story has been important. Based on interviews with 11 nurses and 12 healthcare assistants, Cooney and O'Shea (2019) add to this focus that this entails more than *knowing* the persons life story. The story also needs to be *understood* in order to impact how the personnel should care for the individual person with dementia. This is in line with the care philosophy of Kari Martinsen (2006). Simply mapping out and gathering information about persons in order to categorize is, in itself, of little help. Although the coordinators in the intervention had little contact with the persons with dementia, they described listening to their stories as crucial in order to *'get to know their pulse a little'* (Fæø, Tranvåg, et al., 2020).

According to Martinsen (2006), it is by meeting the other with openness and curiosity that one can be aware of who the other is, and what the other truly needs. This need not exclude the person's life story as told by informal caregivers, nor gather information about the persons function through assessment forms. It does, however, urge healthcare personnel to continue being curious and open about what the gathered information can tell, but not least, what the persons with dementia may tell themselves. In this process, one should also be aware of the persons' *zone of untouchability'* (Martinsen, 2012), that is, what areas of the person's life one should *not* explore, at least not before sufficient trust has been built.

4.5 Structural issues in care and support

The participating dyads in our intervention study described how they experienced how challenging it felt at times to find the appropriate support within a complex system of applications, a complex administration and many care providers (Fæø, Tranvåg, et al., 2020). These issues are common and form part of the rationale for case management approaches in dementia care (Francke et al., 2017; Hale et al., 2020; Khanassov et al., 2014b). We also found how slight differences in the coordinators' approach to help with this, for example in the process of applying for services, led to differing perspectives on how this help was perceived (Fæø, Tranvåg, et al., 2020). Here we can see similarities with our findings in article 2, on how minor details in the support affected the perception of the support as a whole (Fæø, Bruvik, et al., 2020). We also saw how a basic part of the intervention, building a relation to the person with dementia, turned challenging to pursue (Fæø, Tranvåg, et al., 2020). Further, when attempting to recruit participants for the interviews, we saw how complex the life situation might be for some of the dyads. These issues understate the challenges presented by Iliffe et al. (2017) as described earlier, in terms of a need for adjusting the organizing of care coordination for home-dwelling persons with dementia according to a wide perspective of context. In the following I will mention six structural and contextual components affecting the coordination of care for home-dwelling persons with dementia.

First, one needs to know the *person* and the persons preferences and wishes, learning what matters to the individual, in line with the ideals of person-centered care (Brooker & Latham, 2015; Fæø, Bruvik, et al., 2020; Kitwood, 1997). Second, one need to acquire an overview of the persons '*home,'* understood as a complex construction intricately interwoven with the person's lived life (Fæø et al., 2019; Martinsen, 2006; Zingmark et al., 1995). Third, one needs to account for how the person and the person's home are affected by *health* related issues, including the dementia condition. At this point there is also a need to consider potential ethical dilemmas related to safety and avoiding maleficence versus respecting the person's integrity and autonomy (Smebye et al., 2016). Fourth, there is a need to account for the person's *network*, in terms of informal caregivers and their situation and resources (Johannessen et al., 2015). Again there is a need to account for ethical dilemmas concerning the informal caregivers' health and safety versus the person's autonomy (Smebye & Kirkevold, 2013; Smebye et al., 2016). Fifth, there is a need to account for the available *services,* in terms of formal care and support, namely how these are organized and what structural frames they operate within (Bamford et al., 2014; Iliffe et al., 2017; Khanassov et al., 2014a). Sixth, there is the question of who the coordintators are. What competence and experience do they have? What are their working conditions and resources? How are they connected to other services and how do they understand their role (Backhouse, Richards, et al., 2017; Khanassov et al., 2014b)? Finally, there is the question of how all these aspects are interconnected and affect each other. Figure 2 is an attempt to illustrate these structural components affecting the persons with dementia and the coordination of care and support for them.

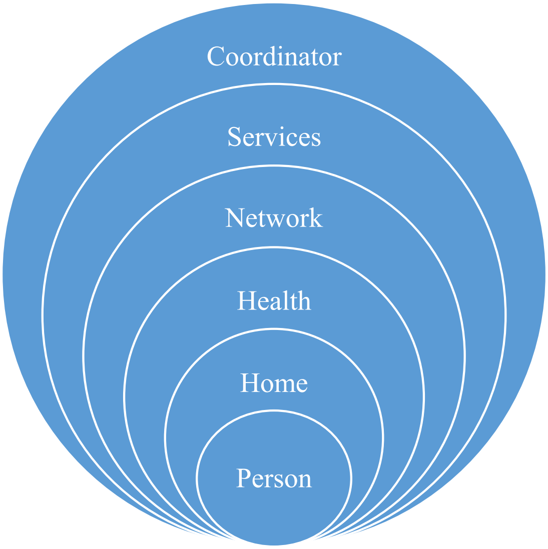

Figure 2. Structural and contextual components affecting coordination of care

4.5.1 Finding a pathway

To draw further on the nest metaphor – the issue is not only about how to help sustain the structure of intricately constructed nests, formed over a long time to fit its habitant(s) perfectly. The nests are also carefully placed within a tree, situated according to its habitants' needs and possibilities in order to be able to maintain their rhythms of life. The tree, again, is situated within a forest with all its complex paths and trails. In short, the nest it situated within a complex ecosystem where all parts, in some way and to a certain degree, are interrelated and interdependent on each other.

The term ‘pathfinder’ was found to be a fitting metaphor to describe the coordinators’ role in supporting the dyads to find their ways to appropriate care and support (Fæø, Tranvåg, et al., 2020). We can see how this metaphor might fit the metaphor above concerning the persons with dementia and their informal caregivers living in a forest, which might at times feel impassable. An aspect that we did not mention in the article, but might be fitting to mention here, is that the coordinators also described how they had became aware of new support measures while they were taking part in the project, even though they had considearble experience in supporting and counseling persons with dementia and their families. This aspect may add to the picture of the conglomerate of available care and support as difficult to grasp and navigate within.

Within this forest, we find the persons with dementia striving to maintain their nests, their rhythms, their ‘being home’ in a life that is increasingly challenging and confusing (Aminzadeh et al., 2010; Fæø et al., 2019). Alongside them, to differing degress, are their informal caregivers, who strive to support their loved ones in a landscape that is unknown and continuously shifting. They also have the task of caring for themselves, sustaining their own ‘being home’, a combination that may be overwhelming (Bremer et al., 2015; Etters et al., 2008; Fæø, Tranvåg, et al., 2020). Then, we have the formal caregivers; they are either coordinators or are through other services set to care for and support the dyads. In the case of coordinators, we found in article 3 how the success of this task might depend on several factors (Fæø, Tranvåg, et al., 2020). These factors have also been emphasized, in differing degrees, by Backhouse, Richards et al. (2017) Bamford et al. (2014) and Khanassov et al. (2014b). First, the coordinator should know the forest, that is, know what support is available, what support might be most fitting for the individual at the moment and how to obtain this support (Backhouse, Richards, et al., 2017; Bamford et al., 2014; Khanassov et al., 2014b). This should also involve looking ahead, using their knowledge and experience on how the condition may progress and suggesting relevant support in good time (Fæø, Tranvåg, et al., 2020; Martinsen, 2006, 2012). Second, there is a need for some structural prerequisites, in terms of resources, time and flexibility within the coordinators' work situation to prioritize their 'pathfinding.' Here a 'pathway' that takes into account the complexity of the forest, and its differences between individuals, may be of help. This point also requires the possibility to uphold contact with the individual person with dementia in order to build a trusting relation (Backhouse, Richards, et al., 2017; Bamford et al., 2014; Fæø, Tranvåg, et al., 2020; Khanassov et al., 2014b). Third, there is also a need for a 'co-pathfinder,' someone to turn to when in doubt or when their role is challenging to fulfill (Fæø, Tranvåg, et al., 2020; McCance & McCormack, 2017). Finally, the coordinators need to understand the gravity of their task (Fæø, Tranvåg, et al., 2020): the ability to be emotionally involved, without being sentimental (Martinsen, 2006), and to view challenging emotions as a 'barometer,' something that may help them find the right way ahead, rather than disturbances. This involves the ability to go beyond what formally lies in their role '*because it's what she needs'* (Fæø, Tranvåg, et al., 2020). This refers to the ability to meet the other, either it is the person with dementia or their informal caregivers, with openness, seeing beyond predetermined categories and grasping and acting on the ethical demand that comes forth in each unique situation (Martinsen, 2006, 2012).

4.5.2 How to make what matter, matter

With these abilities we believe that a dedicated coordinator can help persons with dementia and their informal caregivers find a passable pathway for their lives and prolong their being home with dementia. First, by continuously exploring what matters for the individual; not necessarily by asking directly, but through open dialogue and curiosity about the person's life and values and exploring the construction of their 'home' (Fæø et al., 2019). Second, by empowering the individuals by exploring and going into dialogue about available means of care and support that might help make what matters, matter for the individual (Fæø, Bruvik, et al., 2020). Third, by putting relevant care and support into effect and coordinating implementation of these measures, in line with the individual person's needs and rhythms of life, thus supporting making what matters, matter for the individual (Fæø, Tranvåg, et al., 2020). This circular process is illustrated in Figure 3.

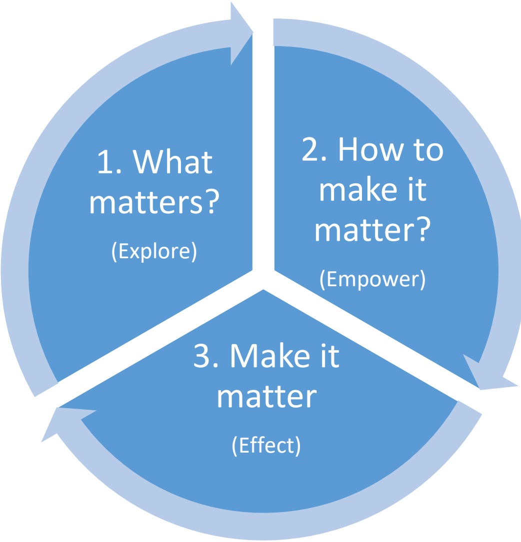

Figure 3: Process of exploring what matters and how to make it matter.

In this way, we believe the coordinators may be strengthened in their effort to support and empower persons with dementia to think and reflect on their own situation; to project and take initiative in their own lives; strengthening their personhood and status as an individual person; and support them in their effort of 'being home,' understood as living in a process of continuous settling and dwelling. Thus, perhaps some of the negative effects of the medical dementia condition in all of its etymological meanings may be reversed (Online Etymology Dictionary, 2020b).

Conclusion

In this project we have explored persons with dementia's experience of 'being home,' and their perception of relevant care and support. Further, we have explored how a coordinator may support dyads, consisting of home dwelling persons with dementia and their informal caregivers, and if a coordinator can contribute to increased empowerment and user participation in decision-making processes concerning this group. A hermeneutical methodology was chosen as a framework to explore the research questions. In line with this approach, the objective has been to gain new insights and expand our horizon of understanding on these phenomena.

We have explored various meanings of the home and how the home is affected by living with a progressing dementia condition. In the prolongation of this we have explored how being home is, or may be, affected by various means of care and support. Within these explorations we have found how all these aspects are complex and, as birds nests, intricately intertwined in individual weavings, or, perhaps, condensations. We have especially seen how minor details may be significant in how the persons perceive the care and support they receive.

Further, we have argued that this individual variety necessitates an increased focus on user participation in decision-making processes involving persons with dementia. In this regard, we have explored how the care philosophy of Kari Martinsen may serve as inspiration, in terms of seeing the other as an equal person, and meeting the other with openness for the others' particularity and needs outside of predetermined categories. These principles respond well to the principles of person-centered care on seeing the persons as individuals and attempt to see the world from their perspective.

Exploring the role of a coordinator, we found how these fulfilled three functions, that is being a safety net; being a pathfinder; and being a source for emotional care and support. We also found that having a trusting work environment, a flexible work situation and available resources was crucial for the coordinators to be able to fulfill their roles. Regarding the objective to increase empowerment and user participation for the persons with dementia, we found that the coordinator, in the form we explored, could contribute. Still, there is a need for further exploration of how to improve this function.

Implications for practice

Living with a dementia condition will, for most, involve being increasingly dependent on care and support from others. Making sure this care and support actually is caring and supporting requires careful attention, as minor details may be decisive in this regard. It requires curiosity about *'what matters'* for the individual and openness towards the possibility that the answers to this question might be found in hidden places. Living with a dementia condition will also, for many, involve reduced ability to comprehend complex information, to judge between alternatives or to communicate needs and wishes. Some may also be openly reluctant towards taking making challenging decisions. Such a reluctance should however not involve exclusion from participation in decision-making processes in general, or not taking the time to listen to the persons views and wishes. Therefore, the question of how to empower persons with dementia to take part in decision-making processes is crucial. Given the individual variance in needs, but not least in remaining strengths and resources, perhaps the question should also be more specified. Perhaps the question in each individual meeting should be: how can this unique person be empowered to take part? This requires seeing past the diagnose and the person's limitations, not seeing that other as a 'person with dementia' but as an equal person, and being open for the ethical demand that may come forth within the meeting. Then, to use professional knowledge to comply to this demand.

Such an approach requires a high level of competence and tact among the healthcare providers who are meeting the individual person. In addition, it requires healthcare systems that are flexible and trust-based, so that healthcare personnel have the required room to go into these meetings and act on the ethical demand with appropriate means. On the other hand it requires a certain degree of standardized and systematic follow-up to ensure that the persons do not run the risk of being subject to arbitrariness.

5.1 Future perspectives

In line with our findings and the research that exists in this field, we believe that a case manager or coordinator approach might be suitable as a starting point to increase user participation and adapt care and support to help the person being home – in a wide understanding of the word. We do, however, believe that such an approach needs to have the necessary flexibility to adjust to the various and shifting needs of the dyads receiving this support, the structural conditions in which it is organised and the coordinators resources. In this regard, we believe the LIVE trial might be an important contribution in acquiring new perspectives on how to arrange for this. It combines standardized, but adaptable basic components, in terms of learning, involvement of GPs in ACP and medication review and the coordinator within a flexible approach to innovation, volunteers and other relevant care and support.

We will also point to a need for further exploration of how to increase user participation in dementia care on a broader scale. User participation in deciding what support to receive is one thing, while the other is to have the opportunity to affect how the services are delivered as well. Thus, the term 'user participation' and what this entails also needs further exploration and clarification. This also entails exploring how to include the views and participation of persons with dementia in research concerning them, as a group. Similar to the call for 'fluidity' in research on case management and coordinator concepts, I will argue that research on user participation in dementia care also should be 'fluid.' Meaning that instead of focusing on standardized models, one should focus on identifying prerequisites and crucial components for user participation to take place, and explore and describe possibilities. Standardized approaches to obtain user participation for persons with dementia implicitly builds upon an assumption that these are persons who inherently are unable to take part on the same premisses as others and should be avoided.

Due to the complexities of this field, both on an individual and on a structural level, we recommend an open, curious approach in the meeting with each individual person, in the organization of care and support and in future research on these issues.

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Article 1

Fæø, S. E., Husebo, B. S., Bruvik, F. K., & Tranvåg, O. (2019). “We live as good a life as we can, in the situation we’re in” – the significance of the home as perceived by persons with dementia. *BMC Geriatrics, 19*(1).

Fæø *et al. BMC Geriatrics* (2019) 19:158
https://doi.org/10.1186/s12877-019-1171-6

BMC Geriatrics

RESEARCH ARTICLE Open Access

"We live as good a life as we can, in the situation we're in" – the significance of the home as perceived by persons with dementia

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Abstract

Background: The coming years will see more persons with dementia living longer at home. However, "the home" is a complex concept with a multitude of meanings, varying among individuals and raising ethical and practical dilemmas in the support provided for this group. This study aims to increase the understanding of experiences and attitudes among persons with dementia related to living at home.

Methods: Qualitative interviews were conducted with 12 persons, 69 to 89 years old, with a dementia diagnosis and living at home. Using a hermeneutical approach, the interviews were analysed as single texts, as parts of a set of texts and as a whole single text. The writings of care philosopher Kari Martinsen on "The home" were chosen as a framework for the theoretical interpretation of the findings.

Results: The participants experienced a vital interconnectedness between the home and their lives, placing their home as a core foundation for life. Through stories of persisting love, they illuminated how their lived lives functioned as a foundation for their homes. Further, they described how progressing dementia disturbed rhythms of life at home, forcing them to adapt and change their routines and rhythms in life. Finally, in the hope of an enhanced future home the participants showed an acceptance of, but also a reluctance to, the prospect of having to move out of their homes at some future point.

Conclusion: The study suggests that the participants' home generated existential meaning for the participating persons with dementia. Their experience of being at home was based on a variety of individual factors working together in various ways. These findings imply a need to understand what factors are important for the individual, as well as how these factors interact in order to provide support for this group of people.

Keywords: Dementia, Home, Home-dwelling, Qualitative, Interview, Care philosophy, Hermeneutics

Background

The world's population is getting older, and the number of persons with dementia is growing rapidly. Dementia has social, economic, and emotional consequences for the people who live with it, for their families and for the health systems that support them [1]. Many persons with dementia live in their own home, which is recognized as a place to retain independence and autonomy, quality of life and functions in activities of daily living [2]. As memory problems and difficulties in orientation and sensation are common, the safety and predictability of a familiar environment is crucial. However, as dementia progresses, the increased need for care and safety measures, makes continued living at home a potential safety risk for this group of people [3]. In addition, dementia-related neuropsychiatric symptoms such as apathy, agitation, depression or sleep disturbances may be increasingly challenging for informal and formal caregivers. In sum, these challenges makes dementia the most common reason for nursing

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home admission, regardless of the individuals' living situation [1, 4].

Although the need for objective security is paramount, nursing home admission may compromise the persons' autonomy and independence, as well as inflict emotional strain and reduce their sense of safety [5]. Many persons with dementia are institutionalized contrary to their own wishes to stay at home [1] and often nursing home admission represents a demarcation as *"the beginning of the end"* [6]. A meta-synthesis of previous studies investigating experience of lived space among community-dwelling persons with dementia [6] shows that *"living with dementia is like living in a space where the walls keep closing in"*. This research indicates that individuals living with dementia may experience that "lived space" diminishes over time, while dementia progresses.

Others highlight narratives of these people longing for and asking to come home, even though they are physically in the home they have lived all their lives [7]. This indicates how the experience of being at home may be detached from being physically present in the home. Likewise Aminzadeh et al. [8] describe how negative and positive emotions connected to home gradually increase for persons with dementia, leading to a disruption in their "emotional home".

Especially vulnerable are persons with dementia living alone, who have been shown to experience a sense of losing time [9] and living in a vague existence, followed by loneliness and forgetfulness [10]. A meta-synthesis on quality of life among persons with dementia found sense of place, understood as experiencing a meaningful attachment to the current environment, to be a critical concept [11].

