

Lived experiences of frailty among home-dwelling older people and family caregivers

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Scientific environment

This thesis was prepared during my PhD project from April 2018 to February 2023 at the Department of Global Public Health and Primary Care, Faculty of Medicine, University of Bergen. Norway's Ministry of Education and Research funded the project with a scholarship to the Western Norway University of Applied Sciences. I attended the Research School in Public Health Care courses at the University of Bergen and the Norwegian Research School for Research and Development of Municipal Health and Care (MUNI-HEALTH-CARE) at the University of Oslo. I have also participated in courses in qualitative methods at Aalborg University and Volda University College.

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family caregivers, raising awareness of how health-care providers can meet their needs by providing individually based care.

I am thankful for my opportunity to immerse myself in a subject close to my heart. The focus and interest surrounding home-dwelling older people and their family caregivers have sustained my attention over many years and will continue to do so when meeting frail older people within education and further research. Thanks to family and friends for commitment, support, hikes, training sessions and conversations. They have been invaluable in gathering the strength to carry out the project.

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Bente Egge Søvde, March 2023

Summary in Norwegian

Bakgrunn: Ei aldrande befolkning, aukande førekomst av skrøpelighet med alderen, og nedsett evne til å utføre daglegdagse aktivitetar, synleggjer utfordringane for den enkelte som lever med skrøpelighet, deira pårørande og helsevesenet.

Mål: Denne studien hadde som mål å utforske dei levde erfaringane til heimebuande eldre som lever med skrøpelighet og deira pårørande.

Metode: Studien har et kvalitativt design forankra i fenomenologi. Dei gjennomførte djupneintervjua med 19 deltakarar, ti eldre som levde med skrøpelighet og ni pårørande i alderen 54-90 år, i deira eigen heim, gav eit rikt materiale. Sentrale teoretiske perspektiv er forankra hos Heidegger. Eksistensialene levd kropp, levd stad, levde relasjonar og levd tid vart brukt i analysearbeidet.

Funn: Den første artikkelen utforska dei levde erfaringane til heimebuande skrøpelege eldre relatert til kroppen, og deltakarane sin balanseong mellom skrøpelighet, styrke og en kropp i stadig endring. I den andre artikkelen utforska vi erfaringane med å meistre livet i grenseland mellom heim og sjukeheim. I situasjonen deltakarane var i, var det viktig å gjenvinne ei kjensle av å kjenne seg heime, uavhengig av kvar dei budde. I den tredje artikkelen, utforska vi erfaringane til pårørande som streva etter å tilpasse seg ein omsorgsprosess som var meiningsfull, men også uføreseieleg og krevjande.

Konklusjon: Samhandlinga skrøpelege heimebuande eldre hadde med omgjevnadane endra seg ettersom kroppen gradvis miste sin tidlegare kapasitet. Likevel hadde dei styrke og vitaliteten til å bu heime med støtte av andre. Pårørande levde doble liv, der dei måtte ta seg av eigen familie, arbeid og sosialt liv, og omsorgsansvaret kunne overgå kapasiteten deira, sjølv om dei prøvde å førebu seg.

Konsekvensar: Skrøpelighet kan overskygge vitalitet, og helsepersonell bør vere klar over dette når de yter og planlegg omsorg for desse menneska. Å inkludere skrøpelege eldre og pårørande i planlegging av omsorg er avgjerande for å finne ut kva som er nødvendig for å klare livet heime no og i framtida.

Summary

Background: The aging population, increasing incidence of frailty with age and increased risk of reduced ability to carry out everyday activities reveal the challenges for the individuals living with frailty, their caregivers and the health-care system.

Aim: This study aimed to explore the lived experiences of frail home-dwelling older people and their family caregivers.

Methods: The study had a qualitative design rooted in phenomenology. Central theoretical perspectives are anchored in Heidegger, and the existential terms lived body, lived place, lived relationships and lived time were used in the analysis work. The in-depth interviews with 19 participants, 10 frail older people and nine family caregivers 54–90 years old, in their own homes, provided rich material.

Findings: The first article explores the lived experiences of frail home-dwelling older people related to the body and the participants' balancing act between frailty, strength and the constantly changing body. In the second article, we explored the experiences of coping with life at home on the verge of moving to a nursing home. In the participants' situation, regaining a feeling of being at home was essential, regardless of where they lived. In the third article, we explored the experiences of family caregivers who struggled to adapt to a caregiving process that was meaningful but also unpredictable and demanding.

Conclusion: Frail home-dwelling older peoples' interaction with their surroundings changed as the body gradually lost its earlier capacity. Yet, they had the strength and vitality to continue their lives at home with support from others. Family caregivers lived double lives and had to care for their families, work and social life, and the caring responsibility could overwhelm their capacity, even if they tried to prepare.

Consequences: Frailty can overshadow vitality, and health-care personnel can be aware of this when they provide and plan care for these people. Including frail older people and family caregivers in planning care is crucial to determine what is essential to manage life at home now and in the future.

List of publications

Paper 1

Søvde BE, Sandvoll AM, Natvik E, Drageset J (2022). In the borderland of the body: how home-dwelling older people experience frailty. *Scand J Caring Sci.* 2022;36(1):255–264. doi:10.1111/scs.12984

Paper 2

Søvde BE, Sandvoll AM, Natvik E, Drageset J (2022). Carrying on life at home or moving to a nursing home: frail older people's experiences of at-homeness. *Int J Qual Stud Health Well-being.* 2022;17(1):2082125. doi:10.1080/17482631.2022.2082125

Paper 3

Søvde BE, Sandvoll AM, Natvik E, Drageset J. Caregiving for frail home-dwelling older people: a qualitative study of family caregivers' experiences. In preparation.

The papers are reprinted with permission from the *Scandinavian Journal of Caring Sciences* and *International Journal of Qualitative Studies on Health and Well-being*.

1. Introduction

“We who are old know that age is more than a disability. It is an intense and varied experience, almost beyond our capacity at times, but something to be carried high. If it is a long defeat, it is also a victory, meaningful for the initiates of time, if not for those who have come less far” (Scott-Maxwell, 2013, p. 5).

In *The measure of my days*, playwright and Jungian analyst Florida Scott-Maxwell (2013) explores the unique predicament of later years: a period of life when one feels cut off from the past and out of step with the present. She highlights the struggles that accompany us throughout our lives: how to achieve well-being, maintain individuality in mass society, and escape suffering, loss and limitation. Researcher Julia Pusztai (2015) shares this field of interest. In her doctoral thesis, she examined older people’s lived experiences of aging. She describes aging as a distinct season of life, with increased, varied and cumulative changes involving loss of some kind: hearing, sight, a loved one, an important role, a pain-free life, driver’s license, loss of physical balance or loss of walking free without a cane or walker, a list that grew with frailty.

Many older people who experience aging adapt to new diagnoses, prescriptions and living and social conditions. Further, these changes and losses also require health care, medication, assistance with everyday activities and socialization. Krystal Warmoth (2015) explored frailty and its different understandings in her doctoral thesis. She described the challenges when health-care professionals, researchers, policy-makers and laypeople categorize people in the later stages of life or approaching death as frail. How they understand and use the term differ, and the older people did not use the term frail about themselves.

The participants in this thesis study¹ are part of a generation born in 1946 or earlier who were Great Depression–era children and World War II young adults, and this historical context weaved into their lives. People’s lives have changed significantly in

relation to health, employment and the duties relating to the home and family caregiving in recent centuries. The duties in the home and family have especially changed for women. The participants in this study experienced both the heydays of being homemakers followed by the rise of women students in higher education, the discovery of penicillin, the eradication of polio, the moon landing, the explosion of computer technology and human genome mapping.

In Norway, this group experienced the discovery of oil in the North Sea, economic growth and women prime ministers. Unlike other age groups, this cohort now comprises more women than men, has many people who are institutionalized, most likely have some type of chronic disease and consume more health-care money and health services than other birth cohorts. The participants in this thesis are admittedly the survivors, outliving most of the others in this birth cohort. Nevertheless, they are compared with the other survivors of their birth cohort who still are fit and robust.

I have worked closely with frail older people and their family caregivers for many years, even if we did not use the term frail. I worked as a home health-care nurse in the early 2000s, and we discussed how to care for vulnerable people who became more ill from infections and varied considerably in general condition and functional level. Planning care for these people was challenging because of their unpredictable health and diffuse problems. There was no known diagnosis or recommendations for how to follow up on these people, apart from extra awareness of changes in their general condition, which required that we know the person and their usual condition. The constant development in frailty research makes me optimistic about the progress in mapping who these people are, finding the proper treatment and, hopefully, preventing frailty. In addition, I think having insight into how it feels to live with a body in disrepair and constantly lose strength and skills is essential. The study intended to explore and subsequently inform the development of current and future nursing and health practice and health and social policy. A growing body of literature has explored the concept of frailty as a medical and natural science phenomenon. However, research exploring the frailty experience from the perspectives of home-dwelling older people and their family caregivers is lacking. This study aims to

contribute to understanding of and knowledge about frailty. I hope to offer nurses and other health-care providers insight that can support and point care in more holistic and meaningful ways to address the needs of unique opportunities and meaning for frail home-dwelling older people and their family caregivers.

1.2 Health and aging

Life expectancy has increased markedly worldwide over the past century because of improved public health. The health status of older people appears to be changing, and older people generally have an increasingly better level of health and functioning (Chang et al., 2022; Storeng et al., 2021; WHO, 2017b). This demographic change has resulted in increasing numbers of older adults in low- and middle-income and high-income countries. Between 2000 and 2050, the percentage of people 60 years or older in the world is estimated to double from about 11% to 22%, an increase from 605 million to 2 billion. The number of people older than 80 years is expected to quadruple to 395 million in the same period (United Nations, 2020). Older adults are a heterogeneous group in which health and functional status vary considerably depending on their genetic, biological and environmental background and other physical, mental and social factors. Individuals with the same chronological age may therefore have different biological ages (Diebel & Rockwood, 2021).

This research project has defined older people as people 65 years and older, but there are challenges related to defining when a person is older (WHO, 2017a). First, at the biological level, aging results from a wide range of molecular and cellular damage over time, leading to a gradual decline in mental and physical capacity, increased risk of illness and, ultimately, death. Second, socioeconomic factors such as people's social and physical environments – including their homes, neighborhoods and communities combined with their personal characteristics – have long-term effects on how people age, directly or through barriers or incentives that influence opportunities, decisions and health behavior. Nevertheless, these changes are neither linear nor consistent and are only loosely associated with a person's chronological age (WHO, 2017a).

Hirshbein (2001) provided insight into views of old age in the United States and argued that the aging person's experience is influenced by their era. In the 1930s and 1940s, professionals started to see old age as a specific medical and social problem that must be solved. Older people became a specific population that required other groups to organize care for them. In the 1940s, older people became a "national problem" that needed a solution (Hirshbein, 2001). Further, there has been a distinction between the third and fourth ages. Expanding literature about the third age and various representations as active, healthy and successful might obscure the darker elements of aging, known as the fourth age, which might be a feared imagination of what old age is, rooted in the visual experience of frailty and dependence, which implies the inability to maintain autonomy and independence in daily life (Higgs & Gilleard, 2016).

There is no definition of old age on which everyone can agree, but the EU's age limit, based on the most common retirement age and used for statistical claims that people 65 years and older can be considered older people, is used here for pragmatic reasons (Norwegian Institute of Public Health, 2023; WHO, 2017b).

According to WHO, 142 million people 60 years and older cannot meet the basic needs required for a meaningful life in their environment. This means they need support to get dressed, take medication or manage their money, bills or finances (United Nations, 2020). The reasons they need help with certain tasks are complex and, in many cases, unclear, but there is broad agreement that frailty affects the ability to carry out everyday activities. Further, a systematic review by Xu et al. (2021) found that age, cognitive impairment, depressive symptoms, risk of disability in the activities of daily living, malnutrition and poor self-rated health were all risk factors for frailty.

Data from Europe show that 60% of older people living at home receive informal care from family caregivers, friends and neighbors. Informal care refers to unpaid help to others because of a health condition or limitations related to aging. Awareness has been growing in health policy of family members' important contribution to the

care of frail older people living at home and the relationship between care burden and frailty (Eurostat, 2019; Plöthner, Schmidt, de Jong, Zeidler, & Damm, 2019; Szebehely & Meagher, 2018; United Nations, 2020). The public sector primarily finances and provides home care in Norway and other Nordic countries. However, this presupposes increased demand for home care organizations in Norway and greater responsibility for family caregivers when older people continue to live at home. The literature refers to family caregivers as informal caregivers or caregivers. In this research project, family caregivers refer to spouses, children, siblings and in-laws who regularly provide non-professional care.

A significant policy related to aging at home or aging-in-place has been a trend for several decades (Bookman, 2008; Walker & Maltby, 2012; Walker, Johns, & Halliday, 2015). The main focus has been on enabling frail older people to live at home if possible and with appropriate support, even if they take risks to maintain their independence (Grenier, Phillipson, & Settersten, 2020; Skilbeck, 2014). In an interview study, Zingmark, Norberg and Sandman (1995) described the phenomenon of being at home as being in meaningful relationships with significant others, things, places and activities. Gillsjø & Schwartz-Barcott (2011) also emphasize these issues in their concept analysis of meanings of home among older women: they found that relationships and experience, as well as place, were considered things to be attached to, feel comfortable and secure with and were related to stories of making a home, both in the sense of having a house and finding a secure and comfortable place in the world. Öhlén et al. (2014) describe the home as a place where people are familiar with the surrounding place and feel safe, connected and centered. Saarnio elaborates on this and claims that having time to get to know new people and places is essential for how older people experience being at home (Saarnio, 2018). In addition, Molony's (2010) meta-synthesis describes the home as a place where one has a personal space with the opportunity to set up a schedule and choose activities.

Thus far, the literature has identified several challenges related to aging and declining health. Munkejord et al. (2018) study underlined that treatment and care were taken care of. Yet, a weaker recognition of social and emotional needs led to a higher risk

of loneliness and unmet needs. Likewise, most older people value continuing to live at home in older age, given that their health and functional level allows it (Munkejord et al., 2018). Before explaining these challenges further, I present the frailty concept, which represents a significant cause of health problems in older age and is the main issue for this project.

1.3 Living with frailty

Frailty is a global public health problem that affects individuals, families, communities and society (Lekan, Collins, & Hayajneh, 2021). Frailty emerged in the context of managed care in the United States in the late 1980s through the practices of health-care providers, including a focus on individual risk measured through standard assessment of bodily functions (Kaufman, 1994). WHO (2017b) defines frailty as a clinically recognizable state in which increased vulnerability brought by age-associated declines in physiological reserve and function across multiple organ systems compromises the ability of older people to cope with everyday or acute stressors (WHO, 2017b, p. 10). In clinical practice and research, frailty is a vital health characteristic, and the rapid growth of the aging population in terms of numbers and longevity has drawn global attention to the needs of frail older people. The term frail broadly describes a person's vulnerability and risk of developing health problems (Cesari, 2019; Junius-Walker et al., 2018). Specifically, frailty has been defined as a syndrome and age-related accumulation of deficits across multiple body systems that result in a dynamic risk state (Rockwood & Howlett, 2018). Frailty may therefore predict outcomes such as dependence and hospitalization more accurately than age or comorbidities, and reduced well-being and frailty can lead to impaired quality of life and loneliness (Durepos et al., 2021; Hoogendijk et al., 2019; Langholz, Strand, Cook, & Hopstock, 2018; Maxwell & Wang, 2017; Warmoth, 2013).

Over the past 15 years, frailty has emerged as one of the most powerful constructs in gerontology, geriatrics and health care, and researchers have highlighted the clinical importance of the concept (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013; Fried

et al., 2001; Gorman, 2015; Op Het Veld et al., 2015; Puts et al., 2007; Xue, 2011). Fried's frailty phenotype and Rockwood's cumulative model are the most commonly used methods in categorizing frailty (Zhang, Tang, Dou, Luo, & Sun, 2022). The phenotype model comprises five physical components to define frailty: unintentional weight loss, self-reported exhaustion, weakness, slow walking speed and low physical activity. Individuals are considered frail when they meet three or more criteria and robust when they have none. Individuals with one or two criteria are defined as prefrail, a state between robust and frail (Fried et al., 2001). The cumulative deficit model proposed by Rockwood and Mitnitski (2010) provides a frailty index based on the presence of deficits as a proportion of the total measured. They assumed that lost functions could culminate with aging and lead to an increased risk of illness complications. Several other indices, checklists and indicators have been proposed for frailty screening (Clegg et al., 2016; Pialoux, Goyard, & Lesourd, 2012; Romero-Ortuno, Walsh, Lawlor, & Kenny, 2010). These instruments can be used to grade the severity of frailty, thereby identifying individuals who might benefit most from a palliative approach and advanced care planning (Amblàs-Novellas et al., 2016).

Frailty has become a compelling global public health issue, and the rapid growth of the aging population has drawn global attention to the needs of frail older people (Lekan et al., 2021; Rockwood & Howlett, 2018). The following chapter presents the commonness of frailty and some important risk factors.

1.3.1 How common is frailty?

Age is an important risk factor for frailty. Frailty affects around 10% of people 65 years and older, affecting about 65% of those 90 years and older. Kojima et al. (2019) say that the frailty criteria used may change the results.

Populations with specific conditions and diseases have a higher prevalence of frailty, such as people with cancer (Handforth et al., 2015), end-stage renal disease (Kojima, 2017) and heart failure (Denfeld et al., 2016), nursing home residents (Kojima, Iliffe, Jivraj, & Walters, 2016) and people living in rural areas (Xu et al., 2021). Although

the risk of becoming frail increases with age, the individual course of frailty varies, and frailty can be reduced, even in old age, by building muscular strength and increasing fitness through diet and exercise (Collard, Boter, Schoevers, & Oude Voshaar, 2012; Kehler et al., 2017; Kojima, Taniguchi, Iliffe, Jivraj, & Walters, 2019; Ma et al., 2018; Puts et al., 2016). Studies over the past two decades have provided important information on frailty, and frailty screening is increasingly recommended in primary care (Travers, Romero-Ortuno, Bailey, & Cooney, 2019).

Nevertheless, guidance is lacking on what to do when frailty is identified.

Treatment and care aimed at preventing undesirable outcomes of frailty may therefore fail to meet the needs and desires of older people (Næss, Wyller, Kirkevold, & Næss, 2019; Obbia, Graham, Duffy, & Gobbens, 2019). However, once frailty is established and develops, other geriatric syndromes are more likely to occur, including falls, incontinence, rapid functional decline, pressure ulcers, mild cognitive impairment and delirium (Dent et al., 2019). The aging population and the rising prevalence suggest that frailty should be a public health priority since older people living at home as long as possible and avoiding unnecessary hospitalization is a political goal (Cesari et al., 2016; Turner & Clegg, 2014). Increasing the knowledge of the social context of home-dwelling older people living with frailty is therefore important.

1.3.2 Frailty and society

Aging populations worldwide face the challenge of maintaining good care for older people despite increasing longevity and demographic changes (Clegg et al., 2013; Fried et al., 2001; Hoogendijk et al., 2014; Kojima, Liljas, & Iliffe, 2019; Kojima et al., 2019). Caring for people with frailty means maintaining functional independence and quality of life while avoiding unnecessary hospitalization or long-term care (Turner & Clegg, 2014). Health-care professionals must therefore assess whether medical and surgical interventions can save lives, restore and maintain health or harm frail older people. Knowing which outcomes are important for frail older people and their family caregivers is essential for planning and providing good care for this

group of people (Gordon et al., 2022). However, using the concept of frailty can be problematic since it results in a group of older people being categorized according to impairment and loss (Grenier et al., 2020).

Naturally, this requires a focus on older people, their aging and health; optimistically, the perspectives on older people have changed over the past decades. There has been an expansion from focusing on dependence and vulnerability to including health, well-being and quality of life in recognized international organizations focusing on healthy aging and the fight against ageism (United Nations, 2020; WHO, 2017a, 2020). The strong emphasis on individuals who can take responsibility for their health and services does not fully reflect who needs home health care. For example, frail older people with complex needs cannot be self-reliant, active and responsible for their own health (Andersen, Hoeck, Nielsen, Ryg, & Delmar, 2020; Fjørtoft, Oksholm, Førland, Delmar, & Alvsvåg, 2022). Likewise, supporting people to live in homes that are right for them —meeting their needs and attending to their preferences—is right at any age (Norwegian Institute of Public Health, 2023). The United Nations Decade of Healthy Ageing 2021–2030 invited governments, civil society, international agencies, academia and media to collaborate to improve older people’s lives, including their families and communities (United Nations, 2020).

Family caregiving refers to unpaid assistance to other people because of health conditions or limitations associated with aging (Verbakel, 2018). 60% of home-dwelling older people receive informal care from relatives, friends and neighbors (Eurostat, 2019). Nordic welfare states offer formal home-based care at a relatively low cost, but the aging population and limited resources challenge this model (Rostgaard, Jacobsen, Kröger, & Peterson, 2022; Szebehely & Meagher, 2018; Verbakel, 2018). Due to the state’s high involvement in long-term care services in the Nordic countries, family caregiving has a more supplementary role than in many other European countries. Even if many people provide services, they are not intensive and can, for example, be combined with work (Rostgaard et al., 2022).