A distinction between being at home physically and being at home emotionally or existentially is common in the literature on dementia [6–8, 12] and in health and care sciences in general [13–17]. In this literature, there is also an understanding of being at home as a progressive process [15, 16]. Care philosopher Kari Martinsen [18] makes a distinction between inhabiting and dwelling, understood as the difference between being physically present in ones' home and 'being' at home, in the existential sense. Building upon phenomenological philosophy, Martinsen's writings on the home maintain the idea that being at home, understood as dwelling, is a fundamental way of being in the world and interpreting life. Dwelling is founded upon a sensation of being free, secure, and at peace. It implies taking care of and preserving one's home, its surroundings and the other dwellers of the house. Furthermore, it means to form the rhythms of one's habits in interaction with others and with the constraints of the house and its environs. Drawing further on the metaphor of rhythms, Martinsen claims that a home has a tone and a song. The task of the health care professional, according to Martinsen, is to find this tone, attune to it, and help maintain the harmony of the home.

The growing literature on the experiences of home-dwelling persons with dementia reveals increasing complexity and variety, calling for more individualized approaches in dementia care. Although qualities of the home have been identified, there is still sparse knowledge on how this varies between individuals. By letting empirical data go into dialogue with theory on the home in a perspective of care philosophy, the study further aimed to provide principles for health care personnel within dementia care. The study addresses the following research questions: (1) How do persons with dementia describe the meaning of home? (2) How do persons with dementia describe their perceptions of living at home – in the present, and in the future?

Methods

For this study we chose an exploratory design founded upon hermeneutical methodology [19] using semi-structured interviews as a tool for data collection.

Participants and recruitment

Participants were recruited at four day-care centres for persons with dementia in a large Norwegian municipality. The following inclusion criteria were formulated: age above 65 years; having a formal dementia diagnosis; being able and willing to participate in an interview-conversation and to consent to such participation. Health-care personnel at the day-care centres assessed the persons' ability to participate and to consent in accordance with the Norwegian Patients' Rights Act [20]. Thirteen participants were recruited to the study. However, one participant withdrew at the day of the interview. Thus, twelve participants, six women and six men, between 69 and 89 years old participated in the study. Half of the participants lived alone, while the other half lived with a spouse. Three participants still lived in the houses they had lived most of their grown lives, the rest had at some point moved to smaller, more convenient apartments.

Data collection

One fundamental principle in hermeneutical methodology is that knowledge and understanding are founded on a contextual perspective. Our understanding of a phenomenon is shaped within the surrounding tradition we are part of. This means that understanding the present is founded upon the persons understanding of the world brought along from the past [19]. Consequently, researchers' pre-understanding will influence the understanding of the phenomenon under investigation. In this study, all researchers had clinical background as a nurse or medical doctor with experience in caring for persons with dementia from home care, nursing homes, hospitals or psychiatric wards. Literature reviews of previous research presented above, and various theories were discussed and taken in to consideration as possible theoretical frameworks for this study. Gadamer [19] recommends an open approach in meeting the other and in acquiring new knowledge. Being asked questions one is unable to answer, may be demanding and lead to unease and insecurity. Openness in questions is therefore particularly recommended in communication with persons with dementia to establish a safe environment and sustain the persons' integrity [7]. The research team developed a thematic interview guide of open questions such as: "Can you tell me something about yourself?"; "Can you tell me something about your home?"; "Do you have any thoughts on the future?" To ensure openness, the interviewer (first author) aimed at arranging the interviews as conversations rather than sessions of questions and answers. The interview-guide was thus shortened to a short-form keyword note for use in the interview. This was done both to keep disturbances at a minimum and to avoid rigidity. Thus, the participants were not necessarily asked the exact same questions, but all interviews touched into the same overarching themes. These themes were: the participants' background; their former and present homes; thoughts on living with dementia; family and informal caregivers; challenges in everyday life; views on the future and end-of-life perspectives. In addition, the participants were asked to describe their perspectives on receiving different support measures. Findings from this part of the interviews are not included in this article. A fundamental aim in the interviews was to gain insight into the participants' experiences and attitudes. All interviews were conducted in a safe and familiar environment either at the participants' home or at the day-care centres, according to the participants' wishes. Caregivers were present during parts or the whole of some interviews on the wish of the participant. The interviewer (first author) paid close attention to the participants' reactions on questions and wordings during the interview to continuously adjust the interview so as to avoid distress. For example, some participants were quite open about having dementia and had no problems on answering *"I don't remember"* if this was the case. This allowed for the use of closed probing questions to pursue interesting topics. Others showed signs of distress if they were unable to answer. On these occasions the interviewer aimed at opening up the questions as much as possible, letting the desire for more information yield to a respect for the participants' integrity. The duration of the interviews varied between 32 and 95 min.

Analysis and interpretation

The interviews were audio-recorded and the interviewer successively transcribed all interviews verbatim and performed initial analyses. The first and last author performed deep analysis on each interview, first separately and then discussing their findings interview by interview, discussing each interview individually, each interview in relation to all the interviews and all the interviews as a whole. Meetings with the other co-authors who shared their perspectives contributed to these conversations. Through the analysis, care philosopher Kari Martinsen's interpretation of the concept of dwelling proved to be a valuable contribution toward our understanding of the collected empirical data. The interpretive process involved moving in circles between understanding the particular and the general, theory and empirical data, following a hermeneutic methodology of interpretive understanding [19]. In this process, data and interpretive understanding of data was also discussed employing user involvement, that is, in-depth dialogues with a co-researcher having several years of user experience as a caregiver for a home-dwelling person with dementia.

Ethics

Healthcare personnel at the day-care centres provided eligible participants with written and oral information about the study. Where available, caregivers were informed by health care personnel or a researcher. Moral sensitivity issues were widely discussed among the authors in preparation for the study [21]. Immediately before the interviews, all participants were reminded of the purpose of the interviews, of procedures regarding the recording and treatment of data as well as their right to withdraw from the study at any time without any consequences. Health care personnel at the day-care centres were encouraged to observe and follow up the participants afterwards. The Regional Committee for Medical and Health Research Ethics, Western Norway (Project number 2016/1630) approved the study.

Results

The study identified two main themes on each of the two research questions. On the meaning of home, we identified the themes *home as a foundation for lived life*, and *persistent love – lived life as a foundation for being home*. Exploring the participants' experiences of living at home with dementia we found that living with dementia progressively required adjustments and caused *disturbed rhythms in life at home*. Finally, the participants expressed their *hopes for the future home*, revealing a reluctance towards the thought of being admitted to a nursing home, although they accepted the fact that this may become necessary. In the result presentation below, participant quotes are marked with age-ranges to ensure anonymity.

Home as a foundation for lived life

All participants described how old age, declining health and dementia had created challenges in their everyday lives. Nevertheless, their immediate response on questions concerning their overall life situation was more or less unanimous:

> *"I think I must say that we live as good a life as we can, in the situation we're in." Man (age 80–84), living with spouse.*

This sense of content despite challenges was characteristic for all participants throughout the interviews. Accompanying this fundamental drive to emphasise the positive sides of life was an expressed wish to stay at home as long as possible, often communicated with complete naturalness:

> *"You know, if I had to move away from home, it would be awful! You know, I do manage on my own. Getting to bed, getting up, getting dressed, even washing myself. I think there is safety in being where you have kind of grown up. (…) Home is home and I am used to doing things there and you know… so life goes on sort of automatically. 'So ist das Leben…'". Woman (age 85–89), living alone.*

Participants underlined how their homes were a place for autonomy as well as a representation of autonomy; at home, they could do what they wanted, at the time and pace that suited them, enjoying the privilege of having a home of ones' own. Moreover, living at home supported them sustain basic activities of daily life through declining health, in harmony with the constraints and opportunities of the house they lived in, and to find joy in these simple habits. An experienced housewife explained in detail how she would prepare the day's dinner, and how meaningful this was to her, further exclaiming:

> *"I'm just looking forward to doing this, I think it's great! … I want to have something to do, domestic things, such as doing the laundry, the dishes, making some food. You know, I make breakfast and supper for myself; I've done that all the time. And then, it's a feast every day, when I'm preparing food for myself, alone. Yes, it's something grand." Woman (age 80–84), living alone.*

This freedom to dwell in the habits, to enjoy the small feasts of everyday life, and find joy in necessary routines of life, seemed to be a fundamental aspect of the participants' daily living. Several participants described how they at some point had given up living in larger houses for a smaller and more convenient apartment. The timeframe and reasons for moving varied. Still, many wanted to describe their earlier homes, both from childhood and adulthood with their own children. In these former homes, they had their memories and their pride in having created a home of their own. Thus, their former homes represented an identity marker for themselves, for their children, and for the family as such. Several described how they tried to transfer the qualities of their former homes to their new apartment, to create continuity:

> *"I've got some decorative shrubs that should have been cut as spring is coming. That's that. But I can do it. If I have some shears I just cut, such nice statues, they stand there in green, you know. Well, now they are not so green, no. Yeah, I like to arrange the garden, I do. And they praised the garden I left. People in the whole area would take walks, quite often, just to see how nice it looked." Woman (age 80–84), living alone.*

This woman had been praised for her garden and although she knew her little garden plot now could no longer compare to her former garden, it was important for her to keep it as best she could. Thus, she adjusted her habits in accordance with the possibilities offered by the garden of the home she now inhabited. In this way, she was able to retain part of her identity and preserve a sense of continuity. Another participant, also living in an apartment, paid little attention to this present home, but continuously switched the focus to his country house on the farm where he grew up:

> *If I'm in the countryside I go out, saw some logs, chop up wood, real birch wood. And if I get tired of that, I can go fishing in the boat. We've got this country house and if we're bored we go to the country. … My sons-in-law are often in the country and they ask "Do you want to come with us to the country?" "Yes!" Man (age 85–89), living with spouse.*

For this participant, it was not the country house per se, that was important, but the activities and habits related to maintaining the household, like chopping wood and fishing. Activities involving the necessities of life from his childhood now continued as pastimes.

> *"It was a splendid time to grow up during the war, when food was scarce. It was grand to have a farm. People came and got to buy milk, and they got to buy butter, we separated milk and made butter. So it was grand, it was. Not everyone had a farm in those days." Man (age 85–89), living with spouse.*

Having had a home, with resources acquired through hard work to provide for others around them, not only for themselves, turned memories of hard times into memories of "*splendid times.*" Being able to return to this home, resuming the hard work as leisure activities helped sustain the feeling of being home. Being at home for this participant had little to do with the flat he inhabited. Instead, he related his sense of being at home to enjoying nature and outdoor activities devoted to providing life necessities. Here he could sustain his habits and the life in which he could feel at home.

Persistent love – lived life as a foundation for being home

All participants shared stories of the relational aspects of the home, from their childhood, from the time of when they were parents themselves or of important persons in their lives at the time. For those still living with their spouse, the marital relationship represented a fundamental safety and an anchor in a time characterized by changes.

> *"My wife and I, we've had – and still have – a long and good life together. Which is quite… in the present situation … Things work out fine, you know, and she supports me in the best manner (laughter). Yes, of course a lot falls on her, I can see that clearly… And it's, from daily food and cleaning and errands and such, that she has to take care of… My wife keeps everything, the clothes and house and home in order. Totally perfect." Man (age 80–84), living with spouse.*

Although most married participants expressed a sense of worry due to an increased burden for their spouse, they still described a good married life and a sense of pride in living together in their home. Having a caring spouse who takes on the main responsibility of the household despite the increased burden, seemed crucial. Moreover, the unity in marriage was emphasized as a quality of the home as such. The home served as a foundation for their married life, at the same time as their married life served as a foundation for their home. Among those participants living alone, some still found a relational foundation in their homes. A woman widowed for some four years expressed a feeling of her husband still being a part of the home, and sensing his presence in times of despair and anxiety. Especially when having trouble finding displaced items*:*

> *"Then I frequently cry out for my husband up there. And, well, then I find what I'm looking for, and I say "thank you very much" … my husband lived there, and in a way, he still lives there. … It would have been different if he hadn't lived there. Then I think it would have been easier to move." Woman (age 85–89), living alone.*

Thus, the emotional ties to her apartment went beyond mere memories and perhaps passing a limit to a transcendental sphere. She described this sensation of his presence in the apartment as crucial for her ability to cope in everyday life. Another woman, whose husband lived in a nursing home, expressed how his physical presence elsewhere seemed to strengthen his absence.

> *"I like it (the apartment) very much, only he is missing. His bed is still there. I use to tell him: "I call for you in the night" … If he could have come home, that would have been lovely. I'm not worried about how things would have been, we would have made it". Woman (age 80–84), living alone.*

While both these women living with dementia called out for their husbands – The latter woman's feeling of loneliness seemed to be made more acute by the knowledge that her husband was a resident in a nursing home. However, the hope of getting him back home seemed to be a motivation for her to continue her routines in daily life:

> *"But if (husband) comes, then I have to make dinner for him… Then we would be together, it's like, it has so much to say to me, that it was one with me. If you're in doubt about something yourself, you can ask and get an answer. Here there is no one; I've got no one to ask of anything. That is the grand thing." Woman (age 80–84), living alone.*

Staying at home represented a prolonging of what once was and being at home sustained a hope for what might still be. For these women, moving away from home would not only mean a moving away from the known and safe and giving up the autonomy represented by the home. It would also mean taking a further step away from the life once shared with a loved one. Although parted from their husbands, they could still hold on to the dwelling place as an expression of their love. In addition to illuminating the relational aspects of the home, these stories of persisting love reveal how the meaning of the home builds on a foundation of lived life.

Disturbed rhythms in life at home

The perspectives on living with dementia at home varied, as did the willingness to talk more specifically about how the symptoms affected their life. The stories that unfolded, revealed a wide range of challenges in their daily life at home:

> *"The worst part today is if I can't find the money, other valuables, and just... not finding something I need." Woman (age 85–89), living alone.*

> *"And then suddenly I've got troubles with that (points to stove). With temperatures and such." Woman (age 75–79), living with spouse.*

> *"When we talk about: we were there and there, then and then. Who were with us and that kind of thing. Thinking about who it was, you know, that's where I slip." Woman (age 80–84), living alone.*

> *"I get up in the middle of the night and get dressed and am on my way out." Man (age 85–89), living with spouse.*

> *"In my time, I knew all the streets, and I could tell you where you could find them, and I have no clue where they are today. So, I have lost that." Woman (age 85–89), living alone.*

The dementia condition created a disturbance in their daily living. It affected the way they organized their life, the continuity in routines, their ability to follow conversations, their preparedness to recognize and go to see places previously familiar to them. In this way, living with dementia affected their choice of actions, their relations to others as well as their outdoor activities. In sum, it influenced how they related to and dwelled in the world, in their daily life at home. Although they perceived their dementia symptoms as being minor and trivial, these symptoms deeply affected the participants' habits, rhythms and relation to their home. They had to form new habits and routines in everyday life. Some also described a tendency for the home, gradually, taking on aspects of confinement. Several participants referred to weather conditions, in combination with health related issues, as factors keeping them from going outside. However, on further probing, reasons for not going out took on forms that were more complex:

> *"But I'm always saying to myself: "Tuesday, I'm having a day off (from day-care centre). Then I think I shall take a trip into town. Yes, I shall do that." Then comes Tuesday… No, either it's raining or, no… and then you don't go. "No, but next Tuesday I can go, or maybe the nex day, this or that day" but I'm not going that day either. But if it is.. it might be something, yes, I can go to the hairdresser. But I have, should have gone, been to the hairdresser a long time ago, but I haven't done that either. But I should. (Interviewer: But what do you do instead?) No, mostly, I just sit in a chair, sleeping… very long days." Woman (age 85–89), living alone.*

This description reveals traces of an ambivalence in daily life at home. The participant had a wish, or at least an intention to go out, but for reasons she had difficulty expressing, she remained at home. She touched on dementia-related themes such as anxiety and weakened initiative, but also bad weather as explanations for not going out. Despite good intentions, she remained at home, although this led to long days, sleeping in a chair. Thus, the home seemed to serve as both a self-imposed confinement as well as a shelter.

Hopes for the future home

As seen, all participants had strong connections to their homes, in different forms and with differing ties. The wish to stay at home as long as possible stood strong. However, all participants were equally aware that at some point, nursing home admission might be necessary, and that if that time comes, they would have to accept it.

> *"I want to be at home as long as I can, but at the moment my family says that… you know, it's not certain that I will be capable of judging that I am no longer able to stay at home. But, if then, my son or daughter says, "Now, mother, now you can't be alone anymore; now you have to go to some home," of course, then I'll have to listen. Because I can't, at least I still understand that much. What I understand later I don't know… But I think that, because I am prepared for it and if you're prepared for it beforehand, then I think it be alright, you know. I hope so." Woman (age 85–89), living alone.*

This woman trusted her family to be able to judge whether she should continue to live at home. Further she emphasized the strength in being mentally prepared for what may come. Although she reflected on the possibility that this "preparedness" might diminish along with her lacking ability to manage alone, it seemed to give her some assurance in the present. Most shared this perception of the nursing home as a necessary resource at some point, but not without some reservations. The same woman added:

> *"But you know, one might be so lucky that one might be spared from all that. So, we'll see how it goes." Woman (age 85–89), living alone.*

Several participants shared this underlying notion of a hope of *"being spared"* from a fate of a necessary admission to a nursing home. Some already had experienced short-term stays in nursing homes, and said that they understood the necessity of this at the time. However, they emphasized how short-term stays had taught them that nursing home living differed from living at home:

> *"You know, I have lived over there, where you could see those people just sitting in a chair. I lived there for a short while, but they understood quickly that I didn't enjoy it. … I wanted so much to bring a carpet, to get a cosier atmosphere. But that wasn't quite a "comme il faut" thing to do. Because, no, it wasn't right. Probably it was that you might… you know, you might slip. And I would claim that I couldn't, but of course, I understood… So that, I think it was a little much like that. And then they didn't come in that often, to talk to me if I was in the room and…". Woman (age 85–89), living alone*

She was not allowed to bring a carpet, as part of her own belongings and as a way of putting a personal mark on her room. Not only did she have to adapt to other habits and routines, she also had to adapt to the rhythms and routines of others. Several participants shared this experience of loss of autonomy and lack of homeliness in the nursing home setting. Whereas the home represented autonomy and identity, the nursing home represented its opposite. However, although reluctant towards nursing home admission, some participants also had some conditions for being able to stay at home as well. Although they described an aversion towards nursing homes, one participant, when asked what she would do if she was no longer able to attend the day-care centre anymore, exclaimed:

> *"No, at that point I would realize that that's it…". Woman (age 85–89), living alone*

This woman was quite lonely and depended on social contact through the day-care centre. However strong her attachment to her home was, her will to stay at home depended on an external factor. This once again reveals how the experience of being at home may extend the boundaries of the physical house.

Discussion

The participants' descriptions of the meaning of home varied. A common trait was the role that the home played and had played in their lives, how long they had lived there, with whom they lived or had lived there, the geographical location, the practical design, the familiar interior design and decor. Within this totality of the home, the participants lived and spent their lives in accordance with the possibilities and limitations offered thereby illustrating the theme *home as a foundation for life.* Correspondingly, they shared stories about how their lived lives had laid the foundation for the home becoming what it was, illustrated through their descriptions of the importance of loving relationships revealing the significance of *persisting love – lived life as a foundation for the home.* Their descriptions of how dementia influenced their lives and forced them to reform their habits and routines led to *disturbed rhythms at home.* The theme *hopes for the future home* revealed the participants' reflections on living at home in the time to come.

As a fundament for life, the home was seen as a place to sustain life necessities through activities of daily living; a home base for meaningful activities and enjoying nature, and a site filled with memories, representing lived life and persisting love. It was seen as the place where they were *"used to doing things … so life goes on sort of automatically".* Similarly, Aminzadeh et al. [8] found that the home served a multitude of purposes for persons with dementia, ranging from being a retreat, as a representation of autonomy and a site for maintaining functional competence to a place for expressing personal values and being a repository for memories. Sustaining these qualities of the home are in line with the primary foundations for dignity preserving dementia care, as described by Tranvåg et al. [22].

In the same way, the participants revealed how their lived life served as a foundation for their home. Through stories of persisting love, despite illness, absence and even death, the participants illustrated how memories, hopes, and support, each in its own way, connected them to their home and served as a resource for continuing to live at home. The quote that *"my husband lived there, and in a way, he still lives there"* illustrates the strong connection between the woman's memories, the sensation of her husband being present and the physical apartment. Thus, we can find a reciprocity between life and the home, each mutually dependant on the other. We also found a reciprocity in the descriptions of how the home served as a foundation for the participants' marriage at the same time as their marriage served as a foundation for their home.

According to Martinsen [18], there is a reciprocal dependency between the person, the house, the world in which the house is situated and the things the house contains. The participants' descriptions illuminate how the respective perceived meaning of the home consists of various interdependent factors. In the example of the fisherman, his sense of being at home depended upon several factors: the country house, his sons-in-law taking him there, the natural surroundings, having the necessary equipment and being himself able to do the actual fishing. This interaction between differing factors is also shown in a meta-ethnography by Han et al. [23]. They describe how people around the person through simple organizational measures may help the persons with dementia to maintain both meaningful activities and also the relations to those involved. This kind of organization makes activities meaningful through interaction, meeting relational needs for the person with dementia.

Central in Martinsen's [18] writings is the idea that human beings shapes their lives into rhythms, in accordance with their needs and the constraints and possibilities of their surrounding environment. Becoming familiar and intimate with the house, the things and the outside world contributes to bolster identity, to find one's place and rhythm in the world – to sustain life, be at peace and create meaning. We find these rhythms in the participants' stories: doing household tasks, orienting themselves inside and outside the apartment, going fishing, tending the garden, holding on to relations and dwelling in good memories. The participants pointed out these simple, basic rhythms as crucial for their ability to keep on living at home, and to be at home as a way of being in the world. Thus, their home functioned as a foundation for living their lives on an ontological level.

Living in these interwoven rhythms is the foundation for Martinsen's concept of dwelling in a home, in contrast to merely inhabiting a house [18]. The findings underline the understanding of dwelling as a continuous process in continuous change as life takes its twists and turns, and this supports the findings of Zingmark [16] and Molony [15]. Accordingly, Martinsen [18] remarks how one is bound to the house and at the same time constantly moving and changing. Although Martinsen did not specifically write on dementia, she describes how illness and disease disturbs the notion of being at home and the rhythms that maintain its structure. Similarly, the participants in this study told of several changes and losses in life that had caused disturbances in these rhythms. With advancing age, the frequency of these changes changed, and with progressing dementia, even more so. Their surroundings, relations, physical and cognitive functions, their ability to handle familiar things, even their relation to the rhythms of day and night had changed and disturbed their sense of freedom and being at peace in their home. In line with the findings of Forsund et al. [6], their lived space became smaller leading to *"very long days."* In a meta-synthesis on the experience of relations in persons with dementia, Eriksen et al. [24] found that persons with dementia experience severe changes in life causing changes in relations. The main categories, being disconnected, being dependent, being a burden and being treated illustrates the sense of degradation in roles and status following dementia.

Despite these disturbances, the participants of the present study described how they would hold on to their rhythms as best they could. Again, the means of holding on to the rhythms varied according to the situations described, their abilities, resources, environment and relations. It was by doing *"these domestic things"* as well as possible, or *"tending the garden"*. For another it was by *"chopping up wood"* or *"fishing in the boat"*. One had a spouse who maintained the rhythms of the dwelling, keeping the house *"totally perfect"*, while yet another found strength in calling *"for my husband up there,"* to re-establish the rhythms when disrupted by distress. In these ways, the participants continuously adapted to the ongoing disturbances.

These perspectives provide as a backdrop for understanding the participants' hopes for a future home. However strong their connection was to their current home, and regardless of what this connection was founded upon, they were aware that as dementia progressed, their ability to withhold their rhythms and to maintain the house as "the home", would not last forever. Thus, they were aware that at some point, they might have to move away from their home. Still, they underlined some important aspects related to these *hopes for the future home.* First, they stressed their reliance on their family to be able to make the decision for them. Second, they emphasized the importance of being prepared. Together, these aspects signal a need for constructive planning ahead for the future with a cooperative effort between the persons with dementia and their caregivers, for example through the use of advance care planning (ACP) [25]. Furthermore, the participants underlined the need to be able to maintain the qualities of the home, including in the nursing home, as illustrated by the woman who wanted to bring a carpet to her short-term stay in order to *"get a cosier atmosphere"* – underscoring the need to understand how sense of home is a process to be prolonged when moving to new facilities.

Implications for future practice

Martinsen claims that to be able to help the other, it is essential to sense the other's tone, meeting the other with openness, unrestricted by categorisations and result orientation [18]. In this way, it is possible to perceive the other's rhythms, to ascertain in what ways the other is 'at home' as a manifestation of being in the world, and thus being able to provide the appropriate support. Emphasis on considering the persons habits, preferences and life history in person centred care is well established within dementia care [26]. The same accounts for the importance of the home [6]. If one considers being at home as an ongoing progression, the open meeting with the other should also be considered a constant process – enabling one to catch the changing rhythms, and to help the other sustain the tone of the house. This study has illustrated how progressing dementia may cause disturbances in the persons' rhythms at an increasing pace, thus disturbing the person's being at home as an existential foundation. To be able to support a person with dementia therefore implies a thorough knowledge of what makes up the person's notion of their home. This entails not only what the main components are but also how these are interwoven to form the conception of the persons' home. Furthermore, it is essential to understand what makes up the person's rhythms of life, to be able to sustain them, sense changes and maintain the tone of the home. We suggest implementation of ACP or similar plans in collaboration with general practitioners and municipal health care personnel as a natural response to a person getting a dementia diagnosis. Further, that the ACP follows the person with dementia through the stages of increasing care. In this way, we hypothesize that the person, at an early stage, will be given a chance to describe his or hers rhythms of life and how these makes out the existential conception of "home" and how this home may be maintained when the person is no longer able to account for this.

Limitations

The study is based upon single interviews with a limited number of persons from one municipality in Norway. Although gender, age, marital status, amount of support and general living conditions varied somewhat, the group was relatively homogeneous. Moreover, most interviews were brought to an end by the interviewer due to observed fatigue in the persons interviewed, indicating that a second interview with the same persons might provide additional depth to the material. As the same researcher performed all interviews, and because the interview guide was flexible, it is possible that other interviewers might have led the participants to emphasize other aspects. Likewise, more interviews might have brought new aspects to the material. However, during the successive initial analysis of the interviews, we experienced that new aspects served to underscore our understanding of the home as intertwined with the individuals' lived life, thus signalling a point of data saturation.

Conclusion

The objective of this study was to explore the perspectives of persons with dementia on living with dementia and living at home, now and in the future. The study revealed that the home had an existential importance for the participants: their home served as a foundation for their lives, and their lived life served as a foundation for their home in a continuously progressing process of dwelling. Dementia caused this progress to accelerate, disturbing their being at home and threatening their hopes for a future at home. What was important was not the home they lived in as such, but the role the home played within a larger existential foundation, as a place for memories, habits and relations. Finally, these differing factors were intricately interwoven in varying degrees and in varying ways from individual to individual. Understanding the construction of the individual's home should therefore be central in support of persons with dementia living at home and to support their sense of being at home in an existential perspective.

Abbreviations

ACP: Advanced care planning

Acknowledgements

We wish to thanks the participants for their willingness to share parts of their lives for this study. Further, we will thank the day-care centres for helping in recruiting participants, arranging interviews and follow-up afterwards. Rune Samdal has contributed with valuable user involvement, sharing his substantial reflections from the family caregiver perspective.

Authors' contributions

All authors contributed to the conception and design of the study. SEF had the main responsibility for recruitment, acquisition, analysis and interpretation of data and drafted the manuscript. OT contributed to the methodological approach and the deep analysis and interpretation of the data material, in addition to suggesting critical revisions of the article. BSH and FB contributed with insights during the data analysis and interpretation and in critical revisions made to the article. All authors have read and approved the final version of the manuscript.

Funding

Extrastiftelsen, with The Norwegian Women's Public Health Association as applicant organisation has funded the PhD-scholarship of SEF and thus the conduction of the study. BSH would like to thank the G.C. Rieber Foundation and the Norwegian Government for supporting our work at the Centre for Elderly and Nursing Home Medicine, University of Bergen, Norway.

Availability of data and materials

All empirical data (sound recordings and transcriptions) are stored on a secure server at the University of Bergen. Due to ethical concerns, the material is not publicly available. Data will be deleted at the end of the project.

Ethics approval and consent to participate

All participants received written and oral information on all aspects of the study and gave written consent to participation. The template for the consent form is available on request. The study was approved by the Regional Committee for Medical and Health Research Ethics, Western Norway. Reference: 2016/1630/REK vest.

Consent for publication

The participants has given their consent for publication of anonymized data from the study.

Competing interests

The authors declare that they have no competing interests.

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Received: 13 July 2018 Accepted: 29 May 2019

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Publisher's Note

Article 2

Fæø, S. E., Bruvik, F. K., Tranvag, O., & Husebo, B. (2020). Home-dwelling persons with dementia’s perception on assistive technology and other care support: A qualitative study. *Nursing Ethics, 27*(4), 991-1002.

Original Manuscript

Nursing Ethics
2020, Vol. 27(4) 991–1002

10.1177/0969733019893098
journals.sagepub.com/home/nej
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Home-dwelling persons with dementia's perception on care support: Qualitative study

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Abstract

Background: Over the last years, there has been a growth in care solutions aiming to support home-dwelling persons with dementia. Assistive technology and voluntarism have emerged as supplements to traditional homecare and daycare centers. However, patient participation is often lacking in decision-making processes, undermining ethical principles and basic human rights.

Research objective: This study explores the perceptions of persons with dementia toward assistive technology, volunteer support, homecare services, and daycare centers.

Research design: A hermeneutical approach was chosen for this study, using a semi-structured interview guide to allow for interviews in the form of open conversations.

Participants and research context: Twelve home-dwelling persons with dementia participated in the study. The participants were recruited through municipal daycare centers.

Ethical considerations: Interviews were facilitated within a safe environment, carefully conducted to safeguard the participants' integrity. The Regional Committee for Medical and Health Research Ethics, Western Norway (Project number 2016/1630) approved the study.

Findings: The participants shared a well of reflections on experience and attitudes toward the aspects explored. They described assistive technology as possibly beneficial, but pointed to several non-beneficial side effects. Likewise, they were hesitant toward volunteer support, depending on how this might fit their individual preferences. Homecare services were perceived as a necessary means of care, its benefits ascribed to a variety of aspects. Similarly, the participants' assessments of daycare centers relied on specific aspects, with high individual variety.

Discussion and conclusion: The study indicates that the margins between whether these specific care interventions were perceived as supportive or infringing may be small and details may have great effect on the persons' everyday life. This indicates that patient participation in decision-making processes for this group is—in addition to be a judicial and ethical requirement—crucial to ensure adequate care and support.

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Keywords
Assistive technology, decision making, dementia, hermeneutics, patient participation, volunteer support, care support, ethics

Introduction

The coming years will see a rapid increase in the number of persons with dementia.[1] The World Health Organization has labeled dementia a global public health priority and a growing number of nations are developing dedicated plans on how to provide adequate care and support for persons with dementia and their carers.[2] To meet these challenges, there has been a substantial growth in care solutions aiming to enable persons with dementia to live better and safer at home. Within governmental dementia plans, especially innovative assistive technology and increased emphasis on the potential within volunteer support have been defined as areas of commitment alongside the traditional homecare and daycare services.[3,4]

Various kinds of assistive technology have seen a massive growth during the past few years. These ranges from traditional safety alarms and stove guards to the more recent electronic pill dispensers, robots, and advanced sensor and monitoring technologies.[5,6] However, although perceived as useful for caregivers, technology that directly helps the person with dementia has proved challenging to implement,[7] and patients often face pressure on when and where to use such equipment.[6] In addition, to uphold social interaction and prevent isolation, there has been a growing emphasis on the use of volunteer support within dementia care.[3,4] However, there is limited research within this field and what exist indicates that it is challenging to optimize this kind of support.[8,9] As a baseline of care, access to homecare services, such as support in medication, personal hygiene, and nutrition, has been a clear demand from this group.[10] Alongside these services, daycare centers, providing meaningful activities is increasingly common, and research indicates several benefits for people living with dementia.[11–13]

Despite growing attention to new ways of thinking care and support for this group, evidence on what works to provide appropriate support is ambiguous. In a large systematic review, Dawson et al.[14] reveals that intervention studies in general show little or no effect on most outcomes, but highlight individualized and flexible care solutions as success factors. These findings are in line with the emphasis of individualized and person-centered care for persons with dementia as this concept has evolved for almost 30 years.[15] Still, insufficient acknowledgment of the complexity of the field and lack of knowledge of the perspectives of persons with dementia and their informal caregivers are described as weaknesses in the evidence base.[14] Lack of patient participation is widely reported within dementia care and persons with dementia experience exclusion from decision-making processes considering their own care often without proper assessment of their capacity to such participation.[16,17] Often, family caregivers or healthcare personnel make these decisions *for* the patient, even when the person with dementia has expressed alternative wishes. However, Elliott et al.[18] state that knowing the person's life story and planning enable caregivers to make choices in line with the person's wishes. As depending on help from others in itself poses as a threat of feeling inferior as a human being,[19] being left out from decision making further constitutes a threat of marginalization and exclusion for persons with dementia.[20] The patients' right to participate in these kinds of processes are considered a basic human right and the United Nations has criticized the denying of these rights based on diagnosis or standardized assessments of mental capacity. Rather, healthcare personnel are instructed to support the person to exercise their legal capacity in this matter.[21,22] This underscores the need for more knowledge about how home-dwelling persons with dementia perceive the support measures offered, how these care solutions influence their everyday life, and how to arrange for optimized patient participation within dementia care.

Aim

The aim of this study was to explore and describe the perceptions of home-dwelling persons with dementia on assistive technology, volunteer support, homecare services, and daycare centers. The following research questions were addressed: (1) How do persons with dementia describe their present and past experiences related to assistive technology, volunteer support, homecare services, and daycare centers? and (2) How do persons with dementia describe their attitudes toward receiving these support measures in the time to come? The overarching purpose was to increase our knowledge of the own perceptions of persons with dementia when given the opportunity to express their personal views.

Methods

A qualitative, exploratory design, based upon hermeneutical methodology was chosen for this study.

Participants and recruitment

Four daycare centers for persons with dementia helped recruit participants after the following inclusion criteria: having a registered dementia diagnosis according to the ICD-10 criteria[23] in their electronic journal, aged 65 years or above, living at home, and able and willing to consent to and participate in an interview conversation. To reduce sharing of sensitive patient data, healthcare personnel at the daycare centers assessed fulfillment of inclusion criteria. They also assessed ability to consent and participate based on an overall assessment of the participants' ability to comprehend and judge the potential risks and benefits of participation in accordance with the Norwegian Patients' Rights Act[24] and the Helsinki Declaration.[25] Thirteen people consented to participate in this study. Among these, one person withdrew due to an acute incident. The participants, six women and six men, were aged between 69 and 89 years old. Six of them were living alone and six were receiving homecare. All participants attended a daycare center and this was the site for recruitment to the study.

Data collection

The hermeneutical methodology rests upon the claim that all understanding and knowledge founds upon context and tradition.[26] This means that the researcher's pre-understanding, based on their own background and experience, will influence the study. This implies a need to reflect on how this pre-understanding affects all parts of the study, from design through conduction as well as during interpretation of the empirical data collected. The researchers in this study had clinical experience with care work for persons with dementia within homecare, nursing homes, hospitals, or psychiatric wards, as a nurse or medical doctor. When communicating with persons with dementia, open questions is recommended to safeguard the others' integrity.[27] Likewise, an open approach in the meeting is recommended within the hermeneutical tradition.[26] Therefore, an open and flexible interview guide was developed to give the interviews a form of open conversations, more than sessions of questions and answers. The interview conversations opened by letting the participants tell about themselves and exploring their perceptions and attitudes toward living at home, at the present time and in the future. Findings from this part of the interviews are published elsewhere—and focus on the significance of the home as such, as described by the participants.[28] The interviewer introduced the themes assistive technology, volunteer support, homecare, and daycare centers where this was natural in the conversation, to explore their own experience and attitudes. Initially, the participants often expressed difficulties in reflecting on measures they had no direct experiences with, but as the conversations evolved and they described challenges in everyday life, we came back to how different measures could help. Most often, they would then give comprehensive reflections on their attitudes toward these suggestions. When given time, space, and explanation, all participants shared substantial reflections on the themes of inquiry. All interviews were conducted either at the participants' home or at the daycare centers, at the wish of the participants.

Analysis and interpretation

All interviews were transcribed verbatim successively, followed by initial analysis of each interview as a single text. After the first two interviews, two of the authors (S.E.F. and O.T.) analyzed the texts to search for unexpected themes to follow up in further interviews and to critically examine the lapse of the interviews. This process was repeated with all researchers participating after five interviews. After all interviews were transcribed, two of the authors (S.E.F. and O.T.) analyzed each interview as single texts, first separately, then in dialogue. Thereafter, the whole research group repeated this process. All texts were then explored as a whole, increasing our understanding of each interview, as well as of the entire text as a whole. Underway, we discussed various theoretical frameworks and how these could potentially lead to additional understanding of the empirical data. In line with hermeneutical principles for interpretive understanding, this circular interpretive movement between the individual texts and the text as a whole characterized the analytical process, which lasted throughout the writing process.[29]

Ethics

Eligible participants were provided with written and oral information about the study by healthcare personnel at the daycare centers, and all participants gave written consent to participate. Information on the purpose of the interview, recording, and data treatment were repeated immediately before every interview along with information on the right to withdraw at any time, without any consequences. Issues of moral sensitivity[27] were highlighted and discussed while preparing the study, and the interviewer paid close attention to the participants' reactions during the interview to avoid distress. Wordings and degree of probing were constantly adjusted to make sure that the participant felt comfortable in the situation. Some participants also had a family caregiver present during the whole or parts of the interviews. Healthcare personnel were encouraged to follow up the participant after the interview. Signs of unease after the interviews were reported in a few participants, but most reported feedbacks of the interviews as a positive experience. All data have been de-identified and are confidentially treated. The study was approved by The Regional Committee for Medical and Health Research Ethics, Western Norway (Project number 2016/1630).