Family caregivers' experience of caregiving is complex and varied. Some experienced depression and anxiety, whereas others found providing care rewarding (Lin, Fee, & Wu, 2012; Moral-Fernández, Frías-Osuna, Moreno-Cámara, Palomino-Moral, & Del-Pino-Casado, 2018; Sardella et al., 2021). Hence, caregiver burdens pose a compelling risk for family caregivers. There is broad agreement that respite prevents caregiver burden (Munkejord, Stefansdottir, & Sveinbjarnardottir, 2020; Ringer, Hazzan, Agarwal, Mutsaers, & Papaioannou, 2017). Few studies attempt to clarify the process of becoming caregivers (Lin et al., 2012; Moral-Fernández et al., 2018). Knowledge of and insight into the relationship between physical frailty and care burden are still lacking (Pinquart & Sörensen, 2011; Plöthner et al., 2019; Ringer et al., 2017). Ensuring the quality of care requires more knowledge and a wide range of experiences and needs of frail older people and their family caregivers' experiences (Grenier, 2020; Nicholson, Meyer, Flatley, & Holman, 2013; Skilbeck, Arthur, & Seymour, 2018).

1.3.3 Policy and frailty in Norway

In Norway, the public sector funds and provides care for older people. The Ministry of Health and Care Services regulates various health-care and social services, including all legislation on benefits of public health care such as home nursing and patient's rights, and the Norwegian Directorate of Health specifies guidelines to provide services to people with physical or mental disabilities. Further, Norway's 365 municipalities are the lowest government level and are responsible for providing primary health care, long-term care services, home care services and social care (Saunes, Karanikolos, & Sagan, 2020).

There is no formal duty of care for family members, but spouses and adult children are essential sources of informal care. Health-care providers are legally obligated to offer necessary information, support and respite to family caregivers since they are crucial in caring for older people (Municipal Health and Services Act, 2011; Norwegian Directorate of Health, 2017; Patients' Rights Act, 1999). A small but growing number of family caregivers with burdensome care duties receive a salary for care granted and paid by the local authorities (Statistics Norway, 2018).

Norway also has a well-developed long-term care system compared with other European countries. Long-term care receives about a quarter of the total public spending on health. Home-based nursing care is publicly financed, but other types of long-term care, including nursing homes, require personal payment (Saunes et al., 2020). However, quite a lot of care for older people, in institutions, care homes and at home, is supported by general tax revenue, and private expenditure in Norway related to the services is often less than in comparable countries (Rostgaard, Jacobsen, Kröger, & Peterson, 2022). Norway is founded on the principles of universal access to health care. The rapid population aging worldwide in recent decades applies to Norway, which has more people living alone than most other countries, especially older women (United Nations, 2020). On average, women tend to live longer than men, and older women who live alone tend to face disadvantages related to poverty, loneliness and depression. Notably, living alone or with a partner seems to affect how frail older people can cope at home when they have problems carrying out everyday activities, which is an overall outcome of frailty (United Nations, 2020).

Given the increasing prevalence of frailty and its strong association with numerous adverse health outcomes, the challenges of frailty make concerns for an already overstretched health-care system readily apparent (Hoogendijk et al., 2019). In Norway, a current debate focuses on whether classifying older people as frail excludes them from hospital treatment and fundamental rights or whether this identifies and signals a need for tailored and adapted treatment to avoid well-intentioned treatment becoming harmful (Barstad, 2020; Wyller & Hem, 2020). Both parties warn about ageism, agree that chronological and biological age differ and underscore the need for individualized and tailored care.

Norway's recent government policy documents dealing with the older adult population encourage older people to be active and take more independent responsibility for themselves (Blix & Ågotnes, 2022). The current political changes have implications for older people, their family caregivers and the welfare sector (Rostgaard et al., 2022). As the population ages, the prevalence and treatment of frailty will likely affect the caregiving role. Therefore, there is a need to raise the

profile of family caregivers and create awareness of their reactions to care (Ringer et al., 2017).

Optimistically, how health and social services for older people have been organized and delivered has changed considerably in the past decade, with the aim of modernizing them to meet the requirements of an aging population and subsequent care requirements. The government's health and hospital plan for 2020–2023 has selected frail older people as one of its most important target groups (*National Health and Hospital Plan 2020–2023*).

1.3.4 Current context

The Nordic welfare model distributes equal and accessible social security to all residents, including access and treatment in the health-care sector, all financed through taxation. Moreover, people in Norway have high expectations about tax-funded care since services target users from all social classes, including those who are well-off (Vabø, Zechner, Stranz, Graff, & Sigurðardóttir, 2022). Home health-care services dramatically differ from those in previous centuries (Vabø et al., 2022). The participants in this study lived through a development in which the public sector has taken over more of the care that previously took place in the home and was carried out by family caregivers.

A Norwegian government strategy encourages local communities to plan for activities and participation for all, including older people. There has been a shift from seeing older people as weak and passive to resourceful individuals (Ministry of Health and Care Services, 2016). A government reform entitled *Live Your Whole Life – A Quality Reform for Older Persons* focuses on the active older age group, enjoying good health and participating in the social community (White paper nr.15 (2017-2018)). This reform presents improved health-care services, aiming that all older people should be able to continue their daily life, even when their health deteriorates and they need health-care services. The notion of aging in the welfare state revolves around choice, prevention and independence. However, independence has a two-pronged approach since it will both support individuals who want to take

care of themselves and refrain from providing government assistance by inviting them to use other resources such as help from a spouse or other family member.

Further, sociologists Higgs and Gilleard (2016) says that increased focus on healthy aging increases the risk of ageism, understood as prejudice against a certain age group, especially older people. An increased focus on in-home health services, followed by weaker recognition of social and emotional needs, leads to a higher risk of unmet needs for the user, since frail older people depend on others to participate in society (Rand, Sternberg, Gasner Winograd, Buckman, & Bentur, 2022). For those who fail to meet these requirements, an active mind serves as a form of compensation, showing that, despite physical frailty, older people still have their wits about them (Higgs & Gilleard, 2016).

To work for sustainability in the care sector, the government encourages family carers, and volunteers to participate actively in caring for older people (White Paper 15 (2017-2018)). Caring for older people in the family may affect a person's ability to combine a longer working life, care for one's health and social involvement. A guide published by the Directorate of Health (2017) addresses these issues, focusing on relatives' rights and the health-care system's duties. Further, vital political initiatives in recent years have included improving the coordination of care between municipalities and hospitals, the Coordination Reform, strengthening primary care and public health, expanding patient choice, reorganizing hospital care and adapting educating and training health personnel to meet the future health needs. However, the evaluation of the Coordination Reform has shown mixed results so far (Riksrevisjonen, 2016; Saunes et al., 2020). Related to this, a new action plan sets out plans for adapting the competencies of health professionals to future health needs (*National Health and Hospital Plan 2020–2023*). One priority in the ongoing reforms is long-term care and creating an age-friendly society (Saunes et al., 2020). A specific challenge is to adapt the services to frail home-dwelling older people. Frailty can be accelerated by a lifestyle with little physical activity and poor nutrition and by illnesses and injuries. Physical activity, good nutrition, good treatment of health conditions and psychological and social support can help prevent older people from

becoming frail and needing help. Detecting frailty early is therefore vital so that measures can be taken and the trend slowed (Norwegian Institute of Public Health, 2023).

1.4 Living at home with frailty – a review of the literature

I conducted several literature searches between April 2018 and February 2023 using available databases for systematic searches to position the thesis within recent literature. I searched for studies that would help me to explore the perceptions of frailty from the perspective of home-dwelling frail older people and their family caregivers. I combined the search terms “frailty” and “home-dwelling”, “older people” and “family caregiver” in published research between 2018 and 2023. Additional search terms used were “embodiment”, “embodied”, “at-homeness” and “caregiving”.

Appendix 1 presents an overview of articles based on both quantitative and qualitative studies.

A growing body of literature reveals many research studies on frailty and physical activity (To, Kuo, Yeh, Liao, & Lee, 2022). Several studies suggest that guided home exercise programs can be an alternative to complex multicomponent exercise programs and reduce the severity of frailty and improve walking, cognitive function and quality of life (Liu et al., 2021; Pérez-Ros, Vila-Candel, & Martínez-Arnau, 2020; Suikkanen et al., 2019). Early identification of frailty and tailored interventions seem necessary to reduce the risk of frailty (Zimmermann, Hansen, & Wagner, 2021). However, a supervised home-based physical exercise regimen did not increase the number of days spent at home compared with usual care (Suikkanen, Soukkio, Aartolahti, Kautiainen, Kääriä, et al., 2021).

Frailty and prefrailty are significant predictors of nursing home placement among community-dwelling older adults (Kojima, 2018). The growing population of frail older adults may need help in managing their health and health services (Overbeek et

al., 2018). A previous study highlighted a significant prevalence of frailty among older adults and first-time applicants for public home care services (Laukli, Sandvik, & Ormstad, 2021). Krogseth et al. emphasize that older people who receive home nursing care are quite frail and thus have an increased risk of hospitalization and death (Krogseth, Rostoft, Benth, Selbaek, & Wyller, 2021). Previous studies have shown that physical ability was more important than cognitive functioning in discharging older people to their rural homes (Joddrell, Potter, De Witte, & Hawley, 2021; Yuan et al., 2021). This is increasing focus on how frail older people can stay at home for as long as possible, and interdisciplinary work turns out to be valuable in reducing readmission among geriatric patients (Morkisch et al., 2020). Previous studies have shown that frail older people require adequate identification of frailty and support, such as advanced care planning to enhance self-care and manage chronic conditions (Bloemhoff et al., 2020; Dollard et al., 2018).

Various dimensions can create security and well-being for home-dwelling older people, such as physical and mental health, access to informal care and social networks. For some, moving to a care home or an adapted apartment in the center of the municipality could contribute to well-being, security and better physical and psychosocial health (Munkejord et al., 2018). A qualitative study from Denmark and Norway highlighted that a deteriorated body entailed compensation to others, in which confrontation with people who are weaker seems to arouse fear of getting into a similar situation. To maintain independence, older people tried to manage as many of their activities as possible, even though it was difficult (Martinsen, Norlyk, & Gramstad, 2022). Frail older people's care and support needs need to be assessed individually to meet the changing and varying care needs of home-dwelling older people (Verver, Merten, de Blok, & Wagner, 2019; Voie, Blix, Helgesen, Larsen, & Mæhre, 2023). Further, health professionals should be aware of local resources available to help older people with frailty, such as home care, medication, cleaning and laundry, food, transport, medical equipment and respite (Moody et al., 2022).

Tao et al. (2023) underscore that the mental outcomes of frail older people are insufficiently studied. Nevertheless, some studies show that frail home-dwelling older adults are at greater risk of being socially isolated because of their physical limitations, lack of social integration and impaired well-being (McKay, Todd-Magel, & Copel, 2020; Shin, Kim, & Son, 2022). Optimistically, engaging in activities can enhance well-being and prevent frailty, such as caring for grandchildren, meeting friends or attending a concert (Zhao, Gao, Li, & Wang, 2019). Nevertheless, frailty is associated with limited participation and involvement (Rand, Sternberg, Gasner Winograd, Buckman, & Bentur, 2022). Prevention programs aimed at reducing frailty are encouraged to include evaluations of the meaning of life since meaningful activities are needed for both home-dwelling older people and those living in nursing homes, to remain independent in society for as long as possible (Cegri, Orfila, Abellana, & Pastor-Valero, 2020; Chew, 2022; Duppen Rn et al., 2019; Hemberg, Nyqvist, & Nasman, 2019; Silva et al., 2020).

Combes (2021) emphasizes the importance of planning for future care, claiming that essential aids for frail older people are to understand what advanced care planning is and why it may be relevant to them. For health-care providers, the work includes recognizing the importance of living well here and now and relational decision-making. The physical environment, interpersonal and social aspects, work organization and caring culture can create a sense of home for older adults in residential care (Matarese et al., 2022). By respecting the wishes of older people and their families, effective rehabilitation can enable older people to live at home (Ohta, Maeki, Maniwa, & Miyakoshi, 2021). These findings may help health-care professionals in developing interventions to maintain and promote participation among older adults.

A qualitative study from Sweden showed that family caregivers tried to offer support in everyday life, but over time, they experienced a breaking point when aging in place was no longer sustainable, resulting in a nursing home application (Spang, Holmefur, Pettersson, & Lidström-Holmqvist, 2023). Family caregivers' continual help and support were pivotal to maintaining the balance point so that frail older people could

continue to age in place (Bjerkmo, Helgesen, & Blix, 2022) .The integrative review study of Ris, Schnepf, and Mahrer Imhof (2019) showed that family members want to be part of the health team, and nurses need contextual factors to involve family caregivers accordingly. In a mixed-methods study, Yip et al. (2022) highlighted that support from formal and informal caregivers is diverse. Some older adults relied heavily on their informal caregivers for help, but others feared burdening them. Recent studies also address how the COVID-19 pandemic has affected older people living at home and with frailty, providing insight into the emotional burden of home care and the increased need for support from family (Weeks et al., 2021).

In summary, this literature review shows repeated emphasis on the importance of tailored care for older people living with frailty, including physical activity and meaningful activities, and being able to participate in society and continue living at home and reduce loneliness. However, living at home requires help from informal caregivers, which can be both meaningful and burdensome (Ris, Schnepf, & Mahrer Imhof, 2019; Yip et al., 2022). There should be increased focus on how home-dwelling older people and caregivers' experience living with frailty when needs are unmet (Yip et al., 2022).

2. Study rationale

With an aging population and increasing prevalence of frailty with age, frailty is a global public health problem affecting individuals, families, communities and societies (Lekan et al., 2021). The growing literature reveals that frailty screening is increasingly recommended in primary care (Travers et al., 2019; United Nations, 2020). Awareness has been growing in health policy of the critical contribution of family members to the care of frail older people living at home and the relationship between care burden and frailty (Plöthner et al., 2019; Szebehely & Meagher, 2018; Yip et al., 2022). A renewed focus and interest in health, well-being and quality of life recently appeared in recognized international organizations to fight ageism (United Nations, 2020; WHO, 2018, 2020). The United Nations Decade for Healthy Ageing 2021–2030 invited governments, civil society, international agencies, academia, media and the private sector to work together to improve the lives of older people, including their families and communities (WHO, 2020).

The increasing prevalence of frailty and its connection with several adverse health outcomes reveal the challenges for the individual who lives with it, their family caregivers and an already overburdened healthcare system. Optimistically, how health and social services for older people have been organized and delivered has changed considerably in the past decade, with the aim of modernizing them to meet the requirements of an aging population and subsequent care needs. Identifying people with frailty is a central theme in Norway's health policy and plans, presenting a new plan to adapt the competencies of health personnel to future health needs (*National Health and Hospital Plan 2020–2023*). One priority in the ongoing reforms is long-term care and creating an age-friendly society (Saunes et al., 2020). A specific challenge is to adapt the services to frail older people living at home. The overarching aim of this study is to understand the lived experiences of frailty from the perspectives of home-dwelling older people and their family caregivers. The importance of medical knowledge and science in understanding, treating and curing illness and knowledge of causes, physiological processes and mechanisms, symptoms and treatment are essential when illness or injury occurs. However, natural science

and medicine have been criticized for taking up too much space within the health sciences, since they are not fully capable of understanding the extent of the experience of living with illness and old age. Providing good health care requires knowledge that provides insight into distinctive, subjective, complex and contextual factors and, thus, our ability to care for the frail people among us (van Wijngaarden, van der Meide, & Dahlberg, 2017). With populations living ever longer in most countries, phenomenological investigation can increase our ability to perceive and contribute to deeper understanding of the phenomenon of living with frailty (van Wijngaarden et al., 2017).

Despite expanding knowledge and interest in older people's health, little is known about how they experience living with frailty in their home, related to declining body and health, and what home means to them. Medical research worldwide includes a disproportionately small number of frail older people, showing that frail older people's experience of their health has been overlooked. Improving the situation of frail older people worldwide therefore requires increasing the focus on research on frail older people (A. Grenier, 2020; A. M. Grenier, 2020). When frail older people live at home, they usually require help and support from family caregivers, and research on family caregivers' experiences related to frailty is lacking (Ris, Schnepf, & Mahrer, 2019). National and international policies should therefore be supplemented with research from the first-person perspective to deepen the understanding of living with frailty and family caregiving for frail older people in their homes. The study's qualitative design seeks to gain more profound knowledge and describe the phenomenon under investigation (Polit, Beck, & Polit, 2021).

2.1 Study objectives

This study aimed to explore the lived experiences of frail home-dwelling older people and their family caregivers. The research questions guiding our investigation were as follows.

Study 1: How do home-dwelling older people experience frailty related to their bodies?

Study 2: How do older people with frailty experience at-homeness?

Study 3: How do family caregivers experience caregiving for frail, home-dwelling older people?

3. Theoretical framework

3.1 Ontological perspective

I had to position myself concerning the inquiry subject, the research questions to be explored and the data collected for analysis to document the ontological basis of the research, aiming for deepened understanding of the study under investigation (Creswell & Poth, 2018). An ontological perspective relates to the nature of reality and its characteristics or, more pointedly, examines what it is to exist or be. This chapter describes the phenomenological lifeworld perspective, and I will elaborate on the meaning of the body, the home, care and time.

3.2 A phenomenological lifeworld perspective

Edmund Husserl (1859–1938) founded phenomenology as a science foregrounding concrete human experience, where the understanding of intentionality is at the core (Husserl, 1970). Etymologically, the word phenomenon means what appears, how things appear to us in our experience and how we experience things in the world around us. Intentionality binds the recognizing subject and the recognized object and transcends the dualism between the subject and the object. Husserl (1970) presented the lifeworld approach as the basic theme of phenomenology, meaning that studying everyday experiences is a valuable source for philosophical exploration and a scientific foundation. It is against the background of our life world that something appears meaningful to us, and it is only in the life world that one thing is what it is and nothing else. In this sense, the lifeworld is, in a fundamental sense, a horizon for everything we experience and do. Husserl's imperative was to go back to the things themselves, in the sense of exploring how various phenomena appear to us through concrete experiences, to search for the essential structures or essences in order to describe the phenomenon (Husserl, 1970). The lifeworld approach was discussed and further developed by Heidegger (1962), Merleau-Ponty (2002) and Gadamer (2013).

According to Heidegger (1962), we are thrown into a world already there, a fundamental life condition to which we must relate. Our possibilities lie in the thrownness, meaning that parts of our life conditions are given to us more than we can shape and change them. This thrownness depicts our interactions with our surroundings in everyday life and our irrevocable compulsion to project ourselves into the future, forming the basis for our choices and interaction. The world is not just a vast place. The surroundings have a special meaning for us. They contain everyday activities, practicalities, encounters with others and our embedded environments, with accessible things to possess and use. The lifeworld is pre-reflective and prelinguistic, meaning that it is the world we inhabit – before we experience and talk about it. We perform meaningful activities by using and gaining practically imposed familiarity with appropriate tools and being involved with other beings and things. As we inhabit the world, human understanding will always be grounded in understanding the world.

Heidegger (1962) underscored that we do not and cannot understand anything from a purely objective position but within the context and involvement in the world. Our preunderstandings cannot be ignored or bracketed but must be foundational for understanding. From this point of departure, I understand the lifeworld as a familiar world that is all I know and can understand, and yet it is not fully revealed for me.

3.2.1 The body

Merleau-Ponty (2002) was inspired by Husserl and Heidegger's philosophy of the lifeworld and further developed the understanding of the lived body. In *Phenomenology of perception* (2002), he foregrounded that our knowledge of the world of others and things is embodied. We know our world bodily and through our embodied actions. Merleau-Ponty (2002) provided an integrated way of thinking in which body and soul, thoughts and feelings cannot be separated, and the lived body inhabit its surroundings. The body is the subject of all experience, a living body that experiences and perceives. It simply is our vantage point. We cannot distance ourselves from the body or have an entire perspective on it. We can look at our body – for example, our hand or leg – yet we cannot fully observe ourselves as embodied human beings as we can observe things and others. Accordingly, Merleau-Ponty

underscored that being human relates to the lived body as a unified whole; the body is the soul, and the soul is the body. This dual status unites the body and soul rather than dividing them into categories, since we both are and have our bodies (Merleau-Ponty, 2002). The embodied subject is seamlessly connected to the world. We are born into something always already there (Merleau-Ponty, 2002).

The lived body is the vantage point for our being and hence, our world perspective. Significant alteration of the body, such as frailty, implies a changed experience of one self and world, often described as limitations or shrinking of the lifeworld.