Results

Assistive technology—safety with side effects

The participants expressed few experiences with or knowledge about assistive technology. Two participants had a stove guard and one had a safety alarm. The participant having a safety alarm expressed how this made her feel safe at home: "I think it's safe and good to have. But I have never used it. No, that's why I use it, (laughs)" (woman, 89). Although she had never needed to use the alarm, she put it to good use as a safety measure, knowing that she could get in touch with help in a case of emergency. The feeling of safety was also emphasized by one participant, considering the stove guard:

> I've got one of these . . . blinking on the wall, if I forget (the stove). Yeah, it turns off . . . But I can hear it at once, you know, and then I get the shivers . . . Oh, it's creepy! (Woman, 82)

The sound of the stove guard made her shudder at the thought of what might have happened. Knowing it would turn off the stove should she forget made her feel safe. However, the other participant with a stove guard had quite a different perception of how this affected her everyday life:

> No, now I won't be doing any more baking. I've got something called "Anna" on the stove because . . . It ruined the whole stove. It turns on and off at its own will. Suddenly it starts howling and a red light appears . . . It was the most foolish thing ever done . . . It was done with good intentions; it was the best to me. But I don't think so. . . . (Woman, 87)

Her lacking competency in handling the stove guard had removed her opportunity to bake, and baking had been a meaningful activity for her. She understood why she had been given the device, but did not perceive its benefit as outweighing the side effect—namely, to be unable to handle the stove. In general, the participants' ability to handle technological equipment was an essential aspect in their attitudes toward these measures. One participant had an initial attitude that receiving assistive technology sounded "despairing." However, after having some possibilities explained to him, he changed attitudes slightly, but with a condition: "I guess it could be okay, but inherently, I can't handle it myself" (man, 83). The participant admitted the possibility that assistive technology might be beneficial, but he was also aware that he would not be able to learn how to operate new equipment.

Most participants shared this initial hesitation toward assistive technology but became more positive as possibilities were discussed. Still, most of them expressed some form of reservations. One woman was quite positive to the possibility of receiving an electronic pill dispenser because she had a wish to reduce the number of visits from homecare services. However, her attitude changed when she was told that the device would "beep" to indicate when it was time to take the medicines: "No, I don't want that beeping!" (woman, 82). The remark was followed by a story about how beeping alarms and the likes would confuse and agitate her. She was adamant that the positive aspects of such a device could not outweigh her antipathy toward its side effects.

Volunteer support—the complexity of preferences

Only one participant had direct experience with volunteer support. She had been assigned a volunteer to help her keep up her interest in going for walks. However, the arrangement did not work out as she had hoped:

> Yes, a lady came and talked . . . and talked and talked, (laughs). It was nice, you know, but there was no walking . . . because she just wanted to sit and talk. (Woman, 82)

We cannot know the intention behind this first meeting. Nevertheless, the woman had expected to go for a walk and was disappointed. She was able to laugh about it, but the quote reveals a vulnerability in building expectations on how support should function. Another participant described how he wanted things to be, as the conversation turned to the theme:

> You know, there are a lot of single people who would have liked to have someone to talk to . . . We could be together, two or three persons; there is room for that, both in the living room and on the patio. (Man, 87)

This man, who lived relatively isolated, clearly envisioned how he and the volunteer(s) might benefit from getting together. However, similar to the hesitant attitude toward new and unknown technological devices, the participants also demonstrated the same attitude toward receiving volunteer support. As the conversations touched on activities that the participants no longer were practicing due to declining health, the interviewer would suggest a volunteer as a possible way to keep up these activities. One participant was positive toward having a volunteer in order to be more active, but having a volunteer to help him keep up the activity he loved most was out of the question:

> I'm not going hunting without a gun and not being able to shoot. Just tag along with someone who's hunting, that's . . . (Laughs), no! I've been hunting so much that . . . If I'm going hunting, it is me who is going hunting . . . I learned that from my father, a very good hunter. There was nothing social (about hunting). Hunting, that was one man against . . . (laughs). (Man, 69)

Hunting was a highly valued activity for this participant, connected with strong emotions involving what his father had taught him. These emotions associated with hunting made the proposal of partaking in a light version of hunting, following a volunteer hunter, almost a personal affront. This reveals that individualization may require more than simply asking about preferences and interests.

Homecare services—the diversity of care experience

Considering homecare, the participants had differing experience. Most of those living alone had homecare services for supervision of medicine use and nutrition. Most were happy with this arrangement, although they perceived the visits as being short and task oriented:

> You know, someone comes to me in the morning, to give me those pills. They chatter every time they see me, you know: "Have you been eating today? Have you had breakfast?" . . . It's good for us to have people like that. They watch over us. . . . You know, they're just stopping by, and then they have to fly off . . . But of course they are very nice and cheerful and smiling. So it's cozy, it is. (Woman, 82)

For this woman, the sense of being seen and taken care of seemed to be the primary perceived benefit of homecare. Even though the visits were short, these comforting and cheerful meetings seemed to brighten up her day. Another female participant, who was anxious about whether she had taken her medicines or not, emphasized the safety in having this taken care of for her.

> The home care service comes and delivers them (the pills) and sees to it that I take them, 'cause I'm so afraid that if they don't watch me . . . I can't be sure that I've taken them. (Woman, 87)

Knowing she would get the right medicines at the right time made her express a feeling of safety while living alone. Thus, although both women got mostly the same kind of support and were largely equally satisfied, they based their gratification on quite different aspects of the support. Among participants not receiving homecare, most were glad to manage without this support. All the while, they were aware that it might be necessary to accept such support in the future:

> For the time being, I've been able to manage on my own, but of course it might be relevant . . . If I need more help, I might be lucky and get something . . . I sort of feel that it's best to ignore it. Because now I know nothing about how it's gonna be, and then I guess it's important to enjoy the time one has left. (Woman, 86)

The participant expressed a wish to cope at home without support as long as possible and tried not to think about having to accept homecare support at some point in the future. Presently, the main focus was on enjoying the here-and-now, not worrying too much about the future. At the same time, the participant realized this possibility and hoped the help would be available when needed—a perspective shared by most of the study participants.

Daycare centers—it's all in the details

All participants had thoughts on the respective daycare centers they were attending. While some had attended their daycare center for several years, others had just started. Likewise, the frequency of attendance varied from 1 to 4 days a week. Most had a positive view of these centers as a place that offered them the opportunity of broaden their everyday environment, as well as sharing meals and activities with others. A woman described how the personnel of the daycare center gave her a personal invitation while she was having an unpleasant stay on a short-term ward:

> There I found my place. I'm very enthused about both of them (personnel) . . . It was what I needed at the time . . . Then, of course, it's wonderful to get ready made dinner. And breakfast, have you seen our breakfast? It's fantastic! (Woman, 87)

The joy of having meals that pleased both eye and palate made the daycare center a highly valued part of this participants' everyday life. During the interview, she referred to the personnel by name several times while telling how they enrichened her day-to-day life. Another participant, having grown up in a rural area, emphasized the minibus trips to the daycare center, where they drove through parts of the rural area to pick up other attendants. After describing all the places they passed on the way, including the place where he grew up, he concluded, "When the weather is good, it's a really nice trip!" (man, 87). Thus, although the participant enjoyed the daycare center as such, he also found a benefit outside the formal confines of the center, which would be further strengthened, in good weather. However, not all participants shared this positive view. A participant who had just started attending a daycare center called it her "after school program" and added,

> The other day, when I was up there, they were going to throw a ball . . . Then I took a chair and sat down behind them, to be spared from having to throw a ball . . . Of course it's a little fun as well, it is, but . . . I can understand that some may like it, but I don't. Perhaps I'm a bit weird. (Woman, 75)

She had to admit that it was a little fun as well. Still, she experienced throwing a ball as something perhaps below her dignity, attacking her integrity. In addition, her dislike and unwillingness to participate in the activity also made her feel left out, leaving her wondering whether she was "weird" or not.

Discussion

The participants shared a well of reflections on their experiences with the support measures in question, as well as attitudes toward future possibilities. To summarize these reflections, across all the measures explored, we found that the criteria for assessing the support measures in question did vary among the participants, often relying on small margins related to their degree of knowledge and understanding of the support measure questioned. Despite initial hesitations, in part ascribed to lacking knowledge or prejudice toward unfamiliar measures, the participants' final judgments relied upon how the various measures might fit their individual needs and affect their everyday lives. A repeated finding within qualitative research, exploring the perspectives of persons with dementia, is an emphasis of sustaining autonomy and control over their own lives.[30–32] Similarly, a review on the perceptions of older people in general, considering assistive technology found that being in control and individual adaptation of the technology was crucial.[33]

In a meta-ethnographic study exploring meaningful activities among persons with dementia, Han et al.[34] describe how similar activities can meet different needs of various persons and, conversely, how dissimilar activities can serve to meet similar needs. This matches the descriptions provided by the participants of this study. When describing their satisfaction with these care and support measures, they emphasized different aspects of homecare and daycare centers. Negative experience or attitudes were seldom attributed to the support measures as such, but to specific aspects of these measures. E.g. beeping devices, the inability to handle equipment, antipathy toward certain activities or a volunteer who failed to meet expectations. Even though they pointed out the presumed benefits of differing measures, this did not outweigh their personal, subjective perceptions of detriment, as the following participant underscored: “I can understand that some may like it, but I don’t.” Strandenæs et al.[12] similarly describes how daycare participants try not to require too much when it comes to activities.

Care philosopher Kari Martinsen describes different ways of seeing and meeting the other as an individual.[35] She distinguishes between two ways of *seeing*—involving two different *eyes*. The one, which she calls *the recording eye*, is an eye that seeks to see individual traits, with intent view to systematize and classify the person, to be able to provide adequate support for individuals matching the specific classification. The woman no longer able to use her stove might illustrate some possible limitations of this recording eye. In this case, classified as a person with dementia, living alone, a stove guard had been installed to reduce fire hazard. The participant understood why the stove guard had been provided, but perceived it as a removal of her opportunity to uphold baking, a meaningful activity for her. Nygård[36] describes how these easily accessible stove guards may be used as substitutes for more individualized care and support.

The other way of seeing is through the lens of what Martinsen[35] calls *the double eye*. This way of seeing goes the reverse; rather than looking for individual traits to classify, one looks for common, recognizable traits in each single person. By taking this detour, one is able to perceive and recognize the individual particularities of the other. Consequently, Martinsen claims it is possible to perceive and meet the other as a whole and individual person and his or her personal appeal for help—detached from diagnosis or predetermined categories. Subsequently, healthcare professionals can see and recognize this appeal when emphasizing person-centeredness as described by Kitwood[37] and seeing each individual living with dementia as an equal person. The female participant of this present study, who was personally invited to the daycare center may illustrate this; apparently, someone saw her need, contacted healthcare personnel at the daycare center, who in turn invited her to come there on a regular basis. When attending the daycare center, the personnel continued to be important persons in her day-to-day life. The other participant, praising the homecare service for their cheerfulness, may also exemplify this. Although the visits were short before they had to “fly off,” the smiles and simple questions of the healthcare personnel made her feel that she was seen, recognized, and taken care of. Thus, both these participants experienced meaningful relations in everyday life, an aspect which has been shown to be important for persons with dementia.[38] For them, it was not the content of the measures as such that made the difference, but the relational qualities they enjoyed when interacting with their care providers. These examples may illustrate the simplicity as well as significance of establishing such relations.

Other examples do however illustrate how easily these relations may be disregarded, as in the case of the participant experiencing that the volunteer only “talked and talked and talked.” The talk was presumably well intentioned—but it was not what the woman expected; she expected to go for a walk. Martinsen[35] describes how the recording eye, when focusing on tasks and problem solving, may make healthcare personnel and others blind to the persons’ actual needs—losing the ability to recognize and support individuality and personal preferences. Although assessing decision-making capacity may be complicated,[39] Smebye et al.[17] document how persons with dementia may participate in decision making in a variety of ways, given that the helper knows and understands the person, and is able to provide manageable choices. Therefore, they claim that the question should not be on whether or not the person may participate, but rather how to empower the person to participate in decision-making processes affecting his or her everyday life. Similarly, although some participants in this study had initial difficulties in following the conversation, when given time, space, and explanation, they were able to reflect and share, not only experiences but also their attitudes concerning hypothetical future needs. This might illustrate both the fault in denying patient participation based on superficial assessments and how simple adaptations might contribute to enable the person with dementia to make reflected judgments considering their own care.

The participants' descriptions of what worked for them, and how it worked, along with their attitudes and personal preferences on relevant future support measures, reveal not only what works but also how this is related to individuality. Knowledge of the thin line between what persons with dementia experienced as supportive versus offensive, dignity preserving versus violating, may help us learn that adjusting support to fit the person are by far more in line with care philosophy[35] than adjusting the person to fit the support measures.

Implications for practice

This study shows that given time and space, home-dwelling persons with dementia may be able and willing to reflect on their experience and attitudes toward assistive technology, volunteer support, homecare services, and daycare centers. Their perceptions of how different measures might or might not fit their needs and personal preferences should therefore naturally be part of the discussion and decision-making process. Knowledge of the thin line between what persons with dementia experienced as supportive versus offensive, dignity preserving versus violating found in this study, may help healthcare personnel to naturally emphasize patient participation as a resource in adjusting support measures to fit each person living with dementia. As previously found by Tranvåg et al.,[40] advocating the person's autonomy and integrity is a primary foundation for dignity-preserving dementia care. By meeting people living with dementia with what care philosopher Martinsen calls a *double eye*, we suggest that healthcare personnel as well as family caregivers might be able to recognize and identify the individual personal appeal for care and support—beyond predetermined needs assumed for a "person with dementia." In addition, in line with Kitwood,[37] enabling the person cared for to come forth as a unique, autonomous person along these lines, will be a way of bringing theory of person-centered care into practice—ensuring their human right of retaining autonomy and integrity as well as participation in decision-making processes considering their own care and support.[21]

Limitations

The study included a relatively homogeneous sample of persons with dementia attending daycare centers in one municipality. A more heterogeneous group could have brought other aspects to light. Conversely, knowledge of the participants' specific diagnose or degree of dementia could have made the study more specific. To strengthen the study's transferability, we have endeavored to provide thick descriptions and elaborated on the variance and peculiarity in the empirical data. Together with a thorough and repeated examination of the empirical data with constant reflection on our pre-understanding and searching for disconfirming evidence, we have striven to establish study trustworthiness.[41]

Conclusion

This study explored the perceptions of persons with dementia of assistive technology, volunteer support, homecare services, and daycare centers. Given time, space, and explanation, the participants expressed a variety of experience and attitudes concerning these support measures. Their responses revealed that there might be a thin line between care and support experienced as supportive versus offensive, dignity preserving versus violating. Furthermore, this balance is based on individual preferences and perceptions of how the care and support might affect the individuals' everyday life. This implies a need for increased attention in clinical care and future research, to develop and implement sound strategies for patient participation in decision-making processes concerning care and support for persons living with dementia.

Acknowledgements

We are thankful for our participants' entrusting engagement in sharing their experience and attitudes with us. We would also like to give a special thanks to the daycare centers for their support in recruiting participants and facilitating interviews. B.S.H. would like to thank the G.C. Rieber Foundation and the Norwegian Directorate of Health for supporting our work at the Center for Elderly and Nursing Home Medicine, University of Bergen, Norway.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The study was funded by the Dam Foundation (formerly the Norwegian Extra Foundation for Health and Rehabilitation) (Grant number: 2016/FO77186) with The Norwegian Women's Public Health Association as applicant organization.

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Article 3

Fæø, S. E., Tranvåg, O., Samdal, R., Husebo, B. S., & Bruvik, F. K. (2020). The compound role of a coordinator for home-dwelling persons with dementia and their informal caregivers: qualitative study. *BMC Health Services Research, 20*(1), 1045.

Fæø *et al. BMC Health Services Research* (2020) 20:1045
https://doi.org/10.1186/s12913-020-05913-z

BMC Health Services Research

RESEARCH ARTICLE Open Access

The compound role of a coordinator for home-dwelling persons with dementia and their informal caregivers: qualitative study

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Abstract

Background: As the number of persons with dementia is increasing, there has been a call for establishing sustainable clinical pathways for coordinating care and support for this group. The LIVE@Home.Path trial is a multicomponent, multi-disciplinary intervention combining learning, innovation, volunteer support and empowerment. To implement the intervention, a municipal coordinator has a crucial role. Implementation research on multicomponent interventions is complex and we conducted a qualitative study, aiming to explore the coordinator role and how a coordinator may empower persons with dementia in decision-making processes.

Methods: Qualitative program evaluation combined with a hermeneutic interpretive approach was chosen as methodological approach. Sixteen dyads, consisting of the person with dementia and their main informal caregiver received the intervention by two coordinators. Of these, six dyads, three informal caregivers alone and the two care coordinators along with their leader, in sum, eighteen persons, participated in in-depth or focus group interviews, sharing their experiences after 6 months intervention.

Results: We found that the coordinators fulfilled three functions for the participating dyads: *being a safety net*, meaning that the dyads might have little needs at the moment, but found safety in a relation to someone who might help if the situation should change; *being a pathfinder*, meaning that they supported the dyads in finding their way through the complicated system of care and support services; *being a source for emotional care and support*, meaning that they listened, acknowledged and gave counsel in times of distress. The coordinators emphasized that a trusting leader and work environment was crucial for them to fulfill these functions. We also found that it was challenging for the coordinators to build a relation to the persons with dementia in order to pursue genuine empowerment in decision-making processes.

Conclusion: We found the framework for follow-up to be a feasible starting point for establishing empowering coordination and a sustainable care pathway for persons with dementia and their informal caregivers. More meeting points between coordinator and person with dementia should be pursued in order to fulfill the persons' fundamental rights to participate in decision-making processes.

Keywords: LIVE@Home.Path, Care coordination, Dementia, Home-dwelling, Decision-making, Case management, Empowerment, Qualitative study

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Background

As the prevalence of dementia is rapidly increasing, the World Health Organization (WHO) has labeled dementia a global public health priority and urged nations to establish dedicated dementia plans to secure adequate support for this group [1, 2]. In the wake of this call, guidelines and models for developing structured care pathways for persons with dementia has been proposed [3, 4].