According to Heidegger (1962), objects are never just things but have meanings regarding the projects and goals they facilitate, such as tools. Using tools can expand and adjust the world and relates to embodied skills and bodily based expertise. We can facilitate our homes so that we can live there despite the bodily decline and use aids. Living with frailty might imply losing a driver's license, a limitation for older people's radius, but getting a walker or an electric scooter can enable them to get out into the world again. In the beginning, there is a distance between the body and the thing, for instance, between the novice electric scooter driver and the scooter. Eventually, the thing's character as a thing may disappear and be experienced as part of the body as the scooter becomes familiar and driven skillfully. Then, an electric scooter is not just a metal structure enabling travel but getting familiar with the scooter and being able to drive it means going outside, socializing or expressing independence.

Living and growing older means that we experience physical decline. Significant changes, such as frailty, entail alienation of the body and existential homelessness, in which something fundamental in the self is foreign and changed. The primordial bond between the lived body and its surroundings is no longer seamless. The estrangement of what once was familiar is captured by the concept of homelessness, drawing on Heidegger's notion of being homeless in the world (Heidegger, 1962). Before elaborating on homelessness, I will describe the concept of at-homeness.

3.2.2 Home

The lived body usually has a transparent quality as the point of access to the world in understanding activities. According to Heidegger, experiencing at-homeness is like a homelike being in the world, where we have a footing. When we experience homelessness, our attachment to the world changes (1962).

Svenaesus (2000b) deepened the understanding of health and illness. He described health as a “homelike being in the world”, connected to the relationship between the body and the environment. When we are healthy, we are in the world with an attuned and transparent understanding, whereas the world appears more clearly when there is a rupture between the living body and the outside world, such as in illness. When we experience illness, we feel homeless in our bodies. A feeling of homelessness can be described as something that previously went smoothly being replaced by something foreign and unknown starting to resist in the body, permeating people’s lives. At-homeness entails an opportunity for humans to realize their goals through acting in the world.

Heidegger (1962) is concerned with how people create meaning through the practical use of a collection of lived tools in various activities. Svenaesus (2000b) goes further and sees the body as a collection of tools, with the hands, for example, being a tool for understanding the world as meaningful. Hand-dependent activities, such as working with wood, will be reduced when an arm is injured. An injured body part can thus change the structure of meaning by enabling a person to see more clearly how essential this activity was for enabling at-homeness. The body is inextricably linked to itself and can never be abandoned, but illness can change people’s perception of one’s own body since it changes functionality. Accordingly, being in the world entails both at-homeness and homelessness.

The rehabilitation process can be long and demanding. Sometimes the process leads to at-homeness, but sometimes people must learn to live with homelessness to a greater or lesser extent if the illness is chronic and unpredictable, such as frailty. To

regain at-homeness, the person must learn to live with the body in other ways. Illness alters the body, our place and access to the world. Nevertheless, it is the center of the lifeworld in which the ambiguous body is both known and unknown.

Svenaesus (2011) does not link at-homeness to a physical home. Nevertheless, the surroundings are essential in creating a space to regain footing, since they can build up or break people down in demanding life changes. People's homes are filled with cherished possessions, and familiar tools make people feel at home. Older people might need the home to regain or experience at-homeness, including significant others and meaningful things to possess and use.

We are thrown into a world that already exists, meaning that the lifeworld we experience as ours is also a world we share with others (Heidegger, 1962). We are familiar with our lifeworld, and yet elements are out of our reach and control, such as biological changes in aging and frailty. Homelessness is an essential condition for human existence linked to our finitude and dependence on others and is brought to the fore by, for instance, illness. According to Heidegger (1962), caring is fundamental to feeling at home, and I will elaborate on the concept of care in the following subsection.

3.2.3 Care

Heidegger describes care as a fundamental existential condition concerning people's essential attachment to the world and other people, elucidating the motives of love, duty and reciprocity (Heidegger, 1962). Caring expresses personal commitment and has a practical side, entailing emotional involvement to look after or provide for others. We show care by helping, providing for, comforting or in some other way showing that we accept the consequences of the commitment we feel. We understand and depend on others by sharing a familiar, everyday world in which we primarily understand ourselves through relationships. We are not just passive users of the world but inhabit it.

Kari Martinsen (2003) describes caring as showing concern for each other through relationality, practicality and morality. Accordingly, care is relational and requires

two parts: the caregiver and the care recipient. The caregiver helps the care recipient with personal hygiene and walks them up the stairs or does whatever the situation may require. This is a mutual relationship in which giving and receiving care are present, with the other person's welfare in mind. Practical care entails trying to understand and meet the situation of the other person, doing the right thing in a specific situation. Moral care implies recognizing and respecting the person, implying solidarity with the other, which includes more than sympathy and sentimental care. Martinsen (2003) suggests that, to carry this out, the caregiver can imagine a role change in which she or he is the care recipient to try to understand what being dependent is like. They will thus provide care so that the care recipients have a real opportunity to live the best life they can despite being dependent on others' help. In everyday situations, we learn caregiving by experiencing care from other people, experiencing that other people receive care and providing care ourselves.

Heidegger (1962) uses the concept of *fürsorge* when describing care. *Fürsorge* means actively caring for someone who needs help, also known as solicitude. *Fürsorge* is related to others and is future-oriented, expressed in our everyday lives in two ways. First, the caregiver puts themselves in the other person's place for as long as possible, taking responsibility for the current situation, such as preparing meals or housekeeping. Second, the caregiver runs ahead of the care recipient to show the way to future opportunities and potential, such as extended help from health-care providers or seeking admission to a nursing home. The caregiver provides care for the other person without expecting anything in return. The caregiver often receives a reward, such as consideration, gratitude and a feeling of doing something good for others. The aim of caregiving is not to reward but to help a frail care recipient to live the best life they can.¹

3.2.4 Time

In phenomenology, temporality expresses how lived time is understood, in contrast to clock time. In *Being and time*, Heidegger (1962) foregrounded time as the unity of

¹ Being a health worker is also a profession and a paid job. Working as a formal caregiver differs from what characterizes the phenomenon of "care", which also applies more profoundly concerning the mission to care for one's patients.

the past, present and future as the basis of human existence and way of being, deeply connected to care. These three axes of time are constantly interacting. The past and the future give meaning to the world and what is happening here and now. We have the past with us; in this sense, the past is something we still are. The past supports the present, while expectations for the future are present. Who we have been and want to be determines who we are now and how we throw ourselves into the future. Caring means respecting the other person's boundaries, life and needs related to the person's direction or future goals, wishes or ambitions.

Svenaesus (2000b) deepened our understanding of lived time related to illness, which ruptures the rhythm of a healthy being, setting the past and future in a new light. When we are ill, we increasingly focus on the present. That is, the present tends to expand in our experience, holding on and holding out. Illness can, for instance, entail intense pain, shortness of breath and other ailments. We must also be aware of age-related changes through attuned understanding of its temporal dimensions. Lived time exists in the body as experienced time, entailing the body's circuits and rhythms, such as breathing, heartbeat, eating and resting. According to Svenaesus (Svenaesus, 2000a), aging is experienced as a gradual change and disturbance in embodied actions, reduced strength or fitness, slower reactions and limited bodily abilities that deviate from previous performance.

For people living with frailty, the time of the body no longer fits into the time of the self. Seeking a new order to make life understandable and possible to endure again becomes paramount. Adjusting activities to bodily limits is part of this re-orientation, such as starting to play the piano in the nursing home instead of church concerts.

Following Martinsen (2013), caregivers' work is structured by clock time, whereas frail older people's lives deeply interweave with lived time and their finitude. This means that their rhythmic context is out of tune if the caregiver cannot be present with and sensitive to the care recipient, who might have conflicting expectations.

4. Methods

I designed a qualitative study rooted in phenomenology to gain insight into the meaning associated with living at home and frailty. The research methods are based on a method that elaborates this study's theoretical and philosophical foundations (Heidegger, 1962; Merleau-Ponty, 2002; Van Manen, 1990, 2014).

This chapter describes and discusses the design and methods used in this study and their implications for the findings. I describe van Manen's *Phenomenology of practice* (2014), which was determined to be a suitable method of analysis for interpreting the data in this study. Subsequently, I examine the researcher's reflexivity. In the second part, I present all three studies separately and explain the ethical considerations related to this project.

I developed the study design in a stepwise process. I defined the research questions and then included the study participants, interviewed them, transcribed, and analyzed the transcripts and started writing.

4.1 Epistemological foundation and study design

The method can be explained as worldviews related to the research process. As Creswell & Creswell Báez (2021) maintain, epistemology is a philosophical assumption referring to what counts as knowledge and how the researcher perceives reality. In this current study, the topic required a design to explore the experiences of the older people and their family caregivers and to focus on how frailty as a phenomenon appeared in their lifeworld. The design had to be open for dialogue and provide research material suitable for in-depth analysis of lived experience. The qualitative research interview enabled this and I thus chose it (Creswell et al., 2021).

Phenomenological research

Heidegger emphasized that phenomenology is a theoretical and philosophical inquiry method questioning what a phenomenon is like, including its meanings (Creswell & Poth, 2018; Heidegger, 1962). In recent years, phenomenology has become central to

developing health sciences, such as nursing and medicine (Errasti-Ibarrondo, Jordán, Díez-Del-Corral, & Arantzamendi, 2018).

The way we are in the world is already involved and engaged in practical and interpersonal reality characterized by meaning and interpretation as universal themes occurring in every person's lifeworld (Merleau-Ponty, 2002). Existentials (the various core elements of existence) might help in assisting the reflective inquiry process to explore phenomena (Heidegger, 1962). Following van Manen (2014, p. 302), we all experience our world and reality through existentials. Although others are suggested, van Manen chose four existentials suitable for exploring life phenomena such as health, illness and meaning: lived body, space, relationship and time. These existentials are considered to permeate the lifeworld of most people, regardless of where they are situated in terms of historical, cultural and social influence. Lived body refers to our embodiment of the world, and lived space refers to where we live and feel at home. Lived relations refer to how we interact in the world, and lived time refers to subjective time versus clock time and objective time (van Manen, 2014).

Phenomenology of practice (2014) inspires this study. Departing from the Utrecht School, it orients itself from epoche (the suspension of the world we take for granted, but not the belief in it) and reduction. Phenomenological reduction attempts to describe and grasp essential insights into the lived experience by varying or comparing the aspects of meaning with empirical examples before reflecting on it.

The purpose of reduction is to remain open to describing a phenomenon as it presents itself to us (Brinkmann & Tanggaard, 2015). Epoche means putting preconceived notions aside or in brackets (Husserl, 1970). When an empirical variation destroys or changes the phenomenon to something else, it can be considered invariant. This means that reduction focuses on what is unique in a phenomenon (Van Manen, 2014).

Brinkmann & Thanggard (2015) use the example of a chair in describing essence, an example also used by Husserl. Understanding the essence of the chair means describing different variations of a chair, such as an armchair, office chair, camping

chair and different uses, such as resting, working and relaxing. Regardless of all the variations, the chair's essence is being something to sit on. Experiential phenomena such as at-homeness are far more complex in terms of grasping the essentials that make the phenomenon what it is.

Reflexivity implies immediate self-awareness as a researcher in different parts of the research role. The ideal purpose of the phenomenological attitude is that the knowledge we already have should not overshadow the development of new knowledge (Husserl, 1970). Nevertheless, Gadamer et al. (2013) underscored that we could never be transparent with ourselves.

In this thesis, I primarily understand *epoche* or bracketing as an ongoing awareness-raising process, helping me to think about how my preunderstanding and other subjective aspects might influence the research findings. I have tried to be aware of this to prevent reaching an interpretation too early. I wrote my preunderstanding – knowledge and thoughts – in a research diary to clarify the understanding of living at home with frailty and being a family caregiver. Although I, as a researcher, was an experienced home nurse and had studied frailty, I was not fully aware of the knowledge gaps, nor did I fully understand my experience of other people being part of the same lifeworld. Nevertheless, I think that this preparation contributed to increasing awareness, openness and curiosity as I confronted the phenomenon and a more solid foundation when preparing for interviews. I tried to cultivate an attitude of wonder, as also van Manen writes about (2014).

4.2 Preparing for interviews

A phenomenological interview depends on the researcher's attitudes. When conducting the interviews in people's homes, I tried to imagine what living at home with the specific frailty of each person would be like. What was it like living in the neighborhood, going outdoors, or trying to get help if they needed it? I tried to formulate questions according to this perspective. In addition, I was conscious of

using everyday language without technical terms to avoid misunderstandings and creating distance from the interviewees. For example, I did not use the term frailty.

I conducted the in-depth interviews as an open dialogue, led by the interview guide as a checklist (Appendixes 2 and 3) and directing me consciously towards the phenomenon of living at home with frailty. The research questions focused on the lived meaning of the experienced moment itself. According to van Manen (2014), lived experience means ordinary experiences that belong to everyday life and do not contain anything hidden or carry a deeper meaning. Inquiring about lived experience, in contrast, examines the phenomenology of the phenomenon.

For any experience of a phenomenon, a feeling, a situation or a relationship, one can ask how it is. Since saying something about what feeling the fresh air on your face, meeting someone you love or being cared for is like is always possible, each of us has access to such experiences and can try to describe them (van Manen, 2017).

4.3 Ethics: procedures and considerations

Before starting the study, I presented it to the Regional Committee for Medical and Research Ethics for Western Norway, and they found that the study was outside their field. Further, I sent the study to the Norwegian Centre for Research Data (Ref. 61202), which approved it (Appendix 6). Relevant hospital and university authorities approved the study as well. I stored the data and contact information separately, and completed the study according to ethics guidelines and the Declaration of Helsinki ("World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects," 2013).

I informed the participants that participation was voluntary. They could withdraw from the interview or refuse to participate without this affecting their treatment. Further, I guaranteed the participants that the information provided would be confidential in each phase of the study process and guaranteed their anonymity. All participants gave written informed consent before the interview started (Appendixes 4 and 5). The participants received written information about the study in advance and

an oral presentation of the aim and purpose before it started. I also provided information on practical matters, such as the intention to record the interviews and storing contact details if I required further information or comment. I presented measures to ensure confidentiality and anonymity and repeatedly highlighted the participants' rights to withdraw from the study without providing any reason (Creswell & Poth, 2018).

The target groups of this project were frail home-dwelling older people and their family caregivers, and I considered them to be vulnerable in their present life situation. I toned down potential issues that may arise when collecting data during interviews, such as imbalance within a relationship, by avoiding leading questions and maintaining an informal atmosphere in the conversations (Creswell & Poth, 2018). Some of the in-depth interviews required several breaks because of the older people's health conditions. I was prepared to end in-depth interviews at any time, if necessary. I ended one interview prematurely, since the participant experienced breathing problems. Fortunately, they invited me to contact them later, which I did, and I conducted a follow-up interview. As researchers, we are obligated to prevent and minimize harm when studying people. Participants should not experience unnecessary discomfort, and strategies should attempt to reduce harm (Creswell & Poth, 2018).

The final ethical consideration concerns confidentiality. In interpreting the data, the research team focused on reporting various perspectives, not taking sides with the participants or reporting only positive results. I interviewed the family caregivers of the participants in study 1 and therefore obtained information about the older people. I was aware of this during all interviews and did not share or comment on any information given in the initial interviews. Respecting the participants' privacy was also crucial. I therefore took extra precautions to safeguard anonymity by assigning numbers instead of names while transcribing the interview texts. In addition, I used numbers or fictional names of institutions, municipalities or health-care providers to distort the identifying information and avoided detailed descriptions when recording the results. These measures relate to anonymity, the most secure means of protecting

confidentiality that is ideally achieved when the researcher cannot link the participants to the data (Polit et al., 2021). In this study, this was not possible because the participants were closely involved. Audio recordings were stored in a research database. The anonymized and transcribed text and written consent forms were kept separately in locked cabinets. All data material will be deleted after the project period (Brinkmann & Tanggaard, 2015).

4.4 Recruitment and participants

When planning the study, I wanted to investigate the everyday life of frail older people and their family caregivers. I used a purposeful sampling strategy, selecting the participants that would most benefit the study and would contribute to the study's aim (Polit et al., 2021). These participants would present typical field examples and give insight into the research question being investigated (Creswell & Poth, 2018). Before deciding on the method, I visited an outpatient clinic for older people to obtain more insight into their broad geriatric assessment of older people. After I spent a few days there, I asked them to help me to recruit participants for the study, and they did. Participants had to fulfil the following criteria:

- 65 years or older;
- had received home health care for 3 months;
- Mini-Mental State Examination score ≥ 18 ; and
- fulfilled three of five of the criteria of Fried et al. (2001) for frailty: unintentional weight loss (4.5 kg in the past year), self-reported exhaustion, weakness (grip strength), slow walking speed and low physical activity.

Participants in study 2 had to be family caregivers to participants in study 1. In this context, the head nurses at the outpatient clinic recruited the participants and forwarded their contact information to me (Tables 1 and 2).

Table 1. Characteristics of the participants in study 1 ($n = 10$)

Characteristics	<i>n</i> (%)
Sex	
Male	3
Female	7
Age (years)	
70–74	1
75–79	1
80–84	3
85–89	3
90–94	2
Help	
Formal help ²	10
Informal help ³	10
Form of living and living place	
Own house with a spouse	4
Own house alone	4
Own house with spouse and family	2
Experience of institutional stay⁴	
Nursing home	8

² Health-care providers in home health care, nursing homes, hospital wards and outpatient clinics.

³ Regular general practitioner or physiotherapist.

⁴ In Norway, brief stays in nursing homes for 4–6 weeks are common.

No nursing home	2
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Table 2. Characteristics of the study participants in study 2 ($n = 9$)

Characteristics	<i>n</i>
Sex	
Male	5
Female	4
Age (years)	
50–59	5
60–69	0
70–79	2
80–89	1
90–99	1
Type of living and place	
Own house with a spouse	5
Own house alone	0
Own house with spouse and family	4
Experience with care	9

Experience with respite care	9
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Further, I contacted the participants to inform them about the study and its purpose and to schedule interviews. They used SHARE FI in frailty screening, building on the five criteria of Fried et al. (2001), and we obtained access to participants screened for frailty using the phenotype model (Romero-Ortuno et al., 2010). The head nurses regularly met home-dwelling older people referred to the outpatient clinic and invited frail older people to bring one significant other to the appointment by their physician to undergo geriatric assessment, including screening for frailty. Although we intended to conduct the interviews with the frail older people first and their family caregivers in the next phase, I was aware of their vulnerable situation and agreed if they wanted to be interviewed the same day.

The interviews were in a place chosen by the participants, most often in their own homes, since frail older people usually feel most comfortable, unreserved and at ease at home. This supported their ability to relate their lived experiences of aging. Many of the family caregivers in study 2 were older people, and the home was also a suitable interview setting for them. We used a purposive sampling strategy and recruited participants who were family caregivers to the participants in substudy 1-2. We recruited 10 participants, but one withdrew before the interview for health reasons. Five men and four women participated; some were related and were family caregivers to the same care recipient. They were spouses, daughters, sons, in-laws and siblings.

The data sources were in-depth interviews with frail home-dwelling older people for studies 1 and 2 and in-depth interviews with family caregivers for study 3. All participants were recruited from outpatient clinics.

4.4.1 Conducting interviews

Qualitative researchers strive to understand other people and their life experiences. Listening to their valuable experiences was therefore essential to answer the research

project's questions. Since this study aimed to understand life-world phenomena related to frailty, I met people who had experienced frailty and family caregivers and invited them for an interview. Inspired by phenomenology and empirical health research, I sought meanings linked to the lived experiences of other people. Aiming for in-depth understanding, I sought detailed descriptions and concrete examples from the participants' lifeworld focusing on the interviewee's understanding and significance of the experience within their world. The participants' stories revealed the meaning and significance of the frailty experience.

The world of lived experience is the source and object of phenomenological research (Van Manen, 2014). As such, this lived experience of frailty was the data source, the method's objective and the focus of the data collection.

I thought through and discussed with the research team whether to invite participants to one or multiple interviews. Because of their health status and/or stressful life as family caregivers, I anticipated that one interview would be sufficient and give them a good opportunity to share their experiences. Further, I assumed that participants would more easily volunteer for one interview rather than two. This turned out to be a good decision because several interviews had to be postponed because of hospital stays or the participants' health status. I interviewed each participant once, except the interview stopped for one participant because of their health status, and a follow-up interview was conducted.

Although I was attentively present and listened actively to the interviewees, I simultaneously started to reflect on what I heard and saw during the interviews. Being in frail older people's homes was especially interesting, since all but two of them gave me a tour of their homes, telling me about their hobbies and interests and showing family photos, furniture or art they had crafted. Further, they showed the changes they had made in their home because of frailty, such as moving their bed downstairs and daily living aids placed in their home. The process of reflecting on their everyday life continued as I wrote reflective notes, transcribed the interviews and discussed the results with other people.

Article 1	Article 2	Article 3
<ul style="list-style-type: none">•10 participants•seven women, three men aged 72 and 90 years•frail older people	<ul style="list-style-type: none">•10 participants•seven women, three men aged 72 and 90 years•frail older people	<ul style="list-style-type: none">•9 participants•5 men, three women aged 52 -90 years•family caregivers

4.4.2 In-depth individual interviews

The phenomenological interview explores and collects experiential material to develop richer and deeper understanding of a human phenomenon (Van Manen, 2014).

The interviews were conducted between December 2018 and December 2019 at a location the participants chose, mostly in their homes. The material includes 19 in-depth interviews that were digitally recorded and lasted between 34 and 94 minutes.

The interviews marked my first physical meeting with the participants, and a relationship of trust had to rapidly be established between us. The interviews were therefore conducted face to face. After ensuring that the participants had beverages available and were seated comfortably, I briefly described my motivation for seeking new knowledge and my previous experience as a home nurse. However, I emphasized that the participants' unique stories about how they experienced living at home with frailty or being a family caregiver were at the core. Nevertheless, I also wanted them to describe the collaboration with health-care providers.

Obtaining significant and rich data depends on the willingness and ability of participants to share their stories. I had planned to collect background information early in the interview to get in touch with the participants, familiarize them with the interview situation and encourage them to talk early (Brinkmann & Tanggaard, 2015). I started by asking for background information about age, education, former occupation and family situation. After that, I asked about their current situation. This gave me an idea of their situation from the start. Most of the interviewees started talking about their current situation without me asking too many questions. Some began with the current situation and moved back and forth on the timeline. They

talked about their parents' situation when they got older, and some told how they died. I listened and asked follow-up questions. If they continued to talk about their youth, I asked structured questions, such as: "Let's take a look at the current situation after you needed help from home health care." This led the interview in a direction that was useful for the focus of the research project (Brinkmann & Tanggaard, 2015, p. 42). Keeping the research questions in mind during the interviews was essential.

Before summing up and closing the interview, I asked the participants in studies 1 about their impressions after the interview. Several participants said they felt good talking about these issues and never or seldom talked about them. They expressed that they achieved renewed understanding of their situation and appreciated that someone was interested in their life stories. Before rounding off the interviews, I asked if they wanted to add anything. Some participants used this opportunity to share their experiences at a nursing home and the lack of time for health-care providers to get to know the residents, saying that health-care providers should be curious to get to know them as people who had lived a long life and get to know them and not only their diagnosis or impairments. Most expressed that they were pleased with the care they received and highly appreciated the health-care providers who made the extra effort. Others summed up their own stories.

Participants in study 2 expressed appreciation for having the opportunity to describe their role as family caregivers to a neutral party, and most viewed participation as being beneficial. Some said that describing their difficult situation was a relief. Some participants used the opportunity to describe the ambiguity they experienced when observing their loved ones alone at home, with escalating frailty. Even if they respected the older people's wish to stay home, family caregivers feared falls, loneliness and deterioration. Others used the opportunity to summarize their situation and seemed to have a clearer view of how it was to be a family caregiver. This is in accordance with what Dahlberg, Dahlberg & Nyström (2008) claimed could be expected from a phenomenological interview. The interviewee and the interviewer should understand the situation better after the interviews.

4.5 Data analysis

In qualitative research interviews, the interview and analysis phases merge (Brinkmann & Tanggaard, 2015). Although the primary analysis occurs after completing the research material, the researcher interprets and analyzes both during the conversation and the interview recording. This way, the researcher has thought about the content when the analysis starts. I recorded all interviews on digital audio and transcribed them shortly afterwards. I chose a relatively precise transcription method, writing word by word, sentence by sentence, with dialect, small words, pauses, laughter and crying. I did this to make the participants as alive as possible in the text. Transcribing the data material was vital for me as a researcher despite being time-consuming. It gave in-depth knowledge of the research material required for further analysis. I wrote a short reflective note after each interview. This helped me to remember contextual information, my impression after the interview and what I initially grasped as the core of the interview situation. I also wrote reflections on my role as a researcher and essential topics for the conversation.

Although I had already started the analysis in the interview, thinking carefully about which analysis method was suitable for writing out the content of meaning in the interview was vital for me. Since I had chosen a phenomenological method, I referred to the phenomenological analysis method of Giorgi & Anstos (1985), which has five steps. Nevertheless, I wanted to avoid being bound by the various steps in the method, since I thought this would be an obstacle to the creative process. I knew the analysis work was hard and demanding, requiring being systematic and structured. The data material was rich, with vivid descriptions of the participants' lived experiences. Van Manen's (2014) evocative writing style also inspired the writing process. He described coming into contact with the text through tone, the expressive and poetic statement that creates resonance with the reader. I tried van Manen's method in the first three interviews and decided to continue with it.

The data comprised 19 individual interviews and reflective notes. I analyzed the data from interviews with home-dwelling older people before the data from the family caregivers, in accordance with van Manen's framework (2014).

According to van Manen (2014), phenomenological analysis has a pathway to follow that provides both a source and a methodological basis, aiming to look for meaningful patterns and insights. First, the analysis starts with holistic reading, reading the whole material to determine what was at stake for the interviewees. Second, selective reading seeks to find parts of the text that can provide a detailed description of the phenomenon. Third, detailed reading entails going through individual sentences or parts thereof to see how they can say something about the phenomenon (Van Manen, 2014).

First, I read all interviews as a whole. To go deeper into the analysis, I thoroughly reviewed three interviews I found to be rich. I read through the transcribed material several times, listened to the interviews when I went for a walk to let my mind wander freely and sought deeper understanding of the meaning of the interview by asking what it was about and what the core was. I wrote a condensed text in which I sought to capture this without caring about the theme or the title. After the transcription, I put headings on the three interviews, trying to capture the central meaning of the text. Then I went through all the respective studies' interviews and wrote a condensed text and heading looking for the core and the variation, attempting to identify significant concepts and topics that were common or deepened and warranted further investigation. In some interviews, the core was prominent. In others, it was a minor part. Some participants spoke at length and coherently, with wordy language. Others expressed themselves more briefly, but their statements were often more focused on the core.

After I wrote written condensed stories from interviews in study 1, I read across the interviews, searching for consistent, essential themes. After choosing van Manen's analysis method, I also noticed the existentials as a tool to structure the analysis and selected them as a lens through which to see the material. In the first part of the study,

two main themes emerged: living with a frail body and living on the border between home and nursing home, mainly linked to the existentials lived body and lived space, both of which had elements of lived relations and time. Since the interviews were rich, I wrote two articles from substudy 1, divided according to the two main themes, to unpack the depth of the interviews.

As such, I divided the data material into two parts when writing articles 1 and 2 and decided to be faithful to van Manen's analysis process. Although creatively analyzing the material was challenging and lacked a clear structure, I found it fruitful.

When reading the two parts selectively, I searched for statements and phrases that seemed vital to describe participants' experiences in the data material. Next, I tried to capture these meanings in the condensed text by choosing central citations that expressed the themes.

Participants sometimes described significant experiences in a narrative form, forming detailed stories with a beginning, middle and end. These narratives conveyed meaningful and often painful events they had experienced. We tried to hold on to these themes by highlighting vocative phrases or capturing individual statements to illustrate the main feature of the theme's meaning.

In the detailed reading approach, I thoroughly read every sentence or sentence cluster and grappled with what the text could reveal about the theme. In this phase, I changed and merged the preliminary terms and headlines. The process comprised writing and reading literature to expand my interpretation space and being reflective, open to experience and sensitive to language to grasp a phenomenon's essential meaning. Writing and rewriting are at the core of reflection, thoughtfulness and deeply interwoven analytical processes in phenomenological research. Reflexive writing is central to gaining insight and new understanding characterized by slow wondering. According to van Manen, writing fixes the thought on paper or a screen, and the words to express the lived experience must be chosen carefully (van Manen, 2014).

I also worked with structure and form by summarizing the theme in tables and figures and adding and subtracting condensed text and quotations until I had the two articles “In the borderland of the body” and “Carrying on life at home or moving to a nursing home”. When I was working on these two articles, the idea of angling the third article towards the theme of the first two emerged. Since the participants in substudy 2 were family caregivers of the participants in substudy 1, I found this idea fruitful. The analysis method in article three was similar, except the material was analyzed as a whole. Article 3 is entitled “Caregiving for frail, home-dwelling older people”.

In this study, I explored frailty as the backdrop for understanding how frail older people and their family caregivers experience the meaning of everyday life. Through the analysis and writing the three articles, I increasingly experienced that the time perspective was not sufficiently explored and that it had a solid relational and existential character that had not come across well enough in the articles. A final level was developed when I viewed the findings in the light of existential temporality. I therefore worked through the material with this in mind while writing the thesis.

5. Results

The overall aim of this study was to obtain and develop knowledge about how frailty might be perceived and experienced from the first-person perspective of frail home-dwelling older people and their family caregivers.

5.1 Paper 1

Søvde BE, Sandvoll AM, Natvik E, Drageset J (2022). In the borderland of the body: how home-dwelling older people experience frailty. *Scand J Caring Sci.* 2022;36(1):255–264. doi: 10.1111/scs.12984

The first article explores the lived experiences of frail home-dwelling older people related to their lived bodies. We described an overarching, essential theme of how frailty is experienced as being in the borderland of the body. The essential theme summarizes the whole and comprises three interrelated themes: 1) the body shuts down, 2) living on the edge and 3) not giving up. This article displays our analysis of interviews with 10 home-dwelling participants.

The stories of the body shutting down also expressed losses, entailing a change in who they were and how they lived in the world. Their frail body entailed a high risk of injury even if they lived a quiet life. To keep safe, participants quit meaningful activities and hobbies. They did not give up but had to adapt to their present situation. Former activities became too risky and were altered to indoor activities such as playing an instrument or painting. Living with a constantly altering body was hard and required ongoing work to balance frailty and strength as the body forms an indelible whole, with strengths and weaknesses, fears and hopes for the future. We described the findings across participants and in depth in the dimensions and discussed the meanings in relation to literature on the phenomenology of the body and previous research.

This study showed a need for more profound knowledge about frail older people's experience of at-homeness and family members' experience in caring for home-

dwelling older people. We urgently need a holistic and flexible approach to using frail older people's resources. This requires collaboration with frail older people, their families and health professionals.

5.2 Paper 2

Søvde BE, Sandvoll AM, Natvik E, Drageset J (2022). Carrying on life at home or moving to a nursing home: frail older people's experiences of at-homeness. *Int J Qual Stud Health Well-being*. 2022;17(1):2082125.

The second article explored frail older people's lived experiences of managing life at home on the verge of moving to a nursing home. Three interrelated themes include 1) being home with cherished people and possessions, 2) giving the nursing home a go and 3) attuning to the natural rhythms. The analysis resulted in a collective finding; the participants wanted to regain a sense of at-homeness in their experience of not being at home.

Being at home with loved ones and possessions depicts participants' anchoring in the home, which includes locality and landscape, gardens, housing, property and views and shared time and space with significant others. The home was a shelter to which they could return and feel safe. As the body changed and became frailer, the home was no longer sufficiently safe and forced participants into an institutional stay where they experienced a new rhythm not in harmony with their own. They received good health care but missed the life they had built up and lived at home, which differed from the institution's fixed and unfamiliar routines. Being away from home had led them into an intense process of thoughts and emotions concerning their situation and future. Returning home after a stay in an institution turned out differently than they had planned, and this insight carried profound uncertainty about the future.

Existential questions emerged, but the participants did not discuss these issues with health-care providers or family caregivers. We described at-homeness in depth and across participants in the three themes and discussed the meanings related to phenomenological literature and theory on at-homeness and previous research.

The world, as it appears to us, including our fellow human beings, can only become a home if it is the object of our care. The insight into the understanding and volition of frail older people can make health-care providers better able to stimulate, seeking understanding of what frail older people find meaningful to regain at-homeness, whether they live at home or in a nursing home.

5.3 Paper 3

The third paper, “Caregiving for frail, home-dwelling older people”, explores family caregivers’ lived experiences, provides detailed descriptions and deepens the understanding of providing care to frail older people. It analyzes interviews with nine family caregivers, five men and four women, related to participants in studies 1 and 2. We identified three interrelated themes: 1) close and distant, 2) the tables have turned and 3) starting to let go – yet being deeply connected. The analysis led to one overall finding: striving to adapt throughout the caring process.

The responsibility for care, place of care and relationships between caregivers and recipients were intertwined. Being a family caregiver had increasing intensity as frailty progressed towards a horizon with an inevitable outcome – relocation or death. Family caregivers had to face the frail, failing bodies of their parents, partners and in-laws and cope with their changed future hopes and prospects when caring took up so much space in their lives. This was an emotional process in which their former caregiver became a care recipient for whom they were responsible. They were deeply concerned about the future and how the situation would develop. Security for the participants’ welfare was pivotal if they entrusted care to others, such as home nursing or nursing home staff. Living at home together was crucial for spousal caregivers, and they were willing to go to great lengths to make it happen. For adult caregivers, different caring roles could feel overwhelming, since they felt torn between their children, parents, partner and work, which affected their self-care.

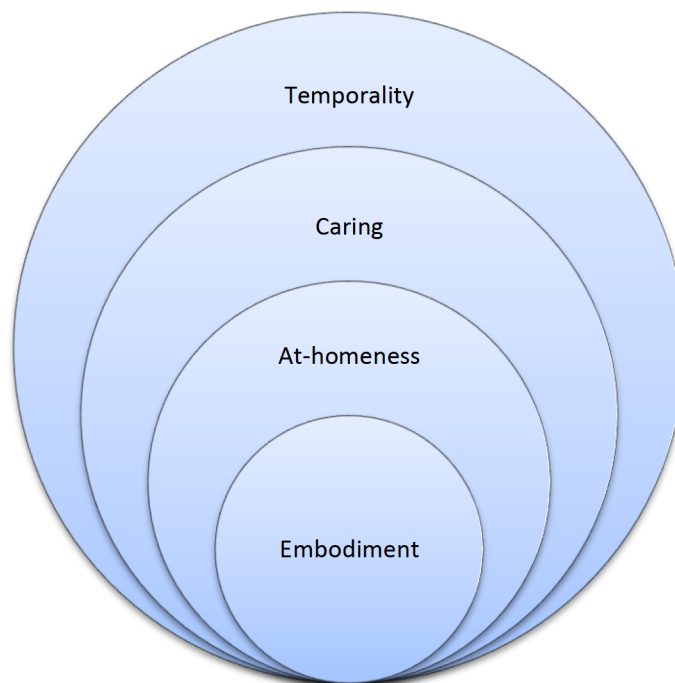
This study provides insight into family caregivers’ ambiguous role as both close relatives and caregivers of frail home-dwelling older people. We describe the findings in depth and discuss the meanings related to phenomenological literature, theoretical

concepts of caring and previous research, primarily studies on caring for home-dwelling older people. In our study, the varying condition of frailty was an additional challenge in care. Knowing what is essential for participants to withstand the care is vital in planning adequate cooperation and support for family caregivers.

6. Discussion

This chapter integrates and discusses the main findings of the three studies in relation to previous research. I discuss the empirical data and the perspectives of the phenomenological concepts of embodiment, at-homeness, caring and temporality to develop deeper understanding of the study results, creating empirical and theoretical understanding. Figure 1 illustrates the connection between the phenomenological concepts.

Figure 1⁵



The results from the current study describe frailty as an unexpected life event followed by a constantly altering and unpredictable body (Sovde, Sandvoll, Natvik, & Drageset, 2022b). The lived body was a prominent premise for how life at home was experienced. The participants' lives and homes intertwine with their life stories,

⁵ Figure 1 shows that embodiment, at-homeness, caring and temporality are closely interwoven. As the outermost circle, the time aspect is the most fundamental since time constitutes life and begins and ends.

rituals and memories. Crossing the threshold of frailty was perceived as deeply existential, forcing the participants to reorganize their everyday lives. The home was no longer sufficiently safe, and an inevitable short stay in the nursing home evoked a sense of finitude. Participants still living with a partner could talk with them, such as the woman with severely reduced lung capacity saying that she and her husband discussed what would happen after she died. For others, existential questions were at the core yet remained unspoken. In the nursing home, the focus was mainly on treatment and care, and participants did not know with whom they could discuss these issues (Sovde, Sandvoll, Natvik, & Drageset, 2022a). Caring responsibilities and interpersonal relationships between family caregivers and care recipients increased in intensity as frailty progressed. Since frailty was unpredictable and fluctuating, meeting care recipients' needs intertwined and entailed changing emotional and relational interactions. The ever-present thought about what the future would bring permeated both parts.

Older people living with frailty depend on care from others to maintain and enhance their health and well-being, including finding meaning in life. Phenomena such as the passage of time, the trajectory of aging and transitions towards something are integral to the human experience. The dimensions of past, present and future constitute the perspective of a person's temporal world. The frail older people in this study were aware of their age and current situation and reflected deeply about the future, illustrating how the lived body is closely linked to temporality when past, present and future weave together. They had lived a long life of sorrows, joys, losses and gains, and they drew on these past experiences to restore their sense of present well-being. With the help of family caregivers, frail older people searched for new strategies to lead meaningful lives, often with adjusted activities.

The study revealed a gap between how frail older people and family caregivers experienced time. Being a family caregiver increased in intensity as frailty developed and involved worry about how worsening frailty threatened care recipients' ability and opportunity to manage at home. Family caregivers said that they planned for the

future to ensure a secure and dignified life for their loved ones but said that their relatives were most concerned with living well here and now.

6.1.1 In the borderland of the body

The essential theme “in the borderland of the body” indicates that living with frailty is an ambiguous situation of balancing frailty, strength and a constantly altering body (Sovde et al., 2022b).

As Figure 1 illustrates, embodiment is the core of our lives. We are our bodies; the lived body is the subject of all experiences and how we interact with the world (Merleau-Ponty, 2002). Our body is always the focus when we orient ourselves. Our finding, “the body shuts down”, highlights that participants lived through a bodily change. As the body gradually lost its earlier capacity, the weakened body became foregrounded and changed its interaction with the world when experiencing frailty, doubt and uncertainty.

The finding, “living on the edge”, shows that frailty is closely related to shifting risks. Previous research has shown that other geriatric syndromes are more likely to occur as frailty develops, including falls and rapid functional decline (Cesari, 2019; Dent et al., 2019; Junius-Walker et al., 2018). Bodily alteration, such as frailty, changes our experience of the world, often described as limitations or shrinking of the lifeworld. A possible understanding of the limitations might be that others can measure and categorize their bodies differently. However, these measurements do not necessarily align with how older people experience themselves. Previous research has shown that older people underscored that frailty appears in the gaze of others, not necessarily how they perceive themselves (Durepos et al., 2022; A. Grenier, 2020; Higgs & Gilleard, 2016; C. Nicholson, Meyer, Flatley, Holman, & Lowton, 2012).

Nevertheless, other people’s gaze and categorization affect how participants are met in society, following Gilleard and Higgs' (2016) statement that frailty is a social imaginary. This study shows that frailty can overshadow vitality, and placing people within a fourth age can affect their ability to participate in activities and society.

In Norway, a recent debate was whether classifying older people as frail excludes them from hospital treatment and fundamental rights or whether identifying frailty signals the need for tailored and adapted treatment to avoid well-intentioned treatment becoming harmful (Barstad, 2020; Wyller & Hem, 2020). Gilleard and Higgs (2016) point out that increased focus on healthy aging increases the risk of ageism, understood as prejudice against a specific age group, especially older people. Other people may see frail older people as the harbinger of future dependence, decay and an additional burden on society, thereby contributing to shrinking their lifeworld, in which few activities are arranged and adapted to older people.

The psychological outcomes of frailty are insufficiently studied (Tao et al., 2023). Nevertheless, some studies highlight that frail older people had a greater risk of being socially isolated because of physical limitations and reduced well-being (McKay et al., 2020; Shin et al., 2022). Other studies underscored that frailty was associated with reduced participation and involvement (Rand et al., 2022). Several studies have shown that participating in meaningful activities enhances well-being and is vital to remain independent in society (Cegri et al., 2020; Duppen Rn et al., 2019; B. Martinsen, Norlyk, & Gramstad, 2022; C. Silva et al., 2019). Zhao et al. (2019) stated that engaging in activities such as meeting a friend or attending concerts enhances well-being and might prevent frailty. It turns out that meaningful activities are essential to living a good life with frailty and creating a sense of belonging. Our study showed that the older people were aware of this and found new, meaningful activities in which the body was less prominent, such as painting or reading.

Heidegger (1962) highlights that we are thrown into a world already there with accessible things to possess and use. Objects are not just things but have meanings regarding the projects and goals they facilitate, such as an electric scooter being a tool for mobility. By using tools, we can expand and adjust our world. Frail older people are realistic and fully aware that their bodies and lives have changed. Nevertheless, they fight to put themselves in the foreground of frailty. Participants in this study facilitated their homes so that they could live there despite bodily decline by using daily living aids to manage to walk inside and outside the house.