Research suggests that persons with dementia living at home may have a high degree of unmet needs ranging from safety issues and general health needs, to legal issues or sustaining meaningful activities. This represents a wide range of needs from a variety of care providers [5]. A review on 'what works' to support this group suggests that multicomponent flexible interventions is necessary in order to meet the complex needs of home dwelling persons with dementia. Additionally, intervention studies aiming to support this group often lack the patients' perspectives and fail to acknowledge the complexity in the patients' life situation [6]. Persons with dementia are depending on a high degree of informal care which in turn represents a potential health risk for their informal caregivers [7]. To meet the diversity of needs within this group, various approaches of case management and care coordination have emerged. Many of these attempts have proved beneficial, but not uniformly across studies. A Cochrane review [8] found that case management approaches in care for home-dwelling persons with dementia might lead to reduced institutionalization and decreased burden and depression among caregivers. However, the results were inconsistent throughout repeated measurements. Similarly, a meta-analysis of research on 'coordinating interventions' in community based dementia care, found significant effects in terms of reduced neuropsychiatric symptoms and caregiver burden [9]. Still, high costs and vaguely defined tasks combined with a multitude of different intervention designs and outcome measures leaves the initiatives fragile and general implementation in practice has been absent. Iliffe [10] suggests 'fluidity' as a concept to build further research on these matters upon – one should attempt to establish a base of necessary components for care coordination to function and share experiences of how these components may be adapted to fit in various contexts. As there are various terms for the varieties within this concept, we will refer to the term used by the authors when referring to other publications. In our study we use the terms 'care coordination' and 'coordinator' respectively.

In the wake of increasing attention on dementia care, there is a growing awareness of these patients' right to participate in decision-making processes concerning their own need for care and support. These are complex issues, especially if the wishes of the person with dementia may be potentially harmful or conflict with the beneficence and autonomy of informal caregivers [11]. Informal caregivers are crucial in the support of persons with dementia, also in decision-making processes and some may perceive it as a relief to leave decisions to others whom they trust [12, 13]. On the other hand, some may find it challenging, even offensive, that others make decisions on their behalf, even if it is close relatives [12–14]. Sustaining independence, agency and autonomy has been found to be important for persons with dementia in order to cope with a dementia condition and to experience dignity and quality of life [15–18]. Cahill [19] highlights that persons with dementia, too often are denied information and inclusion in decision-making processes considering their own care. It has also been documented how this often happens without properly assessing the person's cognitive abilities [12]. The United Nations Convention on the Rights of Persons with Disabilities do however underline that the use of standardized tests to deny a person of legal capacity and human rights, based on mental capacity, is discriminatory and not permitted [20]. Rather, healthcare personnel are required to support the person to exercise legal capacity. Similarly, the WHO emphasize the need to empower persons with dementia to exercise legal capacity and to take part in the development of care structures [21]. Although the right to participate may be explicit parts of services' ideology it may be challenging to pursue this ideal in practice [12]. However challenging it may be to pursue these ideals, we find it crucial to explore how to build structures within the health and care services that may increase patient empowerment and participation in decision-making processes.

The LIVE@Home.Path-trial (LIVE) (ClinicalTrials: NCT04043364, retrospectively registered) is a multicomponent, multi-disciplinary intervention aiming to support dyads, consisting of persons with dementia and their informal caregivers, to live safely and independently at home [22]. LIVE is an acronym for the main components in the intervention, that is: Learning; Innovation, Volunteers and Empowerment. A central part of the Empowerment-component is a dementia coordinator with the tasks of coordinating the LIVE-components and to ensure empowerment of the individual person with dementia throughout the LIVE-intervention process. This aims to ensure that the participants experience that the care and support they are provided are in line with their own perceived needs and wishes.

This present qualitative study is exploring the coordinator role before initiating the LIVE trial. Instead of making a strict, standardized description of the coordinators tasks, we wished to explore how the coordinators role and functions evolved in interaction with the participating dyads, consisting of persons with dementia and their informal caregivers. Further, we wished to explore issues concerning empowerment and patient participation throughout the intervention. The following research questions were addressed: 1) How do the participating dyads and the coordinators experience and describe the coordinator role and functions? 2) How can a coordinator contribute to the empowering of the person with dementia in decision-making processes – in everyday life and in planning present and future care and support?

Methods

To answer the research questions, we used Patton's [23] framework for qualitative program evaluation. This framework focuses on exploring variances in participants' and program stakeholders' experiences through dialog and attentive listening to their stories. A hermeneutic interpretive approach as described by Gadamer [24], was used to guide the qualitative interviews and the interpretive process. This approach focuses on how understanding comes forth through open and expecting dialogue. The principle of openness applies both to the interview situation between researcher and participant and to the interpretive dialogue between reader and text when analyzing interview transcripts [25]. User involvement in research increase the relevance and utility of scientific studies as it brings knowledge based on users unique experience into the research process [26]. A co-researcher with user experience as a long-time caregiver for a person with dementia were engaged in all parts of the study process: in designing the intervention and evaluation, developing interview guide, participating as a co-moderator in a focus group interview, in the analysis process, and throughout the writing process. These contributions proved useful in all phases of the study as he addressed critical remarks to our hypotheses; pointed at potential bottle-necks in the implementation concerning how participants organized their every-day life, how we as researcher best could avoid being an extra burden – while bringing his perspectives and horizon of understanding in the interpretive process.

Study setting

Two specialist nurses, a woman and a man, were engaged as coordinators. Both were engaged at a municipal resource center for dementia and had long experience from nursing homes and home based care for persons with dementia. They also had thorough knowledge of available care and support. The resource center founded its work on the principles of person-centered dementia care as described by Kitwood [27]. The coordinators went on two initial home visits: the first to initiate contact and map out clinical data; the second, about a month after the first, to have an informal conversation with the dyads on "*What's important to you?*" as well as discussing relevant support and aiding in application processes. Further, the coordinators contacted the dyads per telephone once per month to build a relation, evaluate the situation and discuss the way forward. The LIVE-components were discussed as possible solutions along with other existing support measures. After 6 months the dyads were offered a new home visit. In between contact points, the coordinators were available for contact if needed. Besides these established contact points, the coordinators were free to support the participating dyads as they deemed necessary. That meant they were free to judge to what degree they should support in application processes, increase telephone contact, provide extra home visits, arrange meetings with general practitioners and others involved and so on.

Participants

We defined study participants as dyads consisting of the person with dementia and one informal caregiver. Inclusion criteria for the person with dementia were: having a dementia diagnosis; Mini-Mental-State-Examination score 15–24; living at home; ability to consent to participate in the study. The criteria for the caregiver participant was minimum one weekly face-to-face-contact with the person with dementia. Participants were recruited through the network of a municipal resource center for dementia and a local geriatric outpatient clinic. Eligible participants were informed of the study and included successively over a period of 2 months until a target of sixteen participating dyads were included. In a period of 6 to 9 months after the intervention started, six of the participating dyads of persons with dementia and their informal caregivers, plus three informal caregivers alone participated in qualitative interviews to evaluate the intervention. In addition, the two coordinators, along with their leader participated in a evaluative focus group interview [23]. In sum, we interviewed 18 persons to gather empirical data for this study.

See Table 1 for an account of the study participants.

Data gathering

To answer the research questions, a hermeneutical approach, using qualitative interviews to explore the experiences of stakeholders in the project was chosen for gathering empirical data for this study. A basic principle within hermeneutical methodology is that our interpretation of the world around us will always depend on the interpreters' background and pre-understanding [24]. The members of the research team had clinical experience as a medical doctor or registered nurse in care for persons with dementia in hospitals, nursing homes and home care. In addition, a co-researcher with user

Table 1 Study participants. (The coordinators and their leader's age and gender are left out to safeguard anonymity)

ID	Role	Gender	Age	Interview type
A	Informal Caregiver	Female	68	Focus group
B	Person w/dementia	Male	67	Focus group
C	Informal Caregiver	Female	69	Focus group
D	Person w/dementia	Male	83	Focus group
E	Informal Caregiver	Female	65	Focus group
F	Person w/dementia	Male	65	Focus group
G	Informal Caregiver	Male	69	Dyad Interview
H	Person w/dementia	Female	75	Dyad Interview
I	Informal Caregiver	Female	75	Dyad Interview
J	Person w/dementia	Male	78	Dyad Interview
K	Informal Caregiver	Female	57	Dyad Interview
L	Person w/dementia	Male	69	Dyad Interview
M	Informal Caregiver	Female	71	Single Interview
N	Informal Caregiver	Female	59	Single Interview
O	Informal Caregiver	Female	57	Single Interview
P	Coordinator			Focus group
Q	Coordinator			Focus group
R	Coordinator leader			Focus group

experience as an informal caregiver for a person with dementia was part of the research team. As research team, we had close dialogue with the coordinators throughout the intervention. Experiences made on these contact points and issues addressed were used to develop a semi-structured interview guide for the interviews. In addition to exploring experiences with the coordinator role, we also explored experiences with the LIVE-components. Results from this part of the interviews are not included in this study. Interviews were conducted in a period of 6 to 9 months after the study was initiated. Although we would have liked to recruit all 16 dyads, we realized throughout the intervention period that many of the informal caregivers had complex and demanding life situations. Some even had challenges in finding time for the coordinators' home visits. Although these participants might have provided substantial insight we chose not to invite the most fragile of them – based on ethical considerations. Other dyads were out travelling throughout the period allotted for interviews.

Three persons with dementia participated in a patient education course for persons with dementia, in which their informal caregivers was welcome to join. The course was arranged by a local geriatric outpatient clinic and consisted of three two and a half hour sessions. Using opportunity sampling [23], these dyads participated in a focus group interview immediately after one of the course sessions. Thus we managed to arrange a group conversation between three dyads, exploring their experiences as participants in this study. Additionally, to explore various experiences, we used maximum variation sampling [23] to recruit three persons with dementia with their informal caregivers for single dyad interviews and three informal caregivers were interviewed alone in single interviews. These interview participants varied according to age; whether the dyads were living together or not; if and how much formal support they received; how long they had been living with dementia; and how much they had been in contact with the coordinators throughout the intervention period.

Finally, based upon the experiences of the project in total, along with initial analysis of the prior interviews, the gathering of empirical data were concluded with a focus group interview with the coordinators along with their leader. These were recruited as key informants [23], due to their central role in the study. In this interview, the co-researcher with user experience participated as a second co-moderator alongside an experienced co-moderator and the main interviewer. We are aware that our close collaboration and the growing relationship with the coordinators might have affected this focus group interview. Although we encouraged them to describe their personal view, we do not set aside the possibilities that this might have influenced their willingness to share critical remarks about the project. However, we experienced the interviews as open and honest and we believe that the relational interactions might have contributed to more openness around sensitive and emotional aspects.

Ethical considerations

Informed consent is a basic principle when including human beings in research. When including persons with dementia in research, assessing the participants' ability to understand information given might be a challenge. Often, this is solved by consent given by proxy from a family member or legal guardian. This, however, may exclude the person from having any say at all, concerning participation. Above, we have discussed the ethical and legal issues of depriving persons of their legal capacity based on mental or cognitive capacity [19, 20]. Hellström et al. [28] questions if provision of full information of a study's content as a base for consent is actually possible for any person, regardless of cognitive functioning. In the case of persons with dementia, they describe 'maximally informed consent' as a useful concept and perspective. This entails adapting information to the individual person, repeating information, giving time to reflect and ask questions. Before inclusion to this present study, eligible dyads were informed about the main aspects of the intervention and asked to discuss participation with their family. During the first home visit, the coordinators, as specialist nurses, assessed the persons with dementia's ability to consent, based on observations and clinical assessments. The participating dyads were thoroughly informed, together, about all aspects of the intervention and their right to withdraw at any time without further consequence. Information was carefully adapted, through dialogue, to ensure that the persons with dementia had understood the content. The persons with dementia and the informal caregivers both gave written consent to participate. On inclusion, the participating dyads were informed that they might be asked to participate in in-depth interviews as part of a six-month evaluation. They were informed that this was voluntary and that they had the right to decline this request without any consequences for their follow-up. Likewise, they were informed both when invited to participate in interviews and before the interviews started that this was still voluntary, that they at any time could ask to end the interview or that they afterwards had the right to ask for interview data to be deleted. They were also informed on procedures for data gathering and data treatment. As there is only one male and one female coordinator, they will consequently be referred to as '*she/her*' throughout the text, also in quotes from other participants, to protect their privacy. All interview participants consented to participate. The coordinators continued to follow-up all dyads after the study period was over. The study was approved by the Regional Committee for Medical and Health Research Ethics, Northern Norway (2017/1519 REK Nord).

Data analysis

All interviews were audio recorded and transcribed, followed by initial analysis, successively. In this way, findings and horizons of understanding from prior interviews were assessed for potential further pursuit in the following interviews. For example if a participant emphasized new or unexpected themes, we would consider to address these themes in later interviews. Before the interview with the coordinators and their leader, initial analysis of the transcribed interviews were discussed by us as researchers – in search of themes to discuss in this final focus group interview. As a result, descriptions in the results section of general trends or variance among the participating dyads are based both on our interviews with the dyads and informal caregivers, and the coordinators descriptions of the intervention group. After all interviews were conducted and transcribed, they were analyzed separately by the members of the research team, as single texts, all interviews as a whole text and each interview as parts of the whole. Then, the research teams discussed their individual interpretations of the full body of texts in order to establish a shared understanding of the empirical data. This alternation between analyzing the interviews as single texts, as a whole and as parts of a whole characterized the analytical process, in line with hermeneutical methodology [24].

Results

The coordinator role and functions

The participating persons with dementia and their informal caregivers differed in age, symptoms, social network, as well as life situation in general. Accordingly, their need of support from their coordinator varied. The coordinators shared this view and described a high degree of variance in how much, and what kind of, support the dyads received throughout the intervention period. Some expressed being content with a brief telephone conversation once a month, while others used the monthly telephone calls for longer sessions of counselling, organizing various support measures or simply just to talk. It also varied how much the coordinators were contacted outside of the monthly telephone calls. This also had various reasons, ranging from how to prevent pills from falling on the floor while taking them out of the pill box, to arranging care solutions while the informal caregiver needed to travel, or the informal caregivers needing someone to talk to about minor or major concerns. Thus, the dyads' perception of how their coordinator affected their everyday lives did also vary. Besides the home visits, it turned out to be only the informal caregiver who maintained contact with the coordinator, an aspect we will return to later in the results section. The first research question considered the coordinator role and functions. Although most of the dyads' perspectives are described through the informal caregivers, the coordinator role and function affect the dyad as a whole and cannot be detached to only concern the informal caregiver. We found that the coordinators took three different functions in their relations with the dyads, to meet the variance in care needs. That is the function of *being a safety net*, *being a pathfinder*, and *being a source for emotional care and support.* In addition to the questions we had set out to answer, we found that good leadership and a trusting work environment was crucial for the coordinators to function in their roles.

The coordinator as a safety net

In general, all dyads expressed that they were satisfied with being part of the project. Some described how they experienced being at a point where the situation was stable, having the necessary support for the time being. One spouse described how she had struggled earlier, after her husband was diagnosed and they needed to find new solutions to cope with everyday challenges:

> *I feel that perhaps it was too late to get help. The help we needed, we found out on our own and we*

> *had needed it when he got the diagnosis. (…) But if I'd had someone to play ball with from the start… (Participant O, informal caregiver)*

She emphasized how she had been in need of a coordinator at an earlier time, when her husband got the diagnosis. At the moment, she felt she had control and knew where to turn if she or her husband needed anything. However, she was aware that the situation might change and that it was good knowing the coordinator was there. Thus, the coordinator represented a safety net, that they could turn to when necessary, rather than an active contributor in their everyday lives. The spouse of a person who was recently diagnosed with dementia, and had not established any contacts within the system emphasized this dimension even stronger:

> *As I say to (coordinator) when she calls: 'at the moment, everything is fine, but thank you for being here and in the future when we perhaps are in need of help, we know someone will be there for us' (Participant I, informal caregiver)*

Although some dyads perceived that there was little the coordinator could do for them at the moment, they emphasized the reassuring aspect of having a personal coordinator: *'someone who knows us'(Participant I, informal caregiver),* ready to help if the situation should change. The coordinators confirmed this perception and emphasized how the regular contact helped them observe small changes in the dyads' life situation as a whole. Further, the continuous documentation laid a foundation for future assessment of care provision by other instances, especially for the health administration, who are in charge of the formal assignment of public care and support. The coordinators' leader underlined:

> *Later, when they apply for something, nursing home or something, the documentation you do in the patient journal are good background information for the health administration.(Participant R, coordinators leader)*

The coordinators and their leader had a clear comprehension of the importance of observations, documentation and relational knowledge concerning these patients' and informal caregivers' current and future needs.

The coordinator as a pathfinder

One of the informal caregivers described how navigating the health administration and organizing the services for the persons with dementia were challenging and distressing: *I've felt that it's incredibly difficult to find that thread, where do I start to wind? (M)* Several informal caregivers described this sense of not knowing where to start when seeking help. First, they found it difficult to identify and describe what the problem actually was. Second, due to limited knowledge about the municipal care and support services, they found it hard to identify and contact the right instances that might be able to help them. One spouse described how they experienced this in the time following her husband being diagnosed with dementia:

> *It was a lot of phone calls, you know, I called the wrong persons. Then I got through to someone, I think it was at the social security or something, who gave me the number to (right person) and then things started to happen. (Participant C, informal caregiver)*

The dyads described how the coordinators in this situation played a more active part, helping them find and acquire good solutions. Based on the dyads' needs and wishes, this help ranged from giving advice on how to solve everyday challenges, providing simple information on where to find application forms and, in some cases, to coordinate collaboration between services. As concrete examples, the coordinators were counselling representatives of the home care service on how to interact with the person with dementia when preparing his or her breakfast. The coordinators also arranged a meeting place for representatives of the daycare center and the short-term nursing home ward for developing a cooperation ensuring continuity of collaborative routines when the person with dementia had a respite stay at the nursing home. Thus, their support focused on the needs of the persons and were not confined to the LIVE-components. One informal caregiver, who had a full time job and did not live with the person with dementia, described how the coordinator in this way helped them through a challenging life situation:

> *To me, it's been very important (the coordinator's help), because it's a lot of work and many things to follow up, you know. It's appointments with the general practitioner, the ophthalmologist, then he has some skin problems, so it's the dermatologist... Then you need to stay in touch with the homecare services, and remember to buy medicines at the pharmacy and remember this and that and then less and less is working at home. So I felt that having one person to relate to has been very good for me. To kind of see some steps ahead, you know, she can say 'I think you might need… and we might as well apply right away' (…) If I feel that we need some more help, I talk to (coordinator), I don't talk to anybody else. (Participant K, informal caregiver)*

The description illustrates some of the vast complexity in caring for a person with dementia. For this participant, the coordinator had, in many ways, taken over coordination of the care and support as a whole. Although the informal caregiver experienced a heavy burden, the coordinator had an overview over the total situation and did most of the communication with all the different healthcare providers involved. Thus, we have found the metaphor 'pathfinder' as an appropriate concept describing this crucial coordinator function of keeping a survey of the dyads' situation as a whole and leading them on the way to possible means of support. In conversation with the coordinators concerning the time and resources they used on this kind of work, they claimed that in total it did not consume much time. They also experienced that it helped provide purposeful support, thus reducing waste of resources within the health and care services. However, they emphasized how they primarily perceived this consideration as a means to safeguard the persons with dementia:

> *No person with dementia wants to get a lot of people into their homes, nor a lot of services. They want exactly what they need and nothing more. (Participant P, coordinator)*

The coordinators perceived that most participating persons with dementia were reluctant to receive support, especially within their home, and that they wanted to keep support at a minimum. The coordinators' knowledge of the available support and how to attain it, and their thorough knowledge on the dyads' life situation as a whole, enabled them to recommend care and support that was individually adapted. Throughout their follow-up process, the coordinators had slightly differing support approaches when applying for services, – a process that at times might be quite strenuous due to a complex administrative system. While one of the coordinators aimed at informing and guiding on available, adequate services and how to apply, the other coordinator also helped writing application forms as well. Although the practical work did not differ much, the perceptions of how this worked differed, as illustrated by this informal caregiver:

> *(The coordinator) can say "application forms for this and that is on the internet or I can send it in a mail if you have difficulties with the net" or something like that. But it's not like I can say "we need this and that…" you know, to simplify the application process. If you're used to orient on the internet, it's actually nothing she's said that I hadn't found out on my own. But still, it's good to have her, because you can kind of check with her "can I do this or that, does it work like this?" but still, you have to move on, on your own. (Participant G, informal caregiver)*

Although this informal caregiver found it hard to handle this challenging procedure himself, he still found support in being able to seek advice from the coordinator. Overall, despite differences in perceptions, most dyads experienced the coordinators as someone who helped them find and consider different possibilities, helping them cope in their everyday lives.