Extensive research has been conducted in recent decades on preventing and delaying frailty. Some optimistic findings include how physical exercise can reduce the severity of frailty and improve walking and quality of life. However, physical exercise did not increase the days spent at home (Liu et al., 2021; Pérez-Ros et al., 2020; Suikkanen et al., 2019; Suikkanen, Soukkio, Aartolahti, Kautiainen, Kaaria, et al., 2021). A possible insight into these findings and previous research is that physical exercise has several benefits but will not necessarily get participants to live longer at home.

Following de Beauvoir (1996), human beings have the potential to choose active and meaningful lives. Nevertheless, growing older means experiencing physical decline. Significant changes, such as frailty, entail alienation of the body, in which something fundamental in the self is foreign and changed.

Policy documents encourage older people to take more independent responsibility for themselves (Blix & Ågotnes, 2022; White Paper 15 (2017-2018)). This study gives insight into what growing old and becoming weaker mean, thereby acknowledging the complex needs of frail older people entering the later phases of life, illustrating Merleau-Ponty's (2002) statement that we are always bodily in the world, with the potential to be vulnerable and to need care. Previous studies have shown that frail older people cannot be self-reliant, active and responsible for their own health and require adequate long-term care and support to enhance self-care and manage their frailty (Bloemhoff et al., 2020; Dollard et al., 2018; Fjørtoft et al., 2022; Martinsen et al., 2022). The participants were aware of their current situation and deeply reflected on their future, leading them to find new strategies to live meaningful lives, despite reduced activity level. They depended on the help of others to perform meaningful activities. The participants had lived a long life with ups and downs, family growth and the loss of spouses and significant others. They drew on these past experiences to maintain a sense of well-being in the present. We illuminate that meaning is closely linked to time and care. Even as their bodies deteriorated, experiencing meaningful activities was essential to preserving their self-worth and maintaining a sense of the

life they used to have. The results show that using their resources and support from others was essential to continue and manage their daily situation in the future.

6.1.2 Carrying on life at home or moving to a nursing home

The empirical discussion contributes to new understanding concerning the overarching theme “carrying on life at home or moving to a nursing home”, indicating that participants lived on the verge of living at home and moving to a nursing home. In their current situation, the participants wanted to regain a sense of at-homeness regardless of whether they lived at home or a nursing home (Sovde et al., 2022a).

As shown in Figure 1, embodiment and at-homeness are weaved together. The older people’s descriptions of home and feeling at home have a double meaning. The bodily changes they experience through frailty can cause them to feel alienated in their bodies. A healthy body has a transparent quality and is our starting-point in the world. Heidegger (1962) claims that at-homeness is a homelike feeling of the world, where we have a footing. Heidegger’s ontological thinking does not focus on the body but points to anxiety as a feeling of homelessness. Svenaeus (Svenaeus, 2000a, 2000b, 2011) builds on this thinking by explaining illness as a homeless condition in the body. At-homeness entails the opportunity for humans to realize their goals by acting in the world. Svenaeus (2011) does not link at-homeness to a physical home. Nevertheless, the surroundings are essential since they can build or break people down in demanding life changes.

According to Svenaeus (2000b), when we are healthy, we are in the world with an attuned and transparent understanding, whereas when illness occurs, the world appears more clearly since there is a rupture between the living body and the outside world. Our study showed that when older people became frail and their bodies could not do what they had previously been able to do, it became more apparent to them what they wanted to prioritize and put their efforts into. The empirical evidence in this study shows that, although the experience of homelessness was linked to bodily processes, homelessness was also solidly linked to home and cherished people and

possessions. The participants saw more clearly what was important to them, and their home had deep existential meaning for those experiencing frailty. Locality, landscape, gardens, dwelling, property and views and, most importantly, shared time and space with significant others were essential to maintain harmony with themselves. Frail older people say that being at home and following the rhythms they have acquired throughout life are essential to be seen as themselves in familiar surroundings. The importance of the home as a backdrop for security, belonging and meaningfulness is well documented (Hilli & Eriksson, 2019; Saarnio, 2018; Saarnio, Bostrom, Gustavsson, & Ohlen, 2016; Zingmark et al., 1995; Öhlén et al., 2014).

However, participants described episodes they could not manage at home or needed acute treatment, for example, after falls. For many, a short-term nursing home stay followed the acute treatment. Our study showed that participants staying at a nursing home and not knowing whether they could return home threatened the experience of at-homeness. Although participants described good treatment and care, the experience of not being at home overshadowed the positive experiences of being safe and surrounded by health-care providers. A short stay in a nursing home awakened a feeling of limited time as they realized that the life they knew, with its familiar rhythms, would soon be over. Including frail older people in planning future care is essential to help them understand what advanced care is and why it is relevant (Combes et al., 2021). Advanced care planning entails decision-making and recognizing frail older people's desire to live well here and now.

When older people experience frailty, the bodily changes can make them feel alienated from their bodies. The experience of frailty combined with moving away from home indicates dual vulnerability frail older people live in and through. The participants experienced the bodily changes as alienating but they were themselves. The participants had to regain harmony with themselves, get to know the body in other ways and regain trust and control over the body again after acute illness and injury such as falls or severe breathing problems. Our findings showed that treatment in a nursing home succeeded somewhat, but there were limitations to participating in

daily activities. The participants described unmet needs to participate in meaningful activities and little or no opportunity to influence the daily rhythm at the nursing home. A woman said she could not participate in the daily routines even if she had the skills. She wanted to be able to prepare meals and get out of bed in the morning as part of managing at home after discharge. Instead of being able to practice this, she had to comply with the rules and routines at the nursing home. Others felt that there were too few activities and little or no opportunity to get out for a walk or fresh air. Previous research has shown that dressing, eating and cooking can transfer the feeling of home to new landscapes so that a new environment still feels like home (Saarnio et al., 2016; Öhlén et al., 2014).

There is broad agreement that many older people cannot manage at home without help, and frailty affects people's ability to carry out activities of daily living (A. Overbeek et al., 2018; United Nations, 2020). The main policy focus of the past decade has been to enable frail older people to live at home if possible and with appropriate support (Grenier et al., 2020; Skilbeck, Arthur, & Seymour, 2018). The reform in Norway, *Live Your Whole Life – A Quality Reform for Older Persons*, highlights the importance of a meaningful everyday life (White Paper 15 (2017-2018)). However, this study shows that frail older people have unmet needs related to meaningful activities and participation possibilities. Several studies suggest that adjusting the environment can contribute to residents feeling at home in an institution. For example, Matarese et al. (2022) highlighted that adapting the physical environment and care culture can create a sense of home for older adults in nursing homes. Previous research has shown that participating in meaningful activities can contribute to a strengthened feeling of being connected to oneself, other people and the environment (Fæø, Husebø, Bruvik, & Tranvåg, 2019). In accordance with this, Rand et al. (2022) emphasize that participation is essential to living meaningful lives, but frailty negatively affects participation. Our study and other studies stress the importance of meaningful activities to prevent loneliness (Chew, 2022; Hemberg, Nasman, & Nyqvist, 2022; Hemberg, Nyqvist, Ueland, & Nasman, 2020).

Our empirical findings on attuning to the natural rhythms showed that the participants urgently needed familiar and natural rhythms to feel at home. They hoped that they could live at home as before, with significant others and meaningful things to possess and use. However, this turned out to be challenging.

Heidegger (1962) saw the practical use of things as the tool used to carry out meaningful activities and how a broken tool interfered with that meaningful activity. Svenaeus (Svenaeus, 2000b) continued this thought, seeing the body as a toolbox for understanding the world as meaningful. Physical activities, such as cooking, are reduced if the body is damaged. In this way, an injured body can change the structure of meaning by seeing more clearly how essential this activity was for enabling at-homeness. Frailty can change people's perception of the body as its functionality changes. Accordingly, being in the world entails both at-homeness and homelessness, and the physical home is not sufficient to regain at-homeness. Living with frailty means living with homelessness to a greater or lesser extent since frailty is unpredictable. The frail older people had to learn to live with the body in other ways since the body, our place and access to the world change with illness.

Several studies show that homelessness concerns experiences of being displaced, unsafe, lost and alienated from oneself and place, other people and things (Molony, 2010; Saarnio et al., 2016; Zingmark et al., 1995). The feeling of homelessness can intensify with age, as the body is more likely to encounter frailty, disability and illness (Pickard, 2018). These studies and our study showed that maintaining everyday rhythms was challenging since the body has a rhythm of its own. As we grow older, we gradually start having problems performing activities we earlier performed with ease, like maintaining the house and the garden. Aging disturbs the rhythm by reducing strength and power to perform activities, further reinforced by frailty and leading to a sense of homelessness. We are familiar with our lifeworld and yet elements are out of our reach and control, such as biological changes in aging and frailty.

Frail older people might struggle with the experience of loneliness and isolation, leading to a higher risk of loneliness and unmet needs for the user (Munkejord et al., 2018; Rostgaard et al., 2022). The participants described a desire to talk about existential issues. The participants described a wish to share their thoughts and feelings about life and finitude. Some talked to their loved ones, but many had lost spouses or close friends with whom they were comfortable discussing existential questions, and they described this as an existential pain and loneliness. Homelessness is an essential condition for human existence, linked to our finitude and dependence on others and is brought to the fore by illness.

Our findings indicated that living with frailty could stress the relationship with the family caregivers, since living with frailty entailed being dependent. The participants in our study said they trusted family caregivers to make best-interest decisions for them since they knew them so well and would know what they wanted if the need arose. Combes et al. (2021) emphasize the importance of planning for future care: for example, talking about life now and their care needs regarding activities of daily living. Following Heidegger (1962), caring is fundamental to feeling at home. This raises an essential question about health-care personnel, family caregivers and frail older people's responsibility and participation in planning and deciding future care, helping them experience at-homeness regardless of where they live.

6.1.3 Caring for home-dwelling older people

The empirical discussion contributes to a new understanding of the overarching theme of "Striving to adapt throughout the care process", which indicates that care for frail, home-dwelling older people was ambiguous, demanding and meaningful. Frail older people's varying health and unpredictable everyday life and the change in the relationship were described as an additional challenge for family caregivers.

According to Heidegger (1962), care is a fundamental existential condition concerning people's connection to the world and other people and illuminates the motives of love, duty and reciprocity. Care expresses commitment to the world, illuminated by helping to provide for other people, showing our acceptance of what

being connected to other people means. We understand and depend on others by sharing a familiar everyday world in which we primarily understand ourselves through relationships. By inhabiting the world, we take action.

Figure 1 shows that care involves embodiment, at-homeness and temporality. Frailty causes bodily changes that affect how the body lives in the world, and those who live with frailty can experience being homeless in their own body. Frail older people balance on a tightrope between home and the nursing home. The experience of losing the grip of living well at home reinforces the feeling of homelessness.

Based on our findings, “close and distant”, the care process started when family caregivers noticed the first signs of illness or frailty, and they described doing what they could to help and described care as a part of the relationship, stemming from love and gratitude for their family member. Initially, informal care services may not be time-consuming and can usually be provided outside working hours, and yet intensifying the caregiver role might affect work and social life (Rostgaard et al., 2022). Martinsen (2003) elucidated this in describing relational care: giving and receiving care with the other’s best interests in mind. Frailty, however, affects the balanced reciprocity when one of the parties has to take care of the other. Our findings highlight that practical care affects the lives of both parties through complex relational changes. Practical care entails trying to understand and meet the situation of other people, doing what they think is best in the situation (Martinsen, 2003). Family caregivers gradually assumed responsibility and communicated with health-care providers, such as physicians, physiotherapists and nurses, and coordinated their relatives’ needs for treatment and care.

Our finding, “the tables have turned”, illuminates events as turning points in which family caregivers expressed a moral responsibility to support relatives who want to stay at home. Following Martinsen (2003), moral care implies recognizing and respecting the care recipient, implying solidarity with the other person and trying to understand dependence. By doing so, family caregivers provided care with the intention of enabling their relatives to live the best life possible with frailty. They also

had to ensure that the care recipients received adequate care. A son experienced his mother being sent home from the hospital after she had assured the hospital personnel that she could care for herself. When he went to check on her, she was confused and unable to take care of her hygiene or call for help. He had to set aside his mother's desire to stay home since he experienced the situation as overwhelming. He realized that his mother could not care for herself, and he could no longer take responsibility for this. In our findings, family caregivers said that their relatives' needs could overwhelm their capacity. They said that the situation was beyond their control even if they tried to prepare, such as the woman responsible for her frail older parents in-law. After returning from the nursing home, her mother-in-law walked out at night, trying to jump from a pier, aiming to end her life.

Our empirical finding, "starting to let go, yet being deeply connected", highlights that family caregivers want to care for their loved ones, but several demanding events put the relationship and caring role at risk. Participants described supporting their relatives as necessary and something they wanted to do. However, when everyday life and practical tasks took up too much space and time, family caregivers feared being too exhausted to care for their relatives adequately. Participants asked whether selfishness, concern for their loved ones or both made them consider a nursing home. Our findings show that being family caregivers sapped their energy and being unable to balance their own life with being a family caregiver led to an overwhelming care burden that was unsustainable in the long term. Our findings show that participants worried about the future and how the situation would evolve.

According to Heidegger (1962), the past and the future give meaning to what happens here and now. Who we are now is determined by who we have been and want to be. Following Heidegger (1962), *fürsorge* is a future-oriented aspect of care, while Martinsen (2003) highlighted that caring means respecting the other person's boundaries related to the person's direction or future goals, wishes or ambitions. This study has shown that the current policy also affects the current and future situation, since the policy changes the care context for frail older people and family caregivers. According to Ringer (2017), the profile of family caregivers needs to be raised and

awareness created of their reactions to care. For instance, respite prevents caregiver burden (Munkejord et al., 2020) and might support family caregivers in withstanding their situations longer.

Family caregivers said that meeting the needs of care recipients was challenging because of the unpredictable and fluctuating nature of frailty, leading to a rift between frail older people and their family caregivers. Being a family caregiver increased in intensity as frailty developed and involved wondering how worsening frailty threatened care recipients' ability and opportunity to manage at home. Previous studies highlight that caregiver burdens pose a compelling risk, since family caregivers report lower quality of life (Chappell, Penning, Kadlec, & Browning, 2021; Pinquart & Sörensen, 2011; Stefánsdóttir, Munkejord, & Sveinbjarnardóttir, 2022). We assume that the caregivers in our study might have the same experiences. In our study, the family caregivers put themselves in the care recipients' place for as long as possible by preparing meals or doing housekeeping. The family caregivers' experience of not doing enough characterized their lives. They could not risk getting sick, so some participants tried to take better care of themselves, for example, by starting yoga to overcome stress or sharing care with others. Participants had to deal with changing their future hopes and prospects, since caring was meaningful but all-consuming.

This study highlights the challenge when conflicting opinions about setting priorities arise. As frailty develops, the caregivers run ahead and *fürsorge* for the care recipient to make way for future opportunities and potential, such as checking the possibilities for extended help from health-care providers or seeking admission to a nursing home. Family caregivers expressed a greater need to plan for the future and ensure a secure and dignified life, whereas the older people were most concerned with living well here and now. The caregivers provided care without expecting anything in return. However, they often received a reward, such as consideration, gratitude and a feeling of doing something good for their relatives. When family caregivers considered seeking admission to a nursing home, they feared ending the relationship as it had been and losing the care recipients' gratitude.

Figure 1 shows that embodiment, at-homeness, caring and temporality are closely interwoven. The findings show that understanding lived time as a component of caregiving and giving it attention are essential. The empirical evidence in this study shows that recognizing older people's thoughts about the past, present and future is essential to understand what living with frailty is like. In the present, participants witnessed the care recipients' discomfort and embodied changes. Thinking about the future, family caregivers realized that they had to start to plan a change in the care situation, albeit feeling connected and morally responsible for the care recipients' well-being and for ensuring that they had adequate care. For spousal caregivers, this change entailed asking for an altered living condition for them as well. They had to consider whether they would live without their partner or seek nursing home admission for themselves.

There is solid political support in Norway for older people to live at home for as long as possible. The government encourages family caregivers, volunteers and older adults to co-produce the services (White paper nr.15 (2017-2018)). As such, there is political encouragement for family caregivers to be involved in care. According to our findings, caring for relatives can affect a person's ability to combine a longer working life, taking care of their health and social engagement. Previous studies have shown that family caregivers take on significant responsibility for caring for their relatives at home, often without adequate information and support, to ensure the quality of care.

Nevertheless, their strong bond with their relatives and the mutual love they experienced made letting go difficult, even if affected self-care (Ris, Schnepf, & Mahrer Imhof, 2019). The findings in our study deepen this by further highlighting their struggle to adapt to ambiguous and complex situations. Caring means being with someone who exists in a time that is out of rhythm.

Our study further points to the need to involve family caregivers to strive for sustainability in the care sector. Previous research underscores that, by respecting the wishes of older people and their families, effective rehabilitation can enable older

people to live at home (Ohta et al., 2021). Combes (2021) states that future care planning concerns family life, environment and equipment regarding meaningful activities connected to one's home and garden. For some, it also includes training or information to prepare for dealing with deterioration or making the right decisions if the situation changes. There is broad agreement that enabling frail older people to live at home as long as possible, where relatives can provide care and provide self-care, requires new knowledge, including the experiences of frail older people and their family caregivers (Grenier, 2020; Caroline Nicholson, Meyer, Flatley, & Holman, 2013; Skilbeck et al., 2018).

Previous studies show that older people differ significantly in how much they rely on their family caregivers. Some lean strongly on relatives for support, but others fear burdening them (Yip et al., 2022). The findings from our study support this, since the interactions between caregivers and recipients differ. The current study's findings indicate that collaboration between the frail person, family caregivers and health-care providers would enhance the understanding and support of frail older people and their family caregivers, contributing to good and coherent health services.

7. Methodological considerations

This chapter clarifies and deepens the methodological choices.

There has been discussion on the quality criteria in qualitative research in recent decades. It has been argued that reliability and validity, which depart from the quantitative research tradition, are not always fruitful in evaluating quality in qualitative research. Validity is usually defined as the degree to which the inferences made in the study are accurate and well founded (Polit et al., 2021). In qualitative research, people's well-being, capacity to run their life projects and, for example, their individual needs and preferences are paramount (van Wijngaarden et al., 2017). According to Polit and Beck (2021), these terms are associated with a positivist paradigm and might hinder creativity in qualitative research.

Although not without critics, the quality criteria most often cited by qualitative researchers are those proposed by Lincoln and Guba (1985), who established criteria for trustworthiness in qualitative studies: credibility, dependability, confirmability, transferability and authenticity. In the following, I will elaborate on credibility and transferability as quality criteria for validity in the current study.

Credibility indicates the internal connection between epistemology, research questions and methods necessary to produce sound qualitative research, referring to conducting research. This involves the quality of the study design, data collection, analysis, description of findings and collaboration with others during the research process (Creswell & Creswell Báez, 2018; Lincoln & Guba, 1985).

Prolonged engagement with the participants in this study strengthened the credibility. When the project started, I visited an outpatient clinic for older people to get more insight into their work. The participants were recruited by a third party, the head nurses at outpatient clinics, for ethical reasons. To be invited to the study, participants had to fulfill three of the five criteria for frailty of Fried et al. (2001). These criteria ensured that participants were frail and yet recruiting participants was time-consuming. Their physicians referring them to the outpatient clinic might have

contributed to the selection of participants. This may have meant that resourceful older people and family caregivers participated. It is also conceivable that some older people are very extra frail and have experienced consequences of frailty, such as falls. Another way of recruiting, such as home nursing, could have produced other participants. There, however, one could imagine that the concept of frailty was not so well known, and the frailty criteria could have become more uncertain.

Becoming familiar with the field over time and across several contexts enabled me to build trust with the participants. There is a tacit assumption that empathy between the researcher and the participants will increase the possibility of collecting more detailed data, producing more credible and trustworthy research findings (Morse, 2015). I also tried to enhance the credibility of the study by creating an open atmosphere during the interviews, summarizing parts of the conversation, asking the participants to determine or adjust their statements and inviting them to tell more.

Even though participants talked about deteriorating bodies, none used the term frail but instead talked about poor walking ability or problems with breathing and performing daily activities. I therefore did not use the term frail when interviewing participants or family caregivers but instead used everyday language with which they were familiar, such as living with various ailments. Being sensitive to their language and values, and using their words, was essential for building up trust and enriching the conversations.

According to Morse (2015), the sample size depends on the nature, scope and complexity of the phenomenon, considering the whole data set. We strove to ensure rich descriptions of the phenomenon being investigated. The purpose of writing rich descriptions was to provide details about the setting and people, enhancing the transferability of the study. I described the study context; participants' selection and characteristics; data collection; and data analysis.

Further, the participants varied in age, sex, health status, level of home care services, home help and place of residence. Rich descriptions of the experiences and background information enable readers to obtain deeper understanding and compare

the experiences with experiences they have seen in other situations. Since the interviews provided rich and detailed descriptions and the participants varied, including negative cases, I found that the data set held firmly.

When this project started, the knowledge of the lived experiences with frailty of older people and their family caregivers was sparse. Since the participants gave rich and detailed descriptions of their experiences with frailty, I decided to take the material's character as a starting-point for phenomenological analysis. According to Polit and Beck (2021), the phenomenological approach is particularly beneficial if the concept is insufficiently defined or conceptualized.

Zahavi (2021) and Zahavi & Martiny (2019) claim that a phenomenological approach should be based on phenomenological theory. Zahavi & Martiny (2019) questioned the philosophical basis of van Manen's approach, claiming that he misinterpreted the phenomenological method's various aspects and further argued for a solid theoretical foundation rather than using these methodological terms (Zahavi, 2021).

However, by using a theoretical framework from the start, frontloading the project might lead the interviews in a particular direction and cover what is essential to the individual. I chose an open attitude in this study and tried to bracket my preunderstandings. Since I received rich data about the participants' experiences, also in areas I had not expected, I consider this a good choice. Finding a direction when using an analysis method without clear steps was challenging. I therefore chose to use existentials in the analysis work.

I used existentials as a conceptual framework and did not impose them on the interviewee, being aware of the existentials in the same way as the concepts of frailty and aging. The existentials provided a lens that enabled me to provide a specific perspective on the phenomenon by focusing on and exploring the specific content when analyzing, aiming to understand and describe the findings. In this project, the lived body, the lived space and the lived human relationship were the lenses that gave the perspectives in the articles, while lived time was the window that gave perspective to the findings as a whole. These existentials enabled me as a researcher

to obtain access to people's lived experiences and develop deeper understanding of the nature and meaning of everyday experience.

Following van Manen (2014), research results should be meaningful to more people than just those involved in the study. In the current study, I sought to obtain knowledge that went beyond the individuals I interviewed. Providing an essential structure of meaning based on the existentials in this project strengthened the transferability. Since existentials are fundamental to all people, I hope that there will be elements that others can recognize and that can be experienced in other situations.

Communicating validity was essential to enhance the transferability of the study (Brinkmann & Tanggaard, 2015). In accordance with the suggestions of Creswell & Creswell Báez (2021), we, as a research team, were responsible for the study's relevance and accuracy. In this study, the various phases in the research process have been discussed with others. Being a group of four contributed to broader understanding of the data. To ensure that the research process in general and specifically analysis and findings were discussed with several people, supervisors had access to the transcribed material stored on a secure research server. Analyzing data with the supervisors improved the study's reliability by getting more people to thematize the same transcribed content (Creswell & Poth, 2018).

I also acknowledged the peer reviewers' feedback on our papers (Creswell & Creswell Báez, 2021). However, reviewers in the journal did not have access to data because of confidentiality and are therefore a limited source for understanding the findings. Nevertheless, I have received valuable input to ongoing discussions in the research field, which have been fruitful to raise in discussing the findings. Such input also means that others in the field can familiarize themselves with the project and make valuable contributions.

I appreciate feedback and discussions from presentations on research schools and conference presentations in municipal health care, geriatrics and phenomenology. Inputs from research conferences and research schools have been helpful, such as clarifying what is at stake for the individual or specific questions about variation.

Presenting the results, including participant quotations, enhanced transferability and credibility in the study. I find authenticity and empathy closely interrelated with the researcher's role, and I will elaborate further in the next section. An authentic text invites the reader to develop deepened sensitivity to the issue when the author portrays the feelings, experiences and context of the participants' lives, which enables the readers to assess the applicability of the findings according to context and settings (Creswell & Creswell Báez, 2021; Lincoln & Guba, 1985).

7.1 The role of the researcher

Reflexivity involves attending systematically and continually to the context of knowledge construction and how the researchers affect data collection, analysis and interpretation (Polit & Beck, 2018). I contacted all study participants. I conducted all interviews, which enabled a consistent approach, and I mitigated the potential for interpretation bias by using a reflexive diary and engaging in close dialogue with my supervisors, facilitating my openness to alternative interpretations of the data. However, I cannot fully be aware of my preunderstanding. Nevertheless, I did try to clarify it, and I will elaborate on my role in the interview setting, data analysis and writing and presenting findings.

Being a nurse educator, an experienced home health-care nurse and a researcher might have affected the interview situation in which I may have made premature conclusions. However, my background as a home health-care nurse was probably also a strength because of my communication experience with patients and family caregivers and my confidence in working in other people's homes.

Aiming for a relaxed atmosphere, I started with an everyday conversation when entering participants' homes before I told a bit about myself and my background. I ensured that participants were comfortably seated, in study 1, mostly in their favorite chairs. In study 2, family caregivers took a more active role and planned and chose where we should sit. In the conversation in both studies, I was relaxed and laid back, yet focused, and aimed for eye contact to show my interest in their stories when it felt

natural. I had prepared sufficient time to ensure a relaxed atmosphere and to be able to close the conversation without a need to hurry. I let the participants talk freely, especially at the start, but had the research questions in mind and gently tried to draw attention back to the research questions or other points I wanted to know more about: for example, by saying: “You mentioned your stay at the nursing home; can you tell me a bit more about that?”. Since the analysis starts already in the interview situation, I tried to capture and elaborate on moments I considered important for the participants in the interview situation. I was conscious of not interrupting the participants but waited until there was a natural pause to avoid seeming dismissive or uninterested in what they had to say. During the data collection, the frail older people and their family caregivers willingly shared their experiences and personal stories, providing us with detailed descriptions and a thorough data foundation. However, by conducting interviews in participants’ homes, unexpected situations occurred, such as visits from home health-care personnel, phone calls or family members passing by. I paused the recording in these situations, and these conversations were not part of the transcripts.

I interviewed participants in studies 1 and 2 on the same day or after interviewing those with frailty. Some lived together in the same house. I knew I had a duty of confidentiality, and I did not comment on what one of the parties had said in the individual interview. However, I had no control over what the participants told each other, and it turned out that being interviewed was a topic of discussion. When I came to interview a spouse as a family caregiver, they were both present and said they had argued just before I arrived. I said that I understood that talking about sensitive topics could be upsetting and offered to return later. They did not want this and said that they felt good to talk about these topics, which otherwise lay unsaid between them. This shows that the researcher’s role cannot be objective and that we participate in the same lifeworld as those we interview.

As van Manen (2014) recommended, the analysis attempted to grasp what was at stake for the others. To deepen my understanding of the interviews, I read the transcripts and listened to the interviews several times in different locations: during a

trip outside, alone in the car or at the office. Listening to the interviews, I asked myself what was at stake for the others. Although I had detailed transcripts, listening to the participants' voices, intonation, pauses and repetitions gave deeper understanding and meaning to the words they expressed. In addition, I reflected on my role as a researcher. Did I give the participants sufficient pause before elaborating on the question? Listening to the interviews made me aware that I progressed too quickly in some places and could have dwelt longer on some topics. In one case, this was so obvious that I asked to return to continue the interview, which I did. The participant had breathing problems in this interview, which probably contributed to my proceeding quickly, so the interview would not be too time-consuming and burdensome for the participant. Conducting a new interview provided opportunities to elaborate on points that needed to be further elaborated. Phenomenology is a way of thinking and writing aiming to bring to light the understanding of human nature and world conditions and cannot be separated from the practice of writing (van Manen, 2014). Writing the results of qualitative analysis is an active struggle to understand and recognize the lived meanings of the phenomena studied (Polit & Beck, 2018). In this study, phenomenological writing was inspired by dialogue with my supervisors, other researchers and doctoral students, nursing students and nurse educators, myself and my own experiences with the phenomena. Van Manen (2014) emphasizes that wonder arises when one's own experience meets the thoughts and wonders of others, especially those that titillate with their difference or withstand elaboration and explanation. This meant being open to new insights. Initially, it was a balancing act between being inspired by the input and being aware that I knew the data and project and had to find my way. The most valuable part of the dialogue with others was clarifying my findings and looking for variation and differences once more. In this way, dialogue with others widened my understanding and horizon, and other questions helped me to clarify the writings.

Reading and listening to novels and poetry about aging has also inspired me to grasp the essential meaning of frailty. Following van Manen (2014), experiential descriptions in literature and art help to challenge and stretch phenomenologists' interpretative sensibilities. Using van Manen's *Phenomenology of practice* has given

room for creativity. It has also presented challenges, since there are no clear steps in the analysis but rather a path that can be followed in which one can be inspired by such things as literature, poetry and art to practice the ability to interpret. Without fixed steps to follow, describing how themes emerged and describing the analysis were challenging. I read and listened to audiobooks, both research and fiction, to open up new insights and get tips on bringing clarity to the text.

One inspiration for me was Florida Scott-Maxwell (2013), who portrays her deteriorating health as follows:

We are stretched too far; our gamut is painfully wide. Little things have become big; nothing in us works well, our bodies have become unreliable. We have to make an effort to do the simplest thing... When a new disability arrives, I look about to see if death has come, and I call quietly, "Death is that you? Are you there?" So far the disability has answered, "Don't be silly, it's me" (p. 36).

This poetic statement comes close to my beginning understanding of frailty as lived experience. Scott-Maxwell expressed her aging experience as living with a fluctuating and unreliable body. Due to former experiences in the past, a new disability was expected. In the present situation, the author immediately thought of the future. Is it death, or do I have more time? In this, she enables understanding of how the lived body is always related to temporality, as past, present and future weave together.

Van Manen emphasizes that a phenomenological text will produce intensifications, which will evoke something in the reader, whereas phenomenological writing will help the readers recognize themselves in the description. Reading what others write about events paramount to their existence that they have experienced has stretched my ability to understand and recognize what the interviewees said. Reading other literature helped me to expand my vocabulary and find inspiration for formulations and ways of describing the feelings and meanings I wanted to express in the papers and this thesis. This mainly applied to English literature since English is not my native language, and my vocabulary is thus limited.

The term “phenomenological nod” describes an interpretation that is a recognizable experience we have either had or can imagine having. For van Manen (1990, p. 27), a good phenomenological description adequately elucidates some aspect of the world that resonates with our sense of lived life. Using existentials as lenses through which to see the material has enabled me to see and recognize central human phenomena that are valid for everyone, regardless of age and health, but that become especially prominent among frail older people and their family caregivers.

This study has provided knowledge about how frailty has changed life in complicated ways but has also been insightful and enriching for the participants. The changes have been viewed based on theoretical concepts embracing human perspectives with an existential aspect, enriching and giving a deeper understanding of lived experience in the encounter with frailty. In this way, the theoretical perspective has given thinking and structure to understanding the empirical, while empirical and lived experiences have concretized the existentials, making them more accessible and close to experience.

8. Conclusions

The overall aim of this study was to explore and describe the lived experiences of frail home-dwelling older people and their family caregivers.

Based on the findings, participants with frailty lived through a bodily change. The participants' interaction with their surroundings changed as the body gradually lost its earlier capacity and they risked illness and injury. Despite reduced activity levels, the participants did not give up and found new strategies to live meaningful lives.

Experiencing meaningful activities was essential to preserving their self-worth and maintaining a sense of the life they used to have. The results show that using their resources and support from others was essential to continue and manage their daily situation now and in the future.

The findings show that the participants clearly saw what they considered important, and their home was essential. The experience of frailty combined with moving away from home indicates the dual vulnerability frail older people live in and through. Our findings showed that treatment in a nursing home succeeded somewhat, but there were limitations to participating in personally adapted daily activities. The results show that participants had the strength and vitality to continue their lives at home, where they could follow their own rhythm and live in familiar surroundings and nature.

This study shows that the varying health of frail older people challenged family caregivers. They gradually assumed responsibility for coordinating their relatives' needs for treatment and care. The time dimension played a role in the relationship with family caregivers since they wanted to ensure that the participants were well both here and now and in the future. The findings show that family caregivers lived dual lives and had to care for their families, work and continue their social life, and the caregiving responsibility could overwhelm their capacity, even if they tried to prepare.

The current study provides new insight based on the first-person perspective that can contribute to understanding and discussing care for frail older people living at home and how to care for and collaborate with family caregivers.

8.1 Implications for practice

Frailty can overshadow vitality, and health-care personnel can be aware of this when they provide and plan care for these people. Including frail older people in planning care is crucial to determine what is essential to manage life at home, entailing decision-making and recognizing their desire to live well both here and now and in the future. Meaningful activities are essential in planning care for frail older people to provide good-quality care. Supporting people in living in homes that are right for them, meeting their needs and attending to their preferences will be right at any age.

A future-oriented approach is also necessary for health-care providers to support family caregivers in withstanding the caregiving situation and facilitating respite when necessary. Future care planning concerns family life, the environment and meaningful activities and where to stay if health deteriorates. We therefore recommend that family caregivers could be involved early and invited to participate and say what they need and how they can contribute by caring for frail older relatives.

As the population ages, the prevalence and treatment of frailty will likely affect the caregiving role. This study's findings indicate that cooperation between the frail person, relatives and health personnel can increase understanding and support for frail older people and their relatives, contributing to good and coherent health services.

8.2 Recommendations for future research

Involving people with frailty and their caregivers can offer valuable insight to health-care providers. Because of the increased focus on patient participation and the involvement of family caregivers, this project can be a starting-point for further investigations into how health-care providers experience frailty and the involvement of family caregivers. Focus group interviews with health-care providers would

provide new knowledge about how they involve frail older people and family caregivers when planning care. More research approaches are needed to make future research relevant for older people living at home and their family caregivers.

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EMPIRICAL STUDIES

In the borderland of the body: How home-dwelling older people experience frailty

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Abstract

Rationale: The increasing number of frail home-dwelling older people has sharpened the focus on discovering and implementing suitable treatment and care in clinical practice, aiming to prevent loss of physical functioning and preserve their autonomy and well-being. People's embodied experiences may yield rich descriptions to help to understand frailty. Thoroughly understanding older people's individual perceptions is especially relevant because the numbers of home-dwelling older people are increasing, and people tend to develop more health problems and become frailer as they age. Their perspectives are important to develop knowledge and high-quality care.

Aim: To explore the lived experiences of frail home-dwelling older people.

Methods: We conducted a phenomenological study to obtain in-depth descriptions of the phenomenon. We interviewed 10 home-dwelling older adults (seven women and three men, 72–90 years old) in depth about their lived experience of frailty. We analysed the data using a hermeneutic phenomenological approach described by van Manen.

Findings: The lived experience of frailty is described in one essential theme: frailty as being in the borderland of the body, including three interrelated subthemes: (1) the body shuts down; (2) living on the edge; and (3) not giving up.

Conclusions: Our study gives insight into lived experiences with frailty among home-dwelling older people related to their own body. Older people's experience of meaningful activities strengthened their feeling of being themselves, despite their frail and deteriorating body. Healthcare providers must consider the strategies of frail older people to consider both their vulnerabilities and self-perceived strengths. The resources and deficits of frail older people present in the state of being frail need to be recognised.

KEYWORDS

embodiment, frailty, home-dwelling, in-depth interview, lived experience, older people, phenomenology, strength, well-being

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INTRODUCTION

In health care, frailty refers to a loss of biological reserves that reduces the body's ability to recover from illness and other stressful events [1–3]. Frailty is defined in several ways, usually as a progressive age-related decline resulting in reduced reserves of capacity and an increased risk of adverse health outcomes [1–3]. Further, frailty is used as an umbrella term that covers ageing decline and loss in health and well-being, including physical, mental and social functioning [4–9]. Frailty affects about 10% of people 65 years and older [10], and the prevalence increases progressively with age, affecting about 65% of those 90 years and older [11]. Frail older people are at significantly higher risk of future challenges with activities of daily living [12–18]. The increasing number of frail home-dwelling older people has sharpened the focus on discovering and implementing suitable treatment and care in clinical practice, aiming to prevent loss of physical functioning and to preserve their autonomy and well-being [19–21]. Depression and independence are both adverse outcomes of frailty and might threaten frail older people's well-being and autonomy [22, 23].

Various frailty treatment models have been developed and investigated, producing a considerable diversity of treatment [21, 24]. Consequently, most quantitative studies investigating treatment are inconclusive [9, 10, 19–21, 25–27], although multidisciplinary treatment including exercising and healthy diet seems to have favourable effects [17, 21, 28]. It is therefore not possible to conclude what treatment and care are most appropriate [17, 28]. Clinical practitioners tend to view frailty within a biomedical and functional framework without emphasising the older people's perspectives [29]. Treatment and care aimed at preventing undesirable outcomes of frailty therefore risk failing to meet the needs and desires of older people [30, 31]. Even with extensive attention and research globally, literature exploring the experience of frailty from older people's perspectives is lacking [23, 29, 32]. However, a few qualitative and mixed-methods studies have provided valuable insight, revealing how frail older people experience frailty, such as whether they define themselves as frail or not [7, 8, 33–35]. Studies show that frailty harms older people's daily lives [7, 8, 20]. People may experience living with frailty as being disconnected from life: being trapped in a frail and deteriorated body [36]. Further, the experience of fluctuating health relates to episodes of uncertainty that threaten older people's resilience [23]. Qualitative studies of the bodily experiences of frail home-dwelling older people are especially lacking [29, 32, 34, 37, 38].

People's embodied experiences may yield rich descriptions to help in understanding the experience of health, illness [39] and frailty [29, 32, 38, 40]. Thoroughly understanding older people's individual perceptions is especially relevant because the numbers of home-dwelling older people

are increasing, and people tend to develop more health problems and become frailer as they age [3, 11, 28]. This study aimed to explore the lived experiences of frail home-dwelling older people. The research question guiding our investigation was as follows: How do home-dwelling older people experience frailty?

THEORETICAL FRAMEWORK

The study is rooted in a phenomenological understanding of the body, health and illness. Merleau-Ponty emphasised the body as the primary site of knowing the world [41]. We are seamlessly embedded in the social world we inhabit. Embodiment refers to the lived body, how we bodily live in meaningful ways in relation to the world and others [41]. The lived body is ambiguous, having a dual status: we both have and are our body. The body is both the subject and object of intentionality as we constantly navigate everyday life. Intentionality indicates the inseparable connectedness of the person to the world [42].

METHOD

We designed the study as a hermeneutical phenomenological study, inspired by the methods of van Manen [42]. Hermeneutical phenomenological research is the study of the lifeworld: the world as we immediately experience it pre-reflectively, rather than as we conceptualise, categorise or reflect on it [43]. The grounding in phenomenology means that it seeks to understand in-depth specific phenomena in the lifeworld by focusing on the experience and perceptions of those who live them through [41]: in this case, the lived experiences of frailty from the perspectives of home-dwelling older adults. Researchers must be attentive and open to realise the meanings of a phenomenon. We therefore thought carefully about how to access the experiences we wanted to obtain. In preparing the interview guide, we considered which questions we wanted to ask and how to stimulate participants to describe their experiences vividly and immediately. The researchers include three experienced health researchers and one PhD student with experience from qualitative and quantitative research, ageing and phenomenology. Bracketing describes the act of setting aside different perceptions of reality in the natural world to study the essential structures of the world [42]. The researchers were conscious about their pre-understanding and were aware of its strengths and limitations. Our point of departure as healthcare workers is that frailty negatively affects older people's lives and frail home-dwelling older people need comprehensive health services, and this therefore provides an important context for studying their lived experiences.

RECRUITMENT AND PARTICIPANTS

We used a purposive sampling strategy and sought participants who could provide insight into the phenomena studied [44]. Head nurses at two geriatric outpatient clinics invited the participants. To be eligible, people had to be enrolled in home health care for at least 3 months and meet three of five of Fried's frailty criteria: unintentional weight loss, self-reported exhaustion, weakness, slow walking speed and low physical activity [1]. Fried's phenotype model is a widely used assessment tool in research literature. It enables better clinical operationalisation in numerous healthcare practice settings [45]. It is well suited to examine community-dwelling

older adults and feasible in clinical contexts outside and inside Norway [18, 46]. People 65 years and older with Mini-Mental State Examination scores ≤ 18 were excluded. The participants, seven women and three men, were 72–90 years old. Six lived with their partner and four lived alone. One withdrew because of deteriorating health. Table 1 presents the participants' characteristics.