The coordinator as a source for emotional care and support

Some informal caregivers also found the coordinators contributions in terms of emotional care and support vital. The need for this kind of care might be due to a general high level of distress and vulnerability, experiencing a crisis during the project period or simply dealing with the multiplicity of small everyday challenges. One spouse described how she almost despaired when they had come home from a travel and she couldn't reach the coordinator.

> *I couldn't reach her that day, I felt that I almost (grips around her throat and chokes)… but then I got through and then it's half an hour and then all problems are solved… plus some I didn't knew I had. (Participant A, informal caregiver)*

The remark illustrates how the coordinator may be seen as someone who help making everyday challenges and suffering endurable. Further, it indicates how the coordinator might serve as a problem-solver over the telephone. The coordinator did not only answer to the dyads' everyday challenges, she also brought to light related issues that the dyads did not think about themselves, as well as presenting possible solutions to them. Other informal caregivers emphasized the benefit of having the coordinator to contact, also for emotional support:

> *If I've been desperate, you know, this and this has happened. Then I call and talk to her and usually, she has a good idea, so it's very good talking to her. (Participant M, informal caregiver)*

The importance of having someone to talk to one-to-one, who knew them and their current life situation were addressed by several informal caregivers. Combined with input on how to cope with their present challenges, these opportunities to talk to a coordinator that listened and supported them was crucial for them. One of the coordinators described how they experienced this vital aspect as well: *"I feel that I often am that 'container' that listens and confirms' (Participant P, coordinator).* A daughter, caring for her father with dementia described how essential it was for her to be seen and taken care of herself, by the coordinator:

> *I get to talk to someone who perhaps has another view and some knowledge, because I know very little about this myself. (…) And someone who tells me: 'you know, you need to take a time-out!' I need that someone tells me (…)I feel that it's not only one-way communication, that it's only me who calls and ask if anything comes up, but that they actually make contact… (Participant N, informal caregiver)*

Consequently, some informal caregivers experienced the benefit of getting support, but also a little push, to help them make difficult decisions and taking care of themselves in times when caring for the family member with dementia became all-consuming. Some of the dyads also found themselves in the midst of challenging life situations not related to the dementia condition itself. One coordinator experienced how a complex family conflict created an extra burden for the dyad. Although there was little the coordinator could do about the issue at hand, she still found it crucial to listen, support and acknowledge the dyads' attempt to cope with the situation:

> *At least it has become (natural), because it's what she needs. (…) And she does a lot of good things (…) so she kind of needs someone who listens and supports and say 'this was good'(Participant P, coordinator)*

Although peripheral to the direct support of the person with dementia, the coordinator recognized how the surroundings affected the everyday life of the person with dementia. Thus, aiding to relieve the tense situation within the family would be beneficial for the well-being of the person with dementia.

Emphasis on trust based working conditions for the coordinators

Although not an initial focus of inquiry, the coordinators underlined the importance of having a trust based relationship to their supervisors to be able to fulfill their tasks as coordinators:

> *From the first moment the project was presented, we've had full support and recognition on this as something to prioritize and spend time on. And that has made it easy to get going and I think that is important. About having a leader and get time to do the tasks. We haven't spent time on defending why we have to take this and that home visit, you know. And that's not to be taken for granted. (Participant Q, coordinator)*

An important aspect for the coordinators in order to be able do their tasks was to get recognition and trust from their superiors on their priorities and choices of action. Likewise to get support and supervision in challenging situations:

> *I sometimes get a bad conscience and a little stomach ache… but then, I am quite good at talking about all my feelings (laughs). But to me it's important, in this job, to have good colleagues that I can talk to, because I don't talk about it at home. And I think that it's quite natural to have these feelings, so I don't really think it's a problem. Perhaps it's a little barometer, I don't know. I use (other coordinator) a lot, and (leader). Good supporters. (Participant P, coordinator)*

The coordinators described how they experienced feelings of unease and emotional distress as a part of their work as a coordinator. Although straining, the coordinators did not describe this as a negative thing: rather the negative emotions were perceived as an indicator of the ability to build empathy and get involved in a relationship with the participant. Equally important though, was the emotional and professional support from co-workers and leaders. The leader agreed and confirmed how this kind of support should be prioritized:

> *Let them get the chance to reflect and mature as coordinators, I think a lot about that. I want to handpick personnel, you know. It is something very serious about being a coordinator, because you have such an impact on peoples' lives and you're not to be too easy on it either.(Participant R, coordinators leader)*

The mutual trust and recognition between the coordinators and their leader seemed to be crucial for the feasibility of the trial. This statement further reveals a serious awareness of the gravity of the coordinators work. Both coordinators and their leader described a determinate focus on how to support the individual, regardless of if and how this support was measureable or might fit into goal attainment scales.

Empowering the person with dementia in decision-making processes

Considering the second research question, we found that meeting the person with dementia alone during the first home visit was perceived crucial for the coordinators to get an impression of the persons' values and preferences.

However, the coordinators found it challenging to maintain an empowering relation with the person with dementia throughout the study period.

Challenges in establishing relationship with the person with dementia

During the first home visits, the coordinators had one-to-one conversations with the participants living with dementia, based on the question '*What's important to you?*' in addition to mapping out clinical data. The second home visit solely focused on building a relation with the dyads. Here, they emphasized involving the persons with dementia in the dialogue and getting their views on the themes of discussion. This was deemed valuable to be able to get an impression of the person and the persons' values and preferences.

> *"You get to hear a lot about their lives and experiences and you get to know what's important to them, and what has been important to them. … You sort of get to know their pulse a little… You get an image of who this is. If I ask 'what's important to you, now?' it's not always that easy to get an answer." (Participant P, coordinator)*

In this statement we also see a recognition of how the answer to the question of '*What's important to you*' not necessarily is found by asking directly, but rather is hidden somewhere within the participants' narratives. However, during the continuous follow-up by telephone, which was intended to sustain the contact with both members of the dyads, the coordinators found it challenging to uphold direct contact with the persons living with dementia. The frequency of once a month and contact by telephone made this challenging, especially because of the person's illness-related memory problems:

> *Calling to someone who has dementia… It's not a good way to communicate, you know. And building a relation to someone with dementia and meeting once every third month or half-a-year is not good either. Because the person with dementia won't remember you and will get anxious every time. … It might have worked in some cases, but it's not right towards the person with dementia. (Participant P, coordinator)*

Thus, the monthly follow-up by telephone turned out to be only between the coordinators and informal caregivers and none of the persons with dementia initiated contact with the coordinators themselves. Most of the persons with dementia described experiences with support that were facilitated as part of the follow-up and one of the persons with dementia described it like this:

> *We've got this and that, so it's been great… comes home and we sit and talk, so it's been good. She's coming next Friday. (Participant F, person with dementia)*

This person had a clear view of who the coordinator was and valued the home visits and the support they had received through their coordinator. The other participating persons with dementia, did however describe little conception of who their coordinator was and what their exact role was. The following conversation between interviewer (I), person with dementia (P) and informal caregiver (C) illustrates this issue.

I*: Do you feel that you have a relation to (coordinator)?*
P: I really can't say that.
C: Do you know who we are talking about?
P: No… I know I have met her…
C: Many times, she's been visiting us several times.
P: You know, I don't recognize all those actors out there.
…
C: I think that if you'd seen her, you would have recognized her.
P: I guess

> *(Participants K/L, informal caregiver /person with dementia)*

It must be underlined that the person in question throughout the interview had little difficulties in recollecting details and aspects from his everyday life. Some persons with dementia expressed a remembrance of the meetings and the coordinators as nice persons, but they expressed little perception of the coordinators as someone who helped and supported them in any way. Thus, although the persons with dementia took active part in the interview conversations and shared their experiences of the support they received in general, they had little substantial response regarding their perception of the coordinator role.

Discussion

Concerning the first research question, about the coordinators' role and functions, the participating informal caregivers described how they experienced three different coordinator functions. First, they described how the coordinators served as a means of safety and comfort. Although some perceived that there was not much the coordinator could do at the time, they appreciated that there was a person who knew them and their situation, who was ready to help them if needed. Second, the coordinator served as a co-planner and organizer of care and support. This function was flexible and ranged from giving basic information on available care and support to more or less taking over coordination of the many health and care services involved. Third, the coordinator served as valuable emotional support and care for the informal caregivers in times of distress. These three functions built upon each other. Based upon the relation and knowledge of the total situation gained through the basic phone calls, support could be more individually adapted, when needed. Further, the building of a strong relation made a foundation for providing adequate emotional support. In total, getting to follow up the persons with dementia and their caregivers over time, with a view on the whole situation, laid the ground for a wide perspective making holistic care and support possible.

In line with the encouragement from Iliffe et al. [10] we will establish these three functions as crucial components for care and support coordination for this group to function. Further, we find the concept of 'fluidity' to be adequate also to describe the internal relation between the components described. They overlapped and the borders between these functions were at times fluctuating. The coordinator functions as described should therefore not be seen as distinct tasks to be pursued as such, but as functions that should get room to arise in the interaction between the coordinator and the dyad. Moving away from task-oriented standardization is supported by care philosopher Kari Martinsen [29]. She asserts the importance of meeting the other, in this case the dyad, with openness and wondering. This requires a fine balance between managing to see past the immediate without invading the others' private sphere. The coordinators' different approaches to support in application processes exemplifies how complex it may be to find this balance in practical approaches. It also illustrates how relatively small differences in approaches may affect participants' assessments of the support they are receiving.

The coordinators and their leader underlined the importance of mutual trust and good relations to ensure the necessary flexibility to provide adequate follow up of the participants. Equally important, they described a need to ensure professional and emotional support for the coordinators. These descriptions also involved the coordinators' recognition and acknowledgement of their own vulnerability in meeting the dyads. Martinsen [29] emphasize how emotional involvement calls for increased attention, making room for good professional judgments of what is at stake in the situation. She makes a clear distinction of this kind of involvement as opposed to sentimentalism. Sentimentalism, she claims, might emerge as a result of suppressing emotions for the sake of professionalism. Within leadership theory, the importance of good leader-employee-relationships and mutual trust has shown to have high effect on productivity as well as the employees' mental health [30]. Kitwood [27] emphasize the crucial role of leadership and work environment within person-centered dementia care. Likewise, as the concept of person-centered care has been further developed into a theoretical nursing practice framework, the aspect of work environment and leadership has been established as integral parts. McCance and McCormack [31] describes how personal prerequisites in the healthcare personnel, such as competency, skills, values and commitment as well as structural aspects in the care environment, including supportive systems, staff relationships and power sharing are crucial to succeed with this kind of work. Their framework also includes 'sympathetic presence' as a prerequisite, again underlining the need for emotional involvement in order to do professional judgments. Although these aspects were not initially addressed in this present study, we found clear similarities between coordinators' descriptions of the prerequisites to be able to perform their tasks and the prerequisites described within the person-centered framework. Similarly, a qualitative review of stakeholders' perspectives on coordinating care in dementia emphasize the importance of support for the coordinators [32].

Considering the second research question, on empowerment of the persons with dementia, we found that this was a challenging aim to pursue directly within the structures of the intervention. The initial conversations between coordinator and person with dementia alone, in a trusting environment, were crucial for the coordinators to get to know the person values and preferences. The remark about finding an answer to the question *'What's important to you'* in the persons' narratives illustrate the importance of finding room for such conversations between coordinator and person with dementia. An open approach in these conversations may further help the coordinator gain insight in the persons' rhythms of daily life at home [33]. However, we found that it proved challenging for the coordinators to pursue this objective throughout the intervention period. Both the frequency and means of contact was perceived as suboptimal. Due to these challenges, we have increased the contact points and included a process of Advance Care Planning (ACP) in collaboration with the persons' general practitioners in the main LIVE study [22]. Further, we believe that the persons with dementia might benefit indirectly through the empowering support of the informal caregivers and the support measures instigated by the coordinators. We acknowledge that we should have investigated more thoroughly whether phone calls could have been feasible to maintain contact, at least with some of the persons with dementia.

The issue of ensuring genuine patient participation for home dwelling persons with dementia is complicated. In a multi-case study of ten cases, Smebye et al. [12] describes how healthcare personnel and informal caregivers may engage persons with dementia in shared everyday decision-making, such as choosing among activities, what to eat or when to shower. As such, the informal caregivers play a crucial role in empowering the persons with dementia and are central collaboration partners for healthcare personnel in general when decisions on care and support are made. On the other hand, Smebye et al. [12] also describe instances of not involving the person at all or pseudo-autonomous decision-making. The latter defined as cases where the person with dementia was not adequately informed and decisions were based on mere assumptions about the persons' values and preferences. Similarly, Taghizadeh Larsson and Österholm [34] investigated 24 qualitative articles on decision-making for persons with dementia. Although they found examples where the wish of persons with dementia were respected, exclusion of the person with dementia in decision-making processes was reported as the most frequent finding. Advance Care Planning (ACP) as a repeated process to plan for future care and treatment in line with the patients' values and preferences has been increasingly common within dementia care [35]. Also within this concept, exclusion of the person with dementia, often without giving account for why, was the most frequent finding in a systematic review, including 30 articles [36]. As the available support for persons with dementia is getting more specialized and individually adaptable, the amount of decisions being made concerning care and support is increasing accordingly. The informal caregivers' role in supporting the persons with dementia in decision-making processes should not be underestimated.

Still, to safeguard the human rights [20] of persons with dementia to take active part in decision-making processes, these processes needs to be adapted for this to take place. In a meta-ethnography on agency in dementia, Bosco et al. [37] reveals how acknowledging the persons as active agents and helping them maintain positive views of their abilities are important first steps to help them maintain autonomy. Further, they describe how persons with dementia can be supported in building strategies for making decisions on their own, such as by breaking decisions down to smaller units or using simple aids, such as a diary. In a recent study, we explored home-dwelling persons with dementia's perception on different support measures. We found that, when given time, space and adapted explanations, all participants reflected on hypothetical future scenarios and how support measures could be adapted to suit their needs, even when they had no prior knowledge of the measure [14]. Similarly, Smebye et al. [12] claims that the question of patient participation should not be *if,* but *how,* in line with the demand from the United Nations to support the patient to make decisions regarding their own care [20]. We recommend an increased emphasis on these aspects, both in the training of health care personnel and in the counselling of informal caregivers for persons with dementia, in line with the recommendations of the WHO [21]. In this way, we hypothesize that the coordinators through their counselling and support of the informal caregivers may obtain increased empowerment for the persons with dementia.

Implications for practice and further research

Based on the experiences in this study, we believe the framework for follow-up as presented is a feasible starting point for supporting informal caregivers for persons with dementia living at home. We also recommend that this follow-up start at an early time after a dementia diagnose has been set, both in order to build a strong relation to the dyads, but also to get necessary support in order at an early time. In a systematic review, Backhouse et al. [32] points to a general consensus of the importance of offering care coordination at the point of diagnosis. Based on the three functions we identified and the fluid borders between them, we recommend a flexible approach, with a trusting work environment where the coordinators are given space to distribute their time according to the shifting needs of the participating dyads. This also entails a supportive work environment where the coordinators are given room to reflect, share difficult emotions and mature in their roles.

Informal caregivers are crucial in the daily care for persons with dementia and they are deeply affected by the dementia condition [7, 38]. The concept of 'relational autonomy' [39, 40] highlights this role and emphasize the inclusion of informal caregivers and the persons' wider social context in decision-making processes. This should however not exclude the persons with dementia from participation where this is possible. Non-involvement or pseudo-autonomous decision-making by informal caregivers or healthcare personnel are serious moral and legal issues, denying the patient of basic human rights and depriving them of their status as a person [19]. Conversely, retaining autonomy is crucial for persons with dementia to sustain quality of life and dignity [15, 16, 18]. Additionally, although sometimes difficult to measure, we argue that focused attention on patient empowerment – anchored in an ontological perspective of caring [29] as well as in human rights [20, 21], naturally should include, and not exclude, persons with dementia. In the further development of the LIVE-trial we attempt to strengthen this perspective with more home visits and initiating a process of ACP involving the persons' general practitioners. This entails involving family members, general practitioners and other health care personnel in repeated, structured conversations, started at an early point in the dementia progression, where the person with dementia has the opportunity to share their wishes and values [22]. In this way, we aim to strengthen the inclusion of persons with dementia in decision-making processes, also on medical questions. This will also comply with the suggestions of starting ACP-process early and move the concept beyond questions of end-of-life care [35, 36, 41]. Informal caregivers of persons with dementia are subject to a high burden [7] and making difficult decisions on behalf of the person may increase emotional distress [42]. Healthcare personnel are requested to support persons with dementia to participate in decision-making processes [14, 20]. We recommend them to share this perspective with informal caregivers to increase patient participation in everyday decision-making. However, these are complex issues and the knowledge of how to enhance patient participation for this group is limited. We suggest an increased focus on this issue in future research. In line with recommendations from the WHO, we suggest that research upon these matters include the involvement of persons with dementia and their informal caregivers [2, 43].