INTERVIEWS

We carried out 10 in-depth interviews and one follow-up interview from December 2018 to December 2019 in settings

TABLE 1 Participants

Participant	Age (years)	Sex	Education	Civil status	Formal caregivers	Informal caregivers
1	72	Female	High	Married	Home health care. Regular general practitioner, physiotherapist, occupational therapist, hospital ward, outpatient clinic	Husband, children, friends
2	82	Female	Low	Widow. Lives alone	Home health care, Nursing home, hospital ward, regular general practitioner, outpatient clinic, physiotherapist, support person, pre-hospital care	Siblings, children, neighbours
3	78	Female	High	Lives alone	Regular general practitioner, hospital ward, nursing home, outpatient clinic, occupational therapist, pre-hospital care Has refused to receive home health care	Sister and nephew
4	88	Male	Low	Lives alone	Regular general practitioner, home health care, outpatient clinic, hospital ward, Norwegian Labour and Welfare Administration Has refused nursing home	Sister
5	90	Male	High	Married	Home health care, nursing home, hospital ward, regular general practitioner, outpatient clinic, physiotherapist	Daughter and son-in-law
6	84	Female	Low	Widow, lives alone	Home health care, nursing home, hospital ward, regular general practitioner, outpatient clinic, physiotherapist	Children and grandchildren
7	90	Male	Low	Married	Home health care, nursing home, hospital ward, regular general practitioner, outpatient clinic, physiotherapist, occupational therapist	Daughter-in-law, son, grandchildren
8	87	Female	High	Married	Home health care, nursing home, regular general practitioner, outpatient clinic, physiotherapist, occupational therapist	Daughter-in-law, son, grandchildren
9	89	Female	High	Married	Home health care, nursing home, hospital ward, regular general practitioner, outpatient clinic, physiotherapist, occupational therapist	Husband, son
10	82	Female	Low	Married	Home health care, nursing Home, hospital ward, regular general practitioner, outpatient clinic, physiotherapist	Husband, grandchild

chosen by the participants. The first author performed all interviews face to face. We conducted a pilot interview before collecting data. The interview guide had open questions such as: 'How do you experience living at home with your daily ailments?' and 'Can you tell me about an ordinary day?'. The interviewer tried to ask as few questions as possible and encourage participants to speak freely and elaborate on their stories, asking: 'How did you experience that?' and 'Can you tell me more?'. Having a phenomenological attitude also meant enduring silence and waiting patiently for answers. The interviewer was aware of the participants' vulnerability and offered breaks. The interviews lasted for 35–95 min, averaging 63 min. The interviewer audio-recorded the interviews and transcribed them verbatim.

ETHICAL CONSIDERATIONS

All participants gave written and oral informed consent. The study was presented to the Western Norway Regional Committee for Medical and Health Research Ethics and approved by the Norwegian Centre for Research Data (Ref. 61202). Data were stored and the study completed in accordance with ethical guidelines and the Helsinki Declaration [47].

DATA ANALYSIS

Van Manen describes the phenomenological method not as a controlled set of procedures but as a way towards human understanding [42]. There is an active search for meaning, from an open attitude of wonder. In phenomenological research, writing and rewriting are at the core of reflection and thoughtfulness and deeply interwoven analytical processes [48]. The first author wrote drafts and reflective texts and we discussed them. We started the procedure by reading through all the interviews to get an overall impression. The first author wrote short reflective notes on impressions after reading each interview. We read through the interviews and, after reflective discussions, selected meaningful text units and grouped them by categories. Various questions were posed about the excerpts, asking: What is this about? The first author tried to vary the frames of reference, using contrasts and contradictions, approaching the phenomenon from diverging perspectives. Then, we wrote condensed descriptions and explored them across the participants, seeking similarities and differences. We explored, articulated and reinterpreted, omitted, added or reformulated themes. This way of approaching the text, by moving back and forth, between writing, rereading the material, rewriting and having reflective dialogues, is called holistic reading [42]. We further refined the themes through reflective writing. We aimed to describe the lived

meanings of frailty. We introduce one essential theme describing frailty as being in the borderland of the body, including three interrelated subthemes: (1) the body shuts down; (2) living on the edge; and (3) not giving up.

The essential theme summarises the whole, and the three subthemes describe nuances and variations of living with frailty, including quotes from the participants.

FINDINGS

In the borderland of the body

Living with frailty meant living with an unpredictable body, limiting and shrinking their lifeworld. This bodily experience entailed slow deterioration and an ever-present risk of acute illness and incidents. Frailty was thus perceived as a warning that the participants' lives were about to take an unexpected turn. The experience of frailty changed the participants' lives. The disruption of everyday life, the confrontation with pain, suffering and uncanniness inevitably drew new attention towards the body, its condition, pain and functioning. Nevertheless, they expressed strong will to maintain meaningful activities.

Crossing the threshold into frailty was perceived as deeply existential, a situation they could not escape or recover from, forcing the participants to reorganise their everyday life. The participants were living in the borderland of the body, trying to figure out how to deal with their altering body and sustain the lives they had built for themselves. Although the capacity of their bodies fluctuated, the participants used their personal resources and support from others to continue, attempting to manage their day-to-day situation. The participants had experienced loss and bereavement, change and insecurity before. In the current situation, they drew on this experience and yet strived to maintain a sense of well-being in their lives. Frailty was a balancing act between living within bodily limitations and holding on to themselves and their lifeworld.

The body shuts down

The participants experienced living with frailty as living with a weak and unpredictable body. The stories of the body shutting down also expressed losses, including who they were and how they lived in the world. Participants experienced physical impairment and incapacity, and the body set the agenda for everyday life.

An 82-year-old woman described the decay in her body.

It is like I can see that my fingers crook. I wake up with my fingers all crooked, and I have to bend them into the right position [lifting her

hand, turning it around and demonstrating how she bends her fingers into the right position]. If only my arthritis could be a little better. But otherwise I think I am doing well. I did a lot of needlework earlier, including crocheting, knitting and embroidery. But I can't hold the needles anymore, and then I get grumpy, because the knitting needles fall on the floor, and I can't pick them up. ... But you see, I no longer care about housework, and the vacuum cleaner and I have been enemies for a long time. I don't have to worry about that, I mean, because I can't use it. I have such poor hands, and I'm glad if I can just grab a cup or hold a plate!

For some participants, a strong physical body was connected to work and practical chores in daily life. This was important for their feeling of being in the world. An 88-year-old man described a situation in which he got injured while working with wood. Even if he could find an alternative to heating the house with firewood, this activity had been a regular habit throughout his life. The injury affected other parts of his body that were starting to shut down as well.

It all started with me splitting wood. I was about to split a big wooden cube. And when I lifted the ax over my head, it was difficult to turn in the right position. And then suddenly, I twisted my body, and then my hand hurt so bad. Afterwards I got such tremors; I couldn't even write my name. After the incident, there has been little activity. So then I was hospitalized, and now I am not allowed to use my hands. So I have stopped the work outside. There is very little to do after I got problems with my hands and was no longer able to work. After that I got problems with my stomach and trouble with constipation. This caused some irregularities with sleep, and the medication was not so easy to dose. So I have to make sure I am near the toilet.

The lived experiences of having a strong physical body but gradually declining altered his way of being in the world. The strong body had been his force in the world, but now he perceived his body holding illness and weakness as well. The damage to his hand led to inactivity and constipation problems. He had difficulties dosing his medication for constipation, which led to waking at night with an urgent need to defecate. Fear of defecating in his bed or trousers made him stay close to the toilet. Not being able to work outside anymore represented a loss of the force in the world on which he built his life. Participants faced disruption of daily life from ongoing and increasing impairment.

Living on the edge

Participants experienced reduced strength, slower reactions and physical impairment and incapacity. Breathlessness was overwhelming and frightening. Participants lived at constant risk, despite a slow life, high age and a modest daily schedule. A 72-year-old woman with significantly reduced lung capacity lived at home with her husband. She experienced panic when she felt breathless.

The experience of not breathing: I could crawl up the wall to get a breath of air. I have an urgent need for oxygen. Like tonight, I couldn't sleep. I found no position where I could breathe. So I got up and sat at my desk in the office. I took a dose of medicine, and then I fell asleep at the desk. I was not able to get up on my feet on my own. ... I couldn't move, and then I fell asleep [...] you can worry about falling asleep and then falling on the floor. I am afraid of injuring myself unnecessarily. I get tired of not being able to breathe. The doctors haven't told me much, there is not that much that can be done. I must take my medication and keep exercising. There is nothing more that can be done. I know that when it becomes difficult for me to breathe, it's game over.

She described not being able to breathe sufficiently as living on the edge. Every decision and action, even the smallest mistakes, might be fatal. She knew that if she did not take care of herself, she would decline even faster. She worked hard to keep her body in shape to prevent further loss of muscle mass and felt great responsibility for her health. This was experienced as tiring and time-consuming but deeply meaningful, because it was the only way to obtain more time with her loved ones.

Living with frailty implied a body with fluctuating capacity. Participants had to adjust daily activities to the abilities of their body. Activities previously taken for granted were perceived as risky. This led to bodily uncertainty. Falls or episodes of breathlessness brought the fear of further decline. The participants experienced that each incident worsened their situation, as the body's reserves were gradually drained. Although trying their best to be careful, they sometimes slipped due to forgetfulness or inattention. An 82-year-old woman living alone in a large house described fracturing her femur.

I had locked the door before I went to bed, of course, and I walked inside with my walker. Suddenly, I fell flat on the floor. I do not know what happened, but I think the handle on the walker was a bit slippery. ... I was injured. ...

I didn't faint. I was completely numb, so I did not feel any pain. That's absolutely true. I have brittle bones and all of that, but I did not notice any pain. Because I had put my mobile phone on charge for the night, I managed to crawl across the floor to get the white cable and then I pulled it down. I called my niece, and she called the ambulance, which arrived just before she did [after just over an hour]. The paramedics had to break in through the porch door. It was totally okay. It was necessary. I tried to get up, but you know, it was impossible.

The participants said that they had techniques for getting up after a fall, but this did not necessarily work in practice. The experience of falling without being able to get back up underscored the physical impairment and incapacity of their body. Participants started questioning their capability to walk on stairs without falling or get to the door when the doorbell rang without tripping over their feet. Serious events such as falls, acute breathlessness or injury focused increased attention on the body. Decline in vital functions accumulated for each new episode, increasing their explicit awareness of their body and its strength and frailty. They became more familiar with their unpredictable and yet predictable situation. They knew where it was going, and anything could happen anytime.

Not giving up

Participants experienced their lifeworld as narrowed through illness and bereavement. Their potential to act and move was limited. They could no longer get out and see other people whenever they wanted, since this required planning and support from others. Being frail made participants wonder what the future would bring. Their life involved balancing between feeling safe in a smaller space and risking moving around a little.

To keep safe, participants quit meaningful activities and hobbies. They described these activities as being too risky and feared the consequences if they lost their balance while walking in nature or fell when entering the fishing boat. They experienced quitting activities their bodies could not endure anymore as a loss.

A 90-year-old man could no longer use his car or fishing boat due to illness and old age. Living in a rural area, he depended on support from others to socialise.

Well, I'll be sitting a lot inside. At home. I cannot even get around doing any work outside. And I have the fjord. I have been fishing

for several years but not this year. They [male friends and fishermen] have tried to convince me to join them. But no. ... I have such a hard time getting myself into the boat and out of the boat. ... No ... life is not going to be any different. I'll take a small round inside the house and look out the window [tapping his fingers on the table]. I hope it gets better when this year is over. ... I have an electric scooter now. I waited 4 months for it. I am so old, so I wanted one with a cabin on to protect me from the storms out here. At least I can come around and talk to people.

Despite decline and loss, participants hoped and strived to find other meaningful activities in which the body was less prominent. They worked hard to achieve a meaningful and livable relation with their altering body.

A 90-year-old man lived with his wife and spent most of his time at home. He enjoyed a quiet life. But the silence and loneliness were altering his experience of being himself, of being someone who mattered in the world. He had volunteered as an organist but stopped playing in the church several years ago. A visit at the nursing home inspired him to resume his hobby.

I started playing the piano again. My wife convinced me to play. I played for the residents at the nursing home. And good heavens; they applauded, I have never played so bad in my entire life, but they clapped, good heavens. ... they clapped and stomped. And cried. Now I found out that I need to practice a little, and then I will play at the nursing home. I'm happy to please others.

Engaging with familiar activities made participants feel connected to their lifeworld and being themselves. Participants fought the feeling of frailty and adjusted activities, so they could still experience meaningful activities, such as attending an art class or discussing literature. These activities enhanced participants' feeling of well-being, making their problems less prominent. Some participants had reconciled themselves with life as it was. They tried to maintain their daily activities indoors: reading the newspaper, walking around the house, listening to the radio or watching television and talking with their family on the phone. Daily activities sustained participants' feeling of connectedness to their familiar world. Keeping up their daily activities was not effortless due to pain and a slower body, but they could perform them without having to plan in detail what to do. These activities were deeply embodied, meaning that they knew some parts of life could continue.

DISCUSSION

This study explored the lived experiences of frail home-dwelling older people. The main finding was that living with a frail body is an ambiguous situation of balancing frailty, strength and a constantly altering body.

The subtheme 'the body shuts down' describes bodily decline, lacking strength and ability to perform daily activities as one aspect of frailty. These findings are in accordance with previous studies describing frailty as a negative physical and mental condition [1, 2, 4, 6–9, 49, 50]. Inability to perform daily activities reduced participants' socialisation, making them less attached to their lifeworld. The experience of their body shutting down affected participants' mood and well-being, which in turn intensified the effects of physical disability. In addition, Skilbeck et al. showed that poor mood disturbs frail older people's daily routines [23], and Pan et al. emphasised that frail older people identified their independence by performing daily activities [51].

Our findings expressed in 'living on the edge' underscore that participants had a great risk of injury even though they lived a slow life without much exuberance. This mirrors other studies, underpinning frail older people's significant risk of future challenges with activities of daily living [12, 13, 15, 16, 52]. Negative health outcomes are expected, revealing the complex interactions in the frail body [51]. Participants faced different possible dilemmas when they had difficulties performing activities of daily living; participants might ask others for help, thereby losing a sense of independence. The other options are managing on their own, continuing to live on the edge or adapting former activities to reduce the risk. Our findings show that participants were not giving up (sub-theme 3). These findings add important insight to previous research, showing that participants adjusted previous activities to keep up meaningful activities, still being independent. For example, losing the driving licence made one participant find a new alternative in an electrical scooter to get around. Previous research describes living with frailty as a life in existential loneliness, entrapment and being disconnected from life [36]. Our findings support this to a certain extent, especially when participants lived through their most frail episodes. However, our findings underscore that, living through experiences of frailty, participants gained deeper knowledge about their altering body. Participants describe a fear of being left with a dreary and meaningless everyday life, comprising either no activities at all or participating in activities of no interest to fill the day. Pickard argues that one aspect of health is being able to be and do what one values [29]. This has parallels to Koskinen et al., who state that vitality in suffering enables change [53]. Given our understanding of subthemes 1 and 2, frailty might be experienced as a downward spiral of losses of physical functioning, social engagement and a pervasive risk of injury when performing daily activities,

which is in accordance with the definition of frailty [1, 4, 5, 8, 9, 54]. This downward spiral might lead to symptoms such as reduced life satisfaction or depression, which is a known adverse outcome of frailty [22, 52]. Our findings show that participants realised they could not escape or recover from this situation, and the realities of life led participants to elicit and use their resources to find new strategies and meaningful activities. Previous research states that older people's personal strength is a resource for living a meaningful life [33, 55]. This is corroborated by other research describing frail older people's creativity as a capacity to connect to changing circumstances and adapt to being frail [23, 35, 37].

The overarching theme 'in the borderland of the body', regarding embodiment, shows that the experience of frailty is an ambiguous experience. According to Merleau-Ponty, the lived body enables access to the world, but when threatened by illness and physical decline, this access changes and may threaten one's sense of self and unreflective being in the world [41]. Our findings may thus indicate that living with frailty limited participants' opportunities to live a familiar and meaningful life at home close to their belongings and significant others. Participants had to adapt to their capacity and according to their resources and others available to them. Their focus on the body took precedence, meaning giving the body's limitations and health problems priority. Nevertheless, participants still intuitively are themselves and strive to maintain the sense of being a body, even though illness pushes this limit. Despite their losses, participants struggled to hold onto and live the lives they had built for themselves. They used past experiences of overcoming life challenges to endure and to hold onto what was most important for them.

Frailty has been described as loss of bodily integrity and embodied agency, meaning that frail older people lose their capability to be what they want to be and do what they want to do [7, 56]. Nevertheless, our findings show that participants adjusted their activities due to their altering body and lifeworld. The feeling of inadequacy when meeting former friends in arenas or situations that had become too challenging might be the starting point to find other meaningful and less physically demanding activities: for example, in an art class the body is less prominent. At first, the experience of frailty was frightening and limiting. Participants' bodily borderlines seemed impossible to cross; their lifeworlds were shrinking. As participants got more familiar with their altering body, they started to negotiate these borders, adjusted their activities and tried to push and expand the borders to get more space and possibility to be themselves. According to Merleau-Ponty, the body is both the subject and object of intentionality as we constantly navigate everyday life.[41] Considering this, our understanding may underscore the demanding balancing act participants faced. They acknowledged their limitations but strived to balance the desire to live and the necessity of being safe. In contrast, accepting frailty without negotiating its limits might lead older people to

give up and identify themselves as frail, risking reduced functioning and further decline.[23, 34, 38, 51] Consistent with our findings, Warmoth found that frail older people consider being active important, even at lower levels than previously [7].

As highlighted in previous studies [8, 20, 23, 36, 57], participants experienced frailty in old age as being thrown into an unpleasant journey of uncertainty and unpredictability that changed life itself. Living with frailty inevitably entailed that the body and its shortcomings tended to take over, yet also gave priority to the importance of maintaining other meaningful aspects of one's life and to stay open for ways to continue to do this. If healthcare providers only consider biological changes, they will fail to provide adequate care to this group of people. Further, healthcare providers should more extensively investigate older people's own experiences and resources when developing sound care for this group.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Our study gives insight into the lived experiences with frailty related to the body of home-dwelling older people. Finding out what frail home-dwelling older people consider valuable is therefore important when planning and providing care for such people. Social life is important and affects the health and ability of the individual to manage at home and experience well-being, something that is fundamental in care. In our study, meaningful activities often took place in or related to people's home or neighbourhood and accompanied by significant others. Healthcare providers should more extensively involve and utilise older people's resources and provide care in accordance with this as far as possible. This implies a holistic approach, which requires collaboration with the older people, family members and healthcare providers on different levels. This requires a more flexible organisation of the home healthcare services, in which healthcare providers can adjust the time and care based on the daily condition of the older person. Healthcare providers must strive to facilitate daily living for older people in collaboration with their significant others to plan a manageable life at home as long as possible. This study explored frail older people's experiences of frailty and life at home in depth, describing in detail meaningful activities as essential to feel as oneself and live a good life and hence for experiencing health and well-being. Frail older people's resources need to be recognised.

STRENGTHS AND LIMITATIONS

The study was conducted with frail older people in rural Norway. The cultural setting should be considered regarding the transferability of findings. However, we have shown

some parallel findings in previous studies, indicating that the essential meanings highlighted might be relevant across cultural differences. The sample size was small, but the interviews provided rich experiential data. The strength is that we give voice to vulnerable older people and their perceptions of the phenomenon of frailty related to their body, which is unique. To increase the credibility, dependability, transferability and confirmability [58] of the findings, we aimed for a varied sample, and the first author used her clinical experience when planning and preparing the interviews, preparing the interview guide, and all authors read and participated in the analysis.



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AUTHOR CONTRIBUTIONS

BES, JD and AMS designed the study. The first author collected the data. All authors read and analysed the data. The first author drafted the manuscript, and all authors contributed to the final manuscript.

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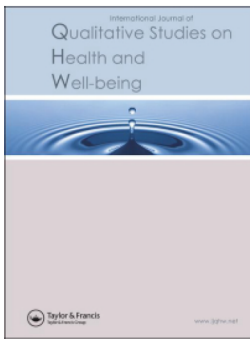
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Carrying on life at home or moving to a nursing home: frail older people's experiences of at-homeness

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ABSTRACT

Aims and objectives: The aim was to explore frail older people's lived experiences of managing life at home on the verge of moving to a nursing home.

Background: As people age, their reserve capacity decreases, increasing the risk of morbidity and frailty. The experience of frailty extends beyond declining health and physical well-being and encompasses various dimensions, including familiarity with both the place and the people around.

Design: A phenomenological study.

Methods: We interviewed ten frail people aged 72–90 years in-depth in their homes. We used phenomenological hermeneutical analysis inspired by van Manen and followed the COREQ checklist.

Results: We identified three main themes: (1) being home with cherished people and possessions, (2) giving the nursing home a go and (3) attuning to the natural rhythms.

Conclusions: Our study gives insight into the lived experiences with frailty related to at-homeness. The experience of being lost in transition represents a uniquely significant experience for frail older people, foregrounding existential issues and carrying the potential of at-homeness.

Relevance to practice: To unleash frail older people's potential for at-homeness, health professionals must meet the needs of frail older people individually. Going beyond signs and symptoms to reveal people's concrete everyday experiences is crucial to understanding frailty.

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KEYWORDS

Frail older people; phenomenology; at-homeness; in-depth interview

Introduction

The rapid growth in the ageing population in terms of both number and longevity has drawn global attention to the needs of older people, especially those who are frail (WHO, 2017). Well-being is a subjective experience that can prevail even in the presence of ill health when balancing older people's resources and challenges (Dodge et al., 2012; Eriksson & Eriksson, 2018). Frailty, defined as the presence of several interacting medical and functional problems associated with low well-being, makes frail older people more vulnerable to adverse outcomes (Clegg et al., 2013; Fried et al., 2001; Kojima et al., 2019). As a compelling global public health issue, frailty affects individuals, families, communities and society (Lekan et al., 2021). Decreasing well-being and increasing levels of frailty might lead to impaired quality of life and loneliness and apply to mental and social functioning (Hoogendijk et al., 2019; Warmoth, 2016).

Ageing at home has been a trend in Scandinavia for several decades (Ministry of Health and Care Services,

Norway, 2018; Walker et al., 2015). Still, in many Western countries older people move from their ordinary homes to institutional care for the final period of their lives (Saarnio et al., 2018, 2017; Statistics Norway, 2019). In Norway, more than 90% of places in nursing homes are public, and public services commonly offer a short-term stay of 4–6 weeks for older people with deteriorating health (Statistics Norway, 2019).

Home is regarded as the place where people recognize themselves, a place where one is known and seen by others, manages oneself, is close to significant others, experiences love and friendship, and is safe (Saarnio et al., 2018). A home is a place where they are familiar with the surrounding place and people, feeling safe, connected and centred (Öhlén et al., 2014).

In Norway, people have continually shaped their homes, linked to daily, weekly, and annual cycles with seasonal and ritual aspects (Pasveer et al., 2020). According to Hilli and Eriksson (2019), the source of vitality lies in the home, where one can show one's true self and innermost feelings.

Strategies for enabling a feeling of at-homeness are consistent with a personalized approach to promoting health and well-being, such as socializing and maintaining independence (Frost et al., 2017, 2018; Saarnio et al., 2019). Moving away from home makes people particularly aware of the importance of the homeness of their home (Baldursson, 2002). Studies from nursing homes describe that living there is considered a lonely and homeless existence (Österlind et al., 2017; Sjöberg et al., 2019). Moving to a nursing home is life-changing, and reported consequences are loss of autonomy, independence and identity (O'Neill et al., 2020).

Ageing populations all over the world face the challenge of maintaining older people's well-being (Clegg et al., 2013; Dodge et al., 2012; Fried et al., 2001; Hoogendijk et al., 2019; Kojima et al., 2019; Warmoth, 2016). Previous research has emphasized that a home is a special place where older people have experienced belonging, security and well-being (Öhlén et al., 2014; Pasveer et al., 2020; Saarnio et al., 2018). Health, well-being and at-homeness urgently need to be promoted throughout frail older people's lives, as many move to nursing homes in the final stages of life, feeling estranged and lonely (Österlind et al., 2017; Sjöberg et al., 2019). The physical changes connected to frailty are subtle and progressive and significantly predict nursing home placement (Clegg et al., 2013;; Lekan et al., 2021; Österlind et al., 2017). Phenomenological studies that examine the negative consequences of frail older people's experiences of being on the verge of living at home and moving to a nursing home are sparse. New insights into frail older people's experience of at-homeness are decisive for planning and caring for this group of people. Studies from the first-person perspective can challenge established assumptions and provide valuable insight to formal and informal caregivers and society. The aim was to explore frail older people's lived experiences of managing life at home on the verge of moving to a nursing home. Our study's research question was: How do frail older people experience at-homeness?

Theoretical framework

Phenomenology is a perspective addressing the foundations of knowledge and its development, often guiding methods appropriate for qualitative health research. Lived experience, subjectivity and the lifeworld are at the core (Heidegger, 1962). The lifeworld is the world we live in, the world of experience we take for granted in daily life (Van Manen, 2014). Our inquiry, reflections, and analysis were guided by the approach of Van Manen (2014). Phenomenological concepts are central to our empirical data analysis, such as vulnerability, dependence on others,

relationships, mortality and existential loneliness (Heidegger, 1962; Vetlesen, 2009). Svenaeus (2010) progressed a view of health as a "homelike being in the world". At-homeness might be considered an aspect of well-being despite illness for frail older people. When healthy, we are attuned to our lifeworld, whereas in illness, the natural rhythm of attunement is replaced with a sense of an unhomelike being in the world (Cooney, 2012).

Methods

We conducted a phenomenological study inspired by the methods of van Manen (Van Manen, 2014) and followed the COREQ checklist. The fundamental phenomenological question is, "How is this experience?". This question allows us to wonder about the meaning of a particular moment of lived life.

Participants and recruitment

We conducted a purposive sampling strategy and searched for participants to provide insight into the phenomenon under study (Patton, 2015). Participants older than 65 years with frailty according to the phenotype model of Fried et al. (2001) and a Mini-Mental State Examination score over 18 showing minimal cognitive impairment were recruited with head nurses' help from two geriatric outpatient clinics. The participants were 72–90 years old. Four lived alone, and six lived with their partner. One withdrew because of deteriorating health. The participants lived at home, and because of their frailty, they have had temporary stays at nursing homes or rehabilitation units.

Table 1 presents the characteristics of the study participants.

We interviewed 10 older people in-depth about their experiences living at home with frailty in December 2018–2019. Before data collection, the first author conducted a pilot interview to ensure that the questions' wording, flow and order were natural and understandable. The first author conducted in-depth face-to-face interviews in the participants' homes to ensure a familiar environment. The style of the interviews was informal, framed as conversations to bring out natural accounts of the everyday experiences we sought to explore. The interview incorporated semi-structured and unstructured interview elements to minimal rigidity and maximum depth. The interviews aimed to capture a detailed description of the phenomenon of at-homeness from the perspective of frail older people (Brinkmann & Kvale, 2014). The researchers included one PhD student with several years of experience in home health care and three experienced health researchers. The research team had experience in

Table 1. Characteristics of study participants ($n = 10$).

Characteristics	n (%)
Sex	
Male	3
Female	7
Age (years)	
70–74	1
75–79	1
80–84	3
85–89	3
90–94	2
Help	
Formal help ^a	10
Informal help ^b	10
Form of living and living place	
Own house with a spouse	4
Own house alone	4
Own house with spouse and family	2
Experience of institutional stay^c	
Nursing home	8
No nursing home	2

^aHealth care providers at home health care, nursing homes, hospital wards and outpatient clinics. Regular general practitioner, physiotherapist.

^bInformal caregivers such as spouses, children, in-laws, siblings, friends or neighbours.

^cIn Norway, brief stays in nursing homes for 4–6 weeks are common.

quantitative and qualitative research, phenomenology and ageing. We sought to capture participants' pre-reflective experiences, which refer to the moment as it was lived rather than how it is theorized, conceptualized or categorized (Merleau-Ponty, 2002). In addition to the verbal conversation, all but two participants voluntarily gave a tour of their homes, where participants identified meaningful objects and spaces for the researcher. The first author wrote reflective notes about the home's mood, content, setting and, more generally, the impression after each interview. These notes provided contextual information for data analysis.

Data analysis

The interpretive data analysis was inspired by Van Manen's (1990) iterative and inductive framework for phenomenological data. The method was to read and rewrite, present preliminary interpretations and questions and highlight important sections to restore the structure of meanings embodied in the human experience represented in the text. The analysis started with all authors reading through the interviews to get an overall impression. Furthermore, we identified and organized themes by collecting excerpts, asking various questions and seeking an understanding of the phenomenon's essential meanings.

After reading each interview in detail, the first author wrote short reflective notes, supported by reflections from a research diary. These notes helped identify key concepts and topics that were common or immersed and warranted further research. The first author prepared the analysis and discussed the new topics with the group of

researchers (JD, AMS and EN). The authors met and regularly discussed during the whole process. We had several rounds to clarify, concretize and abstract the material content of the material and develop themes. The last phase of the data analysis was developing and describing the themes of the phenomenon to obtain more profound knowledge of older people's experiences during the whole process (Van Manen, 2014). The analysis resulted in three final themes: (1) being home—where one lives with cherished people and possessions, (2) giving the nursing home a go and (3) attuning to the natural rhythms.

Ethical considerations

All participants gave written and oral consent before interviews were conducted. We presented the study to the Western Norway Regional Committee for Medical and Health Research Ethics, and the Norwegian Centre for Research data approved it (Ref. 61,202). We followed ethical guidelines ("World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects," 2013).

Findings

Experiencing institutional life was twofold, with a different form of security and easily accessible help from health workers. Experiencing frailty led to a balancing act where the participants lived on the verge of managing at home and moving to a nursing home. Their lives and homes intertwined with their stories, rituals and memories. The home was a shelter where they could return and feel safe. As the body changed and became frailer, the home was no longer sufficiently safe. A temporary stay in an institution was inevitable. An overall finding was that the participants wanted to regain a feeling of at-homeness in their experience of not being at home. Having a short-term stay at the nursing home reinforced a sense of limited time, that the life they knew and appreciated would soon be over. Existential issues, including its finiteness and meaning, became more apparent. The participants described having no one to talk to about these problems and expressed themselves by opposing moving into a nursing home. Participants knew that staying at home was barely possible since their unpredictable bodies made this more troublesome. Even though we presented the three themes separately below, they were coherent and overlapping.

Being home—with cherished people and possessions

The first theme comprised participants' descriptions of grounding and rootedness at home, manifesting

the blurred borders between self, others and the world. First, and most importantly, the home entailed shared time and space with significant others. Being at home included locality and landscapes, participants' gardens, dwellings and views. Cherished possessions enabled and enhanced the feeling of at-homeness and well-being. The participants used their homes and objects, such as family photos, paintings, diplomas, crafts and family treasures, to tell their identities and stories of settlement.

One 90-year-old participant linked feeling alive to living at home, even if frailty made her dependent on her husband. The home had a steep staircase, and she could not go outdoors by herself, but with him, she could. The experience of breathing fresh air in the surrounding nature was vital. Even if she could not walk in the terrain, the couple went for a drive every Sunday to a place with a nice view.

I think I am fine. We are both 90 years old. My husband manages to arrange the garden and everything; he goes shopping and cooks every meal. I get served breakfast every morning, and he prepares the dinner. I hope to continue as it is, with medication and all of that. Moreover, physically and mentally: it is best to be home! (participant 9)

Participants felt at home and complete when with their spouse, experiencing kinship and belonging. In this, they pointed to close family and friends as crucial aspects of their experience of at-homeness. They were aware of their reduced lifespan and reduced capability to manage everyday life. The home was where they spent their lives, where they had built a life, and they fought to be able to stay there. Some expressed reluctance, others resisted, and a few rejected the idea of moving out of their home altogether. The resistance to leaving home was linked to experiencing emptiness and homelessness for oneself and, for some, one's spouse. They were worried about getting along without each other.

One woman described the loss of both her spouse and her home. She had longed for his closeness and the place they spent together as a family. She and her husband planned to spend their retired life in her hometown. Unfortunately, shortly after they moved, he got severely ill and died.

I have made a big mistake; I moved from the city where I lived for 42 years. I miss my friends; I miss the street. Here, I have no friends left. (participant 2)

She felt alone despite daily phone calls with her children. She missed the togetherness and life she had before, where she knew people, and they knew her. It was her hometown, but she did not feel at home. They had planned for a new beginning that instead became an abrupt ending, and now, she tried her best to start a new life on her own. She visited people at the nursing home, and she dined with a relative at the

cafeteria once a week. Nevertheless, she missed feeling connected to the place.

The fear of being left alone was pivotal for the participants. For example, a 72-year-old woman with reduced lung capacity lived with her husband, and she described being restless when away from home, anxious about becoming acutely ill and dying without her loved ones by her side.

I do not want to be away from home. I am afraid that I will not get enough time here ... The doctor and my family have asked me if I would like a (temporary) stay at the nursing home. Just thinking about it gives me a stomach ache. Even if I could get help with inhalations and syringes and whatever it may be, it is almost like a nightmare thinking about it. I would feel very lonely, even if I had a hundred people around me. It is like none of it is mine over there. I do not want to be away from home. (participant 1)

She depended on others and received care, but a temporary stay at a nursing home was out of the question. She clearly said that this was something she feared deeply; leaving home was the worst-case scenario for her.

Giving the nursing home a go

Participants knew they were on the verge of not being able to manage at home, even with help from other people. Recently, frailty had led to a temporary stay at a nursing home, hospital or rehabilitation unit for all of them. The institution's interior was adapted for patients, making it easier to move around. Participants described a longing to breathe fresh air but found walking outdoors by themselves challenging. Some participants were offered trips outside by healthcare providers, which they appreciated, but some had experienced the opposite. For example, during a three-month rehabilitation stay, one participant's goal was to walk outside with his leg prosthesis. He trusted healthcare providers to provide him with a walk outside, but it did not happen.

I did not dare to go out either because I had amputated my foot, and there is a steep hill [outside the nursing home]. I feared I would be unable to walk back up the hill by myself. If I had asked someone, they might have assisted me. (participant 7)

The participants, overall, demonstrated being treated and cared for by healthcare providers. Despite this, several experienced the nursing home with long days and without content, saying they sat there, just waiting for the next meal. They experienced emptiness, fearing that this was their fate. They wanted to decide for themselves, such as their morning routine, preparing meals or walking outside a little.

Participants said they felt seen and recognized by most healthcare providers but not by all employees.

For example, one participant had difficulty putting on her pantyhose in the morning and decided to wear them overnight. On the night shift, a nurse noticed this.

One of the older nurses told me to take off my pantyhose [laughter]. I thought it was funny, but I had to keep myself from laughing. I took it seriously, of course, when she said it so strictly. After this, healthcare providers came after I had gone to bed, standing behind the headboard and looking down. I am sure they were sent to check on me. Especially a couple of them acted like, "this is how we do it around here". (participant 3)

Several participants mentioned that they appreciated the conversations with healthcare providers, looking forward to seeing and talking to them. Some of the employees made an extra effort, stopping by to talk about the news or sharing something from their personal lives, which was highly valued. A visit or a phone call from family lit up the participants' day. In addition, the more extroverted residents started conversations at the dinner table.

It was a bit fulfilling to be there. The healthcare providers were so eager to have me dine with the others. I was myself, talking and laughing. The other residents were pleased when I arrived. Moreover, I felt that it was an excellent place to be. You got all the help you needed and more. However, I felt that my head did not quite fit there, and my body did because it was lousy. (participant 3)

The participant thought that it was encouraging that the other residents appreciated her company and that the employees considered her a resource. She received rehabilitation for her health problem at the nursing home. Nevertheless, she doubted that this was the best place to stay in the future.

Being offered a long-term stay at a nursing home was an eye-opening experience for the participants. They started considering what that could be like for them. From that point, moving into a nursing home became a definite possibility for the near future.

A 90-year-old man had ambiguous experiences in the nursing home, and he described it like this:

Many older people were at death's door, and it was a reminder that this was the last place you would stay. Nevertheless, there was church service once a week, and some of the residents were interesting to talk with. As a 95-year-old woman – she was a storyteller – told stories from old times. Nevertheless, I was not so fond of the other activities at the nursing home; some clowns had more appropriate performances for children than for older people – no, being away from home, in a hospital or a nursing home. I think I would die within a year. (participant 7)

Participants asked themselves whether they could manage at home or whether it was time to reconcile themselves with life at the nursing home. There were

some positive aspects of living at the nursing home, such as getting new acquaintances and being surrounded by caring employees. However, participants said that a long-term stay was a step closer to the end. They described the main issue with staying at the nursing home: the absence of the life they had built and lived at home, the life they knew and highly appreciated. In addition, the at-homeness they felt about their home felt impossible to accomplish because of the institution's different and alienating rhythm and rules.

Attuning to the natural rhythms

After returning home from a stay at an institution, everyday life followed a natural and familiar rhythm. The participants existed between movement and stillness, being inside and outdoors, alone and together with others. Participants managed their household, prepared meals, talked with their partners, watched TV, fed the birds and gazed at life outside the window. However, life was changing, and they needed extended help and support from others to manage their natural daily rhythms. Next of kin typically planned for their homecoming by rebuilding their house, extending the bathroom, or facilitating the entrance to avoid stairs. Healthcare providers helped with medication, injections, inhalations, personal hygiene and wound care. Participants received safety alarms, walking aids, specialized chairs and dinner delivered from the nursing home. Even if participants planned to continue at home, life did not always turn out as planned.

We have dinner delivered every day except Sunday. I can make dinner, but I will have to spend all day by the stove. Of course, I miss it a bit, but we have a big house, so the days pass anyway. (participant 8)

Contributing to the daily practicalities of homemaking was pivotal for her experience of being home. Holding on to what she managed, such as preparing potatoes for Sunday dinner, was essential.

After an extended stay at a hospital and nursing home, a woman returned home, describing vitality because of rehabilitation. However, she longed to use her energy planning and perform the family farm's seasonal activities for generations.

I enjoy working with wood. When spring is here, and my nephew has brought timber from the forest, I sit out in the yard with my old-fashioned saw. I had a great time this summer. I sat outside with the walker. Suddenly a robin came and sat down in front of me. I sat still, and it was lovely! We have deer as well. We have trees above the house. It was the time of the year when the leaves were about to emerge. Then I saw a deer standing on two legs. He stretched to get hold of the freshly sprouted leaf to the edge. And he got it! There was no deer track here when I was away

and no birds. This means that the animals notice whether people are at home or not. It was utterly dead here [when I returned from the nursing home]. Now the birds are back. (participant 3)

She enjoyed working outside when she had the energy for it, and she appreciated the calmness and stillness and forced herself to make herself open to sensing her surroundings. When she returned from the nursing home, she noticed that the place seemed empty and abandoned. She experienced adding life to her home and the surrounding nature adding life to her. She expressed her home and herself as intertwined and mutually dependent on each other to bring life to their spot in the world.

Participants experienced the rhythm of nature as predictable and safe, in contrast to their frail bodies and unpredictable future. These rhythms guide the daily activities of all living beings, such as changes in daylight, temperature and weather throughout the day, from season to season, generation to generation. The participants did not take this rhythm for granted, and it was not just a backdrop for their daily activities. Observing and sensing nature seemed to make them rest in their presence. Own decline and mortality were backgrounded. Participants wanted to feel well here and now. In nature, they found moments of peace and tranquillity. The participants expressed this as experiential wisdom, telling them what they needed and perhaps had to let go.

We have talked a bit about what happens afterwards. My husband and I are good at solving global problems, and our conversations are not empty talk; it must be something more profound. You never know when that day will come. (participant 1)

Participants were aware of their finiteness and end of the life shared with their loved ones. Participants described how they had experienced bereavement earlier in life. The loss of parents, children, partners or siblings deeply intertwined their life stories. A woman strived to come to terms with the death of her closest ones.

I still do not understand that my husband is dead, and I will not accept it. And my sisters, why did they have to die? I have no one I can talk to about this. Not in the hospital, not in the [nursing] home, not with my children. I want to go to communion, but it is challenging to kneel at the altar with my frail body. (participant 2)

She expressed loneliness and yearning for her deceased husband and siblings. The grief of losing loved ones can be brutal to alleviate when feeling abandoned. Another man alluded to the idea of living alone. He had lived a life of loneliness and refused an offer to stay in a nursing home.

I feel better at home than at the nursing home. Here I wander around by myself. I think I have come to

terms with life as it is. However, it's a little sad to live like this for years I would have preferred if death came quickly. Nevertheless, there is nothing I can do about it. I guess I cannot take pills that kill me either. I have never thought of that. I cannot do that. (participant 4)

He described his life as empty. His closest relatives had passed away, and his frail body could not endure the work at the farm any longer. He strived to find meaning in his life within his home's altered and silent atmosphere, being the only one left. Thinking of ways to end his life while refusing such thoughts indicates his experience of having nothing to live for, even though taking his own life was something he could not accomplish. He had come to terms with finiteness and the existential vulnerabilities of life. Nevertheless, he enjoyed seeing other people and appreciated the weekly visits when healthcare providers delivered medicines and changed his bandage, but he said that enduring the time alone in his house between these visits was hard. These visits were the only regular human presence he experienced and were decisive in connecting him with the outside world.

Well, I think it is nice. The nurses are all very friendly, and I look forward to being visited by the home nurses. We don't have much to talk about, but I think it is good to see them. (participant 4)

At-homeness is connected to well-being and to living a meaningful life. Participants expressed more concern about the absence of well-being than about dying. Feeling alive was especially important since frailty led to so many losses and, for some, grief and loneliness. Participants described the experience of frailty, grief and ageing that made them long for something or someone to share their experiences with. Being connected to nature, having spiritual beliefs or sharing their innermost feelings or stories seemed to enhance well-being and a sense of at-homeness.

Discussion

This study provides new insight regarding frail older people's experiences and understanding of at-homeness, highlighting that frailty disrupted participants' rhythm and continuity in everyday life at home. Short-term stays at a nursing home further forced participants' lives into a new rhythm, not in tune with their own. An overall finding was that the participants wanted to regain a feeling of at-homeness, described as an aspect of well-being despite illness (Svenaesus, 2010). The disrupted rhythm differed for participants according to their civil status and living conditions and the interdependence participants and spouses experienced in their shared home, trying to

maintain the shared rhythms on which they had built their lives. The shared responsibility underscored their togetherness when attuning to a changing situation. Previous research states that the home links to self-identity and personal, societal and cultural values, beliefs, norms and meanings (Molony, 2010). Our findings show that frailty forced participants to let go of some of the things they felt were essential to maintain their experience of at-homeness