Strengths and limitations

This study is based on interviews with eighteen stakeholders in an intervention with a relatively small number of participants. One of the reasons for not recruiting more of the persons with dementia who were part of the intervention in the interviews, was that we early got a clear apprehension that they were little involved in the interaction with the coordinators. Thus, we assumed that they might give limited contribution to answering the research questions. When asking about the coordinator follow-up in the interviews, the informal caregivers often took the word while the person with dementia showed signs of uncertainty. In order to safeguard the persons' integrity, in situ, the persons with dementia's views on this theme were not further pursued, except in the situations referred in the results part of the study. In retrospect, we realize that the issue of limited patient participation should have been more closely explored in the interviews and that we should have put more effort in exploring the experiences of the persons with dementia. A co-researcher with user experience was part of the research team throughout all faces of the study.

Conclusion

This study aimed at exploring the role and function of a coordinator for persons with dementia and their informal caregivers. Within systematic frames for a minimum frequency of contacts and overarching tasks, the coordinators were given quite free reins on how to adapt the follow up for the individual. We found that the coordinators fulfilled three functions in relation to the caregivers. That is, the function of representing a safety net; of being a pathfinder; and as a source for emotional care and support. To be able to fulfill their role as coordinator, a trusting working environment was emphasized. Further, we found that it was challenging for the coordinators to establish genuine relations in order to empower the persons with dementia in decision-making processes. This indicates a need for frequent meetings between coordinator and person with dementia and will be pursued in the main study of the LIVE-trial. Further research on how to establish sustainable, genuine patient participation on a broad scale for this group is required.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-020-05913-z.

Additional file 1.
Additional file 2.

Abbreviations

ACP: Advance Care Planning; LIVE: LIVE@Home.Path-trial; WHO: World Health Organization

Acknowledgements

We wish to thank the coordinators and the rest of the team at the collaborative municipal resource centre for dementia for their dedicated efforts to make this study possible. Further, we wish to thank the collaborative geriatric outpatient clinic, the Center for Learning and Mastery; the municipal volunteer coordinator, and the local Dementia Association for their cooperation.. BSH would like to thank the G.C. Rieber Foundation and the Norwegian Government for supporting our work at the Centre for Elderly and Nursing Home Medicine, University of Bergen, Norway. Finally, we wish to thank the participating dyads for being part of the study and sharing their experiences with us.

Authors' contributions

BSH has acquired funding for this study. FB was responsible for developing this study protocol and has acquired the ethical approvals. SEF had the main responsibility for running the intervention and for recruiting participants for the evaluation. SEF has been responsible for data collection and organizing the interpretive process and drafting this manuscript. OT contributed to the methodological approach for evaluating the intervention and operated as co-moderator in the focus group interviews. RS operated as a second co-moderator in the focus group interview with the coordinators and their leader. All authors have given substantial contributions through all parts of the process, have taken active part in the interpretive data analysis and have critically revised the manuscript. All authors have read and approved the final version of the manuscript, have agreed to be personally accountable for their own contributions and have ensured that questions related to the accuracy and integrity of any part of the work are properly investigated, resolved and documented.

Funding

The Dam Foundation (formerly The Norwegian ExtraFoundation for Health and Rehabilitation) [grant number: 2016/FO77186] with The Norwegian Women's Public Health Association as applicant organisation has funded the PhD-scholarship of SEF and thus the conduction of the study.

Availability of data and materials

All empirical data (sound recordings and transcriptions) are stored on a secure server at the University of Bergen. Due to ethical concerns, the material is not publicly available. Data will be deleted at the end of the project.

Ethics approval and consent to participate

All participants received written and oral information, adapted to the persons with dementia, on all aspects of the study. Both the persons with dementia and the informal caregivers gave written consent to participation. As they participated as a dyad, the informal caregivers' consent implied their approval of the persons with dementia's participation. In addition, the coordinators, as specialist nurses, assessed the persons with dementia's ability to consent through observation and clinical assessments. The template for the consent form is available on request. The study was approved by the Regional Committee for Medical and Health Research Ethics, Northern Norway. Reference: 2017/1519/REK Nord.

Consent for publication

The participants has given their consent for publication of anonymized data from the study.

Competing interests

The authors declare that they have no competing interests.

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Received: 3 January 2020 Accepted: 10 November 2020

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Publisher's Note

Appendix I

Interview Guide Study one

Intervjuguide

1. **Kan du si litt om deg selv og din bakgrunn**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse: Hvor kommer du fra? Hva har du drevet med? Hva har vært viktig for deg? Familie? Hobbyer?
2. **Kan du fortelle noe om hvilke tanker du gjør deg rundt det å ha demens?**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse: Umiddelbare reaksjoner, (uro, tap, håp, mestring?). Vet du noe om demens? Kjenner du andre som har (hatt) demens? Hvordan ser du deg selv i forhold til dem? Opplever du at hverdagen har blitt forandret? Eventuelt hvordan?
3. **Vil du fortelle litt om hjemmet ditt? Hva tenker du om det å bo hjemme i tiden fremover?**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse: Hva betyr hjemmet ditt for deg? Hvor lenge har du bodd her? Hva brakte deg hit? Spesielle minner? Ønsker du å bli boende hjemme? Hvor lenge? Hva må til for at du skal føle deg trygg hjemme? Hva er viktig for deg? Hvorfor er dette særlig viktig for deg? Hva er det viktigste aspektet som bidrar til at du kan bo hjemme?
4. **Har du pårørende (familie, naboer, venner) som hjelper deg i hverdagen? Hva tenker du om dette?**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse: Hva får du hjelp til? Hvem hjelper deg? Hvordan oppleves det å ta imot hjelp fra pårørende? Har du behov du ikke ønsker at pårørende skal hjelpe med – nå eller i fremtiden?
5. **Mottar du noen hjelp fra kommunen, utover dagsenter?**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse: Hva får du hjelp til? Hvordan oppleves det å ta imot hjelp? Positive/negative sider ved å ta imot hjelp – nedverdigende, trygt, hyggelig, invaderende? Hva tror du at du kan få behov for senere – hva tenker du om dette?
6. **Kunne du tenke deg å ta imot hjelp fra frivillige?**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse: Til hva? Er det noe du ikke ville ønsket hjelp til fra frivillige
7. **Hender det at du tenker at du skulle hatt mer hjelp enn du får nå med tanke på utfordringer i hverdagen?**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse: Hva? Hvorfor? Hva hindrer deg i å få hjelp til dette? Hvordan kunne dette vært tilrettelagt
8. **I dagens eldreomsorg blir det stadig mer vanlig med tekniske hjelpemidler. Hva tenker du om dette?**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse: Bruker du slike hjelpemidler selv? Kan det vært aktuelt for deg å skulle bruke slike

hjelpemidler i fremtiden? Hvilke? Til hva? Hva tenker du om at det blir mer vanlig med slike hjelpemidler?

9. **Har du gjort deg noen tanker om hvordan du vil ha det når livet går mot slutten?**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse: Ønsker du, slik du ser det i dag, å bo hjemme også når livet går mot slutten; å dø hjemme hvis det kan la seg gjøre? Uansett svar: hva vil da være viktig for deg? Hvorfor er dette særlig viktig for deg? Hva er det viktigste aspektet som kan bidrar til at du kan bo hjemme når livet går mot slutten?
10. **Er det noe annet du kunne tenke deg å snakke om?**
    a. Her kan intervjusamtalen eksempelvis bidra til å belyse sider som er viktig for deltakeren, men som ikke tidligere ikke er blitt snakket om i intervjusamtalen

Appendix II

Information and Consent Form Templates Study one

UNIVERSITETET I BERGEN
Institutt for global helse og samfunnsmedisin

Forespørsel om deltakelse i forskningsprosjektet

Å bo hjemme med demens – en kvalitativ studie

Vi kontakter deg fordi vi ønsker å invitere deg til å delta i en forskningsstudie knyttet til det å bo hjemme med demens. Studien er tilknyttet Senter for Alders- og Sykehjemsmedisin ved Universitetet i Bergen.

Nedenfor gis en oversikt over hva undersøkelsen innebærer. Ta den tiden du trenger til å avgjøre om du ønsker å delta i undersøkelsen. Diskuter gjerne vår forespørsel med familien din.

Bakgrunn

Stadig flere eldre bor hjemme lenger før de eventuelt får en plass på sykehjem. Mange ønsker også å tilbringe så lang tid som mulig i kjente og hjemlige omgivelser. Vi vet imidlertid lite om hva personer med demens tenker om disse temaene. Hensikten med denne studien er å få økt kunnskap om hva personer med demens tenker om det å bo hjemme.

Hva innebærer studien?

Vi ønsker å møte deg til en intervjusamtale på om lag 1- 2 timer. Om det er greit for deg vil samtalen tas opp på lydbånd slik at den kan skrives ned som en ordrett tekst og analyseres. Du kan selv velge om samtalen skal foregå hjemme hos deg selv, på et samtalerom ved Universitet i Bergen, eller et annet egnet sted. Ønsker du å ha med deg en person under samtalen så kan du det. Vi kan på forhånd avtale dekning av eventuelle reiseutgifter om dette blir aktuelt.

Mulige fordeler og ulemper

Å samtale med en annen person som er interessert i ens erfaringer kan være en positiv erfaring. Det å kunne bidra i å skape ny kunnskap som kan komme andre til gode kan også være en positiv erfaring for deltakere i studien. Samtidig kan mange av temaene i denne studien være utfordrende å forholde seg til og snakke om. Du får derfor en oversikt over temaene for samtalen slik at du kan tenke over om du er fortrolig med å delta i en slik samtale. Du står når som helst i samtalen fritt til å endre samtaleemne eller avbryte samtalen. Dette får ingen negative konsekvenser for deg.

Hva skjer med informasjonen om deg?

Informasjonen som registreres skal kun brukes i hensikt med studien. Alle opplysninger vil bli avidentifisert og konfidensielt behandlet. Ingen utenforstående vil kunne gjenkjenne deg i resultatene som publiseres. Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert og godkjent studien.

Frivillig deltagelse

Deltagelse i studien er selvsagt frivillig. Dersom du samtykker til å delta, men senere ombestemmer deg, kan du når som helst trekke deg fra studien uten å oppgi grunn. Dette vil selvsagt ikke medføre noen negative konsekvenser for deg. Alle data om deg vil da bli slettet. Om du ønsker det kan du få tilsendt studiens resultat når disse foreligger. Dersom du samtykker i å delta, vennligst undertegn samtykkeerklæringen som er vedlagt og returner denne til meg i den vedlagte konvolutten. Porto er betalt. Vi tar så kontakt for å avtale tid og sted for intervjuet.

UNIVERSITETET I BERGEN
Institutt for global helse og samfunnsmedisin

Ansvarlige
Intervjusamtalen vil bli gjennomført av Stein Erik Fæø, spesialsykepleier og stipendiat ved Universitetet i Bergen. Ansvarlige for studien er undertegnede, Oscar Tranvåg, postdoktor og Frøydis Bruvik, postdoktor.

Når du signerer vedlagte informasjonsskjema, bekrefter du at du har mottatt dette informasjonsbrevet og at du samtykker til deltagelse i studien.
Dersom du har spørsmål eller kommentarer, er du velkommen til å ta kontakt med Stein Erik Fæø på telefon 55 58 60 67.

Vennlig hilsen

B. A. Husebø

Bettina Husebø, PhD
Leder, Senter for Alders og Sykehjemsmedisin
Institutt for Global Helse og Samfunnsmedisin
Universitetet i Bergen
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UNIVERSITETET I BERGEN
Institutt for global helse og samfunnsmedisin

Samtykke til deltakelse i studien

INFORMASJONSSKJEMA

Jeg samtykker til å delta i studien «Å bo hjemme med demens – en kvalitativ studie» og å delta i intervju av 1-1 ½ timers varighet med doktorgradsstipendiat Stein Erik Fæø.

Jeg er klar over at samtykket er frivillig og at jeg når som helst kan trekke samtykket tilbake uten å gi noen grunn, og at dette ikke vil få noen konsekvenser for meg.

....
Signatur (deltager) Dato

....
Navn i blokkbokstaver

Oversikt over tema for samtalen

Vær oppmerksom på at disse spørsmålene kun er å forstå som en oversikt over aktuelle tema for intervjusamtalen og ikke et fastsatt manus. Dersom det er tema du føler deg ukomfortabel med å snakke om har vi full forståelse for dette.

1. **Kan du si litt om deg selv og din bakgrunn**
2. **Kan du fortelle noe om hvilke tanker du gjør deg rundt det å ha demens?**
3. **Vil du fortelle litt om hjemmet ditt? Hva tenker du om det å bo hjemme i tiden fremover?**
4. **Har du pårørende (familie, naboer, venner) som hjelper deg i hverdagen? Hva tenker du om dette?**
5. **Mottar du noen hjelp fra kommunen, utover dagsenter?**
6. **Kunne du tenke deg å ta imot hjelp fra frivillige?**
7. **Hender det at du tenker at du skulle hatt mer hjelp enn du får nå med tanke på utfordringer i hverdagen?**
8. **I dagens eldreomsorg blir det stadig mer vanlig med tekniske hjelpemidler. Hva tenker du om dette?**
9. **Har du gjort deg noen tanker om hvordan du vil ha det når livet går mot slutten?**
10. **Er det noe annet du kunne tenke deg å snakke om?**

Appendix III

Ethical Approval Study one

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK vest	Camilla Gjerstad	55978499	11.11.2016	2016/1630/REK vest
			Deres dato:	
			20.09.2016	

Vår referanse må oppgis ved alle henvendelser

Bettina Husebø
Universitetet i Bergen

2016/1630 Å bo hjemme med demens. En kvalitativ studie

Forskningsansvarlig: Universitetet i Bergen
Prosjektleder: Bettina Husebø

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK vest) i møtet 27.10.2016. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektomtale

Studien vil utforske hvordan personer med demens selv opplever det å bo hjemme, og hvilke tanker de har om å fortsette å bo hjemme. Studien vil gjennomføres i form av kvalitative intervju. Deltakerne er 10-15 samtykkekompetente personer over 65 år som har en demensdiagnose og som bor i eget hjem.

Vurdering

Forsvarlighetsvurdering
Komiteen anser studien som forsvarlig å gjennomføre og har ingen innvendinger til søknaden eller forskingsprotokollen.

Rekruttering og informasjonsskriv
Deltakerne er samtykkekompetente pasienter med demens og vil bli rekruttert gjennom kommunale dagsentre for personer med demens. Helsepersonell ved dagsentrene vil gjøre en individuell vurdering av samtykkekompetansen. Det vil bli innhentet skriftlig samtykke fra deltakere og muntlig samtykke fra pårørende der disse er tilgjengelig. REK vest har ingen merknader til rekrutteringen eller informasjonsskrivet.

Prosjektslutt
Data vil bli slettet ved prosjektslutt 14.08.18. REK vest har ingen merknader til dette.

Vedtak

REK vest godkjenner prosjektet i samsvar med forelagt søknad.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK vest på eget skjema senest 14.02.2019, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK vest dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

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.

Med vennlig hilsen

Ansgar Berg
Prof. Dr.med
Komitéleder

Camilla Gjerstad
kontorsjef

Kopi til: postmottak@uib.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK vest	Fredrik Rongved	55978498	30.08.2018	2016/1630/REK vest
			Deres dato:	**Deres referanse:**
			10.08.2018	

Vår referanse må oppgis ved alle henvendelser

Bettina Husebø
Senter for alders- og sykehjemsmedisin

2016/1630 Å bo hjemme med demens. En kvalitativ studie

Forskningsansvarlig: Universitetet i Bergen
Prosjektleder: Bettina Husebø

Vi viser til søknad om prosjektendring datert 10.08.2018 for ovennevnte forskningsprosjekt. Søknaden er behandlet av sekretariatet for REK vest på fullmakt, med hjemmel i helseforskningsloven § 11.

Vurdering

Ønsket endring

Prosjektleder ønsker å endre prosjektslutt fra 14.08.2018 til 31.12.2020.

Analysene har tatt noe lengre tid enn beregnet og prosjektgruppen ønsker å ha tilgang til transkripsjoner av intervjudata til artiklene er akseptert og doktorgraden er gjennomført. Data vil ikke bli brukt utover opprinnelig hensikt.

REK vest ved sekretariatet vurderte saken.

Vurdering

REK vest har ingen innvendinger mot ønsket endring.

Vedtak

REK vest godkjenner prosjektendringen i samsvar med forelagt søknad.

Klageadgang
Du kan klage på komiteens vedtak, jf. helseforskningsloven § 10 og 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.

Med vennlig hilsen

Fredrik Rongved
rådgiver

Kopi til: *post@uib.no*

Appendix IV

Interview Guide – Intervention Participants Study two

Intervjuguide - deltagere

Kan du/dere fortelle litt om dette prosjektet du/dere er med på?

Hva handler det om for deg? Hvorfor takket du ja til å være med? Forventninger? Hvilken informasjon fikk du i forkant? Tvil?

Hva har vært viktig for deg/dere i forbindelse med deltagelse i dette prosjektet?

Hvilken betydning har deltagelse hatt for deg? I dagliglivet? Generelt? Har noe endret seg – Hva/hvordan?

Hvordan opplever du/dere relasjonen til koordinatoren?

Begrensninger/muligheter? Trygghet/usikkerhet? Tilgjengelighet? Grad av oppfølging?

Har du/dere gjort erfaringer med… (en og en av komponentene LIVE)?

Hvorfor/hvorfor ikke? Hvordan? Hvordan var det? Hadde dere noe fra før? Hadde dere tenkt på noe av dette tidligere? Hva førte til at dere vurderte dette? Erfaringer? Hva kan bli aktuelt senere?

Hvordan opplever du/dere at deltagelse har påvirket deg/dere som enkeltpersoner?

Som ektepar/familie/(dyade)? Har forholdet til andre (familie/venner) endret seg?

Er det noe du/dere har savnet i prosjektet?

Hva kunne vært gjort annerledes? Har noe vært uklart?

Hva tenker du/dere om å svare på spørreskjema?

Spørsmålene, svaralternativene, settingen. Noen spørsmål/tema dere savner?

Hva tenker du/dere bør være neste skritt i utviklingen av tilbud rettet mot deg/dere og andre i samme situasjon?

Kan du/dere forsøke å beskrive 1-3 tiltak som hadde gjort hverdagen lettere/bedre for deg/dere?

Appendix V

Interview Guide – Coordinators Study two

Intervjuguide – koordinatorer

Kan du beskrive prosjektet som du har vært med på?

Hva handler det om for deg? Hvorfor takket du ja til å være med? Forventninger? Tvil?

Hvordan opplever du relasjonen til deltagerne?

Person med demens? Pårørende? Hvordan fortoner relasjonene seg? Hva kjennetegner gode relasjoner? Hva kjennetegner mindre gode relasjoner?

Deltagerne og de pårørende hadde ulik bakgrunn, sykdomshistorie, alder, nettverk og så videre – kan du si noe om hvordan dette har påvirket din tilnærming til den enkelte?

«Hva er viktig for deg?»-fokuset? Ulikheter i behov – til støtte, veiledning, tjenester, koordinasjon?

Hva tenker du om måten prosjektet var/er bygd opp?

Koordinator-rollen? LIVE-komponentene? Forløpet – hjemmebesøk, telefonkontakt? Tilgjengelige ressurser? Rammer og muligheter sett i forhold til målsetting.

Hvilke erfaringer har du gjort med å samarbeide med andre instanser som ledd i oppfølgingen?

Hvem/hva/hvordan/hvorfor? Hvordan har dette vært? Hva har vært din rolle? Hvordan finne balansen mellom å være en «snarvei» eller «omvei» til apparatet rundt? – Forvaltning kontra tjenester

Hvordan oppleves deltagernes forventninger?

Hvordan opplever du at du klarer å møte forventningene? Hva kjennetegner forventninger det kan være vanskelig å imøtekomme? Hvordan kan dette gjøres på en bedre måte?

Hvilke erfaringer har du med å tilby LIVE-komponentene til deltagerne? (Learning, ICT, Volunteers)

Hvilke holdninger har deltagerne? Hvilken virkning har oppfølging over tid – til å tenke over? Hvordan beskriver deltagerne sine erfaringer?

Hva tenker du om informasjonen/opplæringen du fikk ved oppstart av kurset?

Hva var bra? Hva var mangelfullt? Satt du igjen med ubesvarte spørsmål? Følte du deg klar for å gå i gang med oppgaven? Oppfølgingen underveis? Føringer?

Hvordan opplevde du spørreskjemaene ved første hjemmebesøk?

Spørsmålene? Svaralternativene? Settingen? Nytteverdi for videre oppfølging? Var det noe som opplevdes vanskelig/ubehagelig, eller positivt å spørre om? Åpnet for samtaler – innsikt man vanligvis ikke ville fått? Var det spørsmål dere savnet – som ville vært naturlig å ta med?

Hva er den viktigste lærdommen å ta med til fremtidige koordinatorer?

Appendix VI

Information and Consent Form Templates Study two

Forespørsel om deltakelse i forskningsprosjektet
«Bo hjemme med demens- hva er viktig for deg?»

Bakgrunn og formål

Personer som utredes for hukommelsesvansker har i liten grad kontakt med helsetjenesten det påfølgende året. Vi har derved begrenset kunnskap om hvordan dette året opplever, hvilke behov som oppstår og om mulige tiltak knyttet til omsorgsteknologi, frivillighet og undervisning om sykdommen kan gi en bedre hverdag med verdighet og sikkerhet hjemme. Målet med studien er å få innsikt i forhold som har betydning for livet med demens gjennom deltagernes egne erfaringer. Både personer med demens og deres nærmeste pårørende inviteres til å delta i studien.

Hva innebærer studien?

Deltagelsen innebærer 12 måneders oppfølging ved Lærings og Mestringssenteret eller ved kompetansesenteret for demens i Bergen kommune. I samtalene med deg vil vi kartlegge dine erfaringer og sammen med deg vurdere aktuelle tiltak som kan bedre din situasjon. Dette kan være tiltak knyttet til undervisning, teknologi, frivillige, planlegge egen fremtid og støtte og hjelp fra kommunehelsetjenesten. I løpet av dette året ønsker vi å intervjue deg to ganger samt at du fyller ut skjema med noen spørsmål om din bakgrunn, helsetilstand, livskvalitet og fungering i hverdagen. Du vil videre bli forespurt om vi kan kontakte deg på telefon for mulig årlig samtale de neste fem årene

Hva skjer med informasjonen vi har om deg?

Alle opplysninger behandles uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger slik at ingen data kan føres tilbake til den enkelte pasient verken i analysearbeidet eller når det skal publiseres. Resultatene vil publisert i et internasjonalt tidsskrift slik at det som kommer fram kan bli kjent for helsepersonell.

Informasjonen slettes når prosjektet er gjennomført og senest ved prosjektslutt, 31. desember 2024.

Mulige fordeler

Vi antar at deltagelse vil føre til økt livskvalitet for både deg og dine pårørende og reduksjon av hverdagsutfordringer som ofte følger din sykdom.

Frivillig deltagelse

Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Diskuter gjerne vår forespørsel med familien din.

Ansvarlige

Studien vil bli gjennomført av undertegnede og stipendiat Stein Erik Fæø, postdoc. Oscar Tranvåg, og professor Bettina Husebø alle tilknyttet Senter for alders- og sykehjemsmedisin Institutt for global helse og samfunnsmedisin, Universitetet i Bergen. Studien er meldt til Regional Etisk Komite.

Dersom du har spørsmål eller kommentarer, er du velkommen til å ta kontakt med Stein Erik Fæø (stipendiat) 922 62 081 eller Frøydis Bruvik (prosjektansvarlig): 482 48 234.

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og gir mitt samtykke til å delta i denne studien.

....
Signatur Dato

....
Navn i blokkbokstaver

Vennlig hilsen

Frøydis Bruvik, PhD
Haraldsplass Diakonale sykehus
og Senter for alders- og sykehjemsmedisin, Universitetet i Bergen
Kalfarveien 31, 5020 Bergen

UNIVERSITAS BERGENSIS

Haraldsplass
Diakonale Sykehus

Forespørsel om deltakelse i forskningsprosjektet
«Bo hjemme med demens- hva er viktig for deg?»

Til deg som er nære pårørende til en person som nylig har fått diagnosen demens

Bakgrunn og formål

Personer som etter utredning for hukommelsesvansker får diagnosen demens, har i liten grad kontakt med helsetjenesten det første året etter at diagnosen er satt. Vi har derfor lite kunnskap om hvilke ønsker og behov som oppstår i deres nye livssituasjon. Vi har også sparsom kunnskap om hvorvidt velferdsteknologi, bistand fra frivillige og økt kunnskap gjennom undervisning kan fremme opplevelse av en bedre hverdag med verdighet, livskvalitet og trygghet i hverdagen hjemme. Målet med studien er å utvikle økt kunnskap om dette gjennom å intervjue og samtale med personer som nylig har fått diagnosen demens g deres nærmeste pårørendes, om deres erfaringer knyttet til dette.

Hva innebærer studien?

Deltagelsen innebærer 12 måneders oppfølging ved Lærings og Mestringssenteret eller ved kompetansesenteret for demens i Bergen kommune. I samtalene med deg vil vi kartlegge dine erfaringer og sammen med deg vurdere aktuelle tiltak som kan bedre din situasjon. Dette kan være tiltak knyttet til undervisning, teknologi, bistand av frivillige, planlegge egen fremtid og støtte og hjelp fra kommunehelsetjenesten. I løpet av dette året ønsker vi å intervjue deg to ganger samt at du fyller ut skjema med noen spørsmål om din bakgrunn, helsetilstand, livskvalitet og fungering i hverdagen. Intervjusamtalene vil bli tatt opp på lydbånd slik at vi kan skrive disse ned ordrett for å kunne analysere opplysningene. Du vil videre bli forespurt om vi kan kontakte deg på telefon for mulig årlig samtale de neste fem årene. For å delta i denne studien må du signere samtykkeskjema på neste side.

Hva skjer med informasjonen vi har om deg?

Alle opplysninger behandles uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger slik at ingen data kan føres tilbake til den enkelte pasient verken i analysearbeidet eller når det skal publiseres. Resultatene vil bli publisert i et internasjonalt tidsskrift slik at det som kommer fram kan bli kjent for helsepersonell.

Informasjonen slettes når prosjektet er gjennomført og senest ved prosjektslutt, 31. desember 2024.

Mulige fordeler

Vi antar at deltagelse vil fører til økt livskvalitet for både deg og dine pårørende og reduksjon av hverdagsutfordringer om ofte følger din sykdom.

Frivillig deltagelse

Det er frivillig å delta i studien, og du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Diskuter gjerne vår forespørsel med familien din.

Ansvarlige

Studien vil bli gjennomført av undertegnede og stipendiat Stein Erik Fæø, postdoktor Oscar Tranvåg, og professor Bettina Husebø alle tilknyttet Senter for alders- og sykehjemsmedisin Institutt for global helse og samfunnsmedisin, Universitetet i Bergen. Studien er godkjent av Regional Etisk Komite. **Dersom du har spørsmål eller kommentarer, er du velkommen til å ta kontakt med Stein Erik Fæø (stipendiat) 922 62 081 eller Frøydis Bruvik (prosjektansvarlig): 482 48 234.**

Vennlig hilsen

Frøydis Bruvik, PhD
Haraldsplass Diakonale sykehus og Senter for alders- og sykehjemsmedisin, Universitetet i Bergen

Samtykke til deltakelse i studien

Jeg har mottatt informasjon om studien, og gir mitt samtykke til å delta i studien «Bo hjemme med demens- hva er viktig for deg?»

....

Signatur Dato

....

Navn i blokkbokstaver

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

Dette er et spørsmål til deg om å delta i dybdeintervju i forbindelse med din rolle i forprosjektet til LIVE@Home.Path.

HVA INNEBÆRER PROSJEKTET?

Med tanke på den oppfølgingen du gir deltakerne i prosjektet ønsker vi å gjennomføre et intervju med deg for å få ta del i noen av de erfaringene du har gjort deg. Dette vil enten skje i form av en fokusgruppe, der du vil bli intervjuet sammen med andre involverte, eller du vil bli intervjuet alene av en forsker. Her vil vi spørre deg om hvilke erfaringer du har gjort deg i løpet av prosjektperioden, hva du opplever har fungert godt, hva som har fungert mindre godt og så videre.

Intervjuet vil bli spilt inn på en digital opptaker og transkribert til tekst. Opptaket vil kun bli hørt av den samme personen som intervjuet deg og alle identifiserbare opplysninger vil bli avidentifisert i transkriberingsprosessen. Et lite utvalg forskere vil få tilgang til den transkriberte teksten og alle data vil bli konfidensielt behandlet.

MULIGE FORDELER OG ULEMPER

Intervjuet vil vare mellom 1-2 timer og vil ha form av en samtale. Vi håper at deltakelse i intervjuet vil føre til at du får mulighet til å reflektere nærmere over de erfaringer du har gjort og at deltakelse vil oppleves positivt. Samtidig kan en slik samtale lede til erkjennelse av vanskelige sider som en kanskje ikke har vært oppmerksom tidligere. Vi oppfordrer deg derfor til å ta kontakt med oss eller en god kollega hvis det oppstår vonde følelser i etterkant av intervjuet.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i intervju. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din arbeidssituasjon eller tilknytning til prosjektet. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet innsamlede data, 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 Stein Erik Fæø, 55 58 60 61, stein.fao@uib.no eller Frøydis Bruvik, (telefon), froydis.bruvik@uib.no.

HVA SKJER MED OPPLYSNINGENE OM DEG?

Opplysningene 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. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger. Det er kun Stein Erik Fæø som kjenner denne koblingen.

Opplysningene om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og har gitt forhåndsgodkjenning **[2017/1519]**

KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet kan du ta kontakt med Stein Erik Fæø, 55 58 60 61, stein.fao@uib.no eller Frøydis Bruvik, (telefon), froydis.bruvik@uib.no.

JEG SAMTYKKER TIL Å DELTA I PROSJEKTET OG TIL AT OPPLYSNINGER FRA MEG BRUKES SLIK DET ER BESKREVET

Sted og dato

Signatur

Rolle i prosjektet

Appendix VII

Ethical Approval Study two

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK nord			29.09.2017	2017/1519/REK nord
			Deres dato:	**Deres referanse:**
			08.08.2017	

Vår referanse må oppgis ved alle henvendelser

Frøydis Bruvik
Fagavdeling

2017/1519 Bo hjemme med demens- hva er viktig for deg?

Forskningsansvarlig institusjon: Universitetet i Bergen
Prosjektleder: Frøydis Bruvik

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 14.09.2017. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10.

Prosjektleders prosjektomtale
Studien søker ny kunnskap om hjemmeboende personer med demens og dere nærmeste. Pasientgruppen utgjør >40 % av tjenestemottakerne i primærhelsetjenesten og >80 % av beboerne på sykehjem. Det er forventet en dramatisk økning i antall personer med demens de kommende tiårene. Tidligere studier har i liten grad identifisere tiltak som forebygg belastning og opprettholder livskvalitet i denne pasient og pårørendepopulasjonen. Det antas at variasjonen i sykdomsutvikling, kompleksitet i behov og derav behov for individualiserte tiltak er noe av forklaringen for dette. Gjennom studien søke vi kunnskap om hvilke behov som oppstår første år etter diagnostisering og hvordan aktuelle tiltak kan nyttiggjøres ev den enkelte. Fokus på tidlig fase i demensforløpet gir et potensiale til å person tilpasse oppfølging samt forebygge noen av de negative konsekvensene ved Kunnskap vil videre legge grunnlag for en større intervensjonsstudie som planlegges.

Vurdering

Om prosjektet
I dette prosjektet vil man undersøke de individuelle subjektive perspektivene og erfaringene hos hjemmeboende personer med demens (PMD) og deres nære pårørende det første året etter diagnostisering. Studien vil organiseres som systematisk oppfølging med fokus på "dette er viktig for meg" knyttet til læring og mestring av demens, muligheter og begrensninger i forhold til velferdsteknologi og bistand fra frivillige samt planlegge egen fremtid.

Oppfølgingsprogrammet er organisert som «case management» og inkluderer følgende elementer;
a) Læring og mestring,
b) Teknologi (IKT),
c) Bistand fra frivillige,
d) Forberedende samtaler.

Individuell oppfølging vil identifisere brukernes ressurser, behov, verdier og ønsker, og barrierer for vellykket gjennomføring av intervensjonen.

Forskningsansvarlig institusjon
Prosjektleder er ansatt både ved Haraldsplass Diakonale Sykehus og Universitetet i Bergen, prosjektmedarbeiderne er ansatt ved Universitetet i Bergen og pasientene skal rekrutteres fra Haraldsplass Diakonale Sykehus. Komiteen legger til grunn at begge institusjonene er forskningsansvarlige.

Metode
Hjemmeboende personer med demens og deres pårørende vil bli intervjuet med lydopptak og det skal også brukes spørreskjema.
Prosjektet innebærer tolv måneders oppfølging og man vil forespørre deltagerne om å kunne kontakte dem årlig i fem år med hensyn til kartlegging av deres erfaring knyttet til igangsatte tiltak.

Det opplyses i søknaden at samarbeidspartner ved University of Yale vil delta i analyse av av-identifiserte data. Dette fremgår verken av protokoll eller informasjonsskriv. Dersom samarbeidet rent faktisk innebærer mer enn bare omtalte analysearbeid så må dette beskrives nærmere.

Deltakere
Det tas sikte på å inkludere 20 pasienter som vurderes å ha kompetanse knyttet til å forstå informasjon og betydning av deltagelse i studien og deres pårørende – totalt 40 personer.

Rekruttering
Det opplyses i protokollen at 20 personer med PMD som nylig har gjennomført utredning og er diagnostisert med demens og deres nære pårørende vil rekrutteres fra geriatrisk poliklinikk ved Haraldsplass Diakonale Sykehus og kommunehelsetjenesten/ hukommelsesteam. Prosjektleder har redegjort for rekrutteringen slik:
«Etter at utredning ved poliklinikker er gjennomført og det er konkludert med diagnose vil sykepleier og/ eller ved poliklinikken informere pasienter og pårørende om studien, muntlig og skriftlig. Henvisningen til oppfølging og deltagelse i studien vil så skje gjennom denne etablerte kontakten. Også når det gjelder pasienter fra kommunehelsetjenesten vil det etableres kontakt med hukommelsesteam som informerer om studien skriftlig og muntlig for så å formidle kontakt til oppfølgingen.»

Komiteen har ingen innvendinger mot dette, men minner om at dersom forskningsdeltakeren kan anses å være i et avhengighetsforhold til den som ber om samtykke slik at forskningsdeltakeren vil kunne føle seg presset til å gi samtykke, skal det informerte samtykket innhentes av en annen som forskningsdeltakeren ikke har slikt forhold til jf. helseforskningsloven § 13.

Selv om det er personell med trening og erfaring som skal vurdere om en person kan forespørres om å delta understreker REK at det til syvende og sist er prosjektleders ansvar å vurdere om personen er samtykkekompetent.

Vedtak
Med hjemmel i helseforskningsloven §§ 2 og 10 godkjennes prosjektet.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK nord på eget skjema senest 30.06.2025, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK nord dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

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

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Kopi til:postmottak@uib.no; Bettina.Husebo@uib.no; Oscar.Tranvag@uib.no; Stein.Feo@uib.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK nord	Monika Rydland	77620756	03.01.2019	2017/1519/REK nord
			Deres dato:	**Deres referanse:**
			22.12.2018	

Vår referanse må oppgis ved alle henvendelser

Frøydis Bruvik
Fagavdeling

2017/1519 Bo hjemme med demens- hva er viktig for deg?

Forskningsansvarlig institusjon: Universitetet i Bergen
Prosjektleder: Frøydis Bruvik

Vi viser til søknad om prosjektendring datert 22.12.2018 for ovennevnte forskningsprosjekt.

Søknaden er behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) ved sekretariatsleder, på fullmakt gitt av komiteen med hjemmel i forskningsetikkforskriften § 7, første ledd, andre punktum. Søknaden er vurdert med hjemmel i helseforskningsloven § 11.

Vurdering

Av søknaden fremgår det at det søkes om godkjenning for å gjennomføre fokusgruppeintervju med fagpersonene som har gjennomført intervensjonen i prosjektet.
Isolert sett ville det omsøkte kunne gjøres uten godkjenning av REK, men søknaden er behandlet fordi det er en del av prosjektet. REK forutsetter at de som blir intervjuet ikke skal bryte sin lovpålagte taushetsplikt som helsepersonell.

REK har ingen innvendinger til omsøkte endring, men gjør oppmerksom på at følgende avsnitt fra ny mal for informasjon og samtykke må settes inn i avsnittet "Godkjenning", etter opplysning om saksnummer hos REK:

"Etter ny personopplysningslov har dataansvarlig ***[Sett inn navn på dataansvarlig]*** *og prosjektleder* ***[sett inn navn på prosjektleder]*** *et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2 og ditt samtykke.*

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet."

Etter fullmakt er det fattet slikt

vedtak

Med hjemmel i helseforskningsloven § 11 godkjennes prosjektendringen.

Endringen godkjennes under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, endringssøknaden, oppdatert protokoll og de bestemmelser som følger av helseforskningsloven med forskrifter. For øvrig gjelder de vilkår som er satt i forbindelse med tidligere godkjenning av prosjektet.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding på eget skjema senest et halvt år etter prosjektslutt, jf. helseforskningslovens § 12. Dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden må prosjektleder sende søknad om prosjektendring til REK, jf. helseforskningslovens § 11.

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

Med vennlig hilsen

May Britt Rossvoll
sekretariatsleder

Monika Rydland
rådgiver

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NORDIC ECOLABEL 241 PRINTED MATTER 731

Graphic design: Communication Division, UiB / Print: Skipnes Kommunikasjon AS

uib.no

ISBN: 9788230851081 (print)
9788230868386 (PDF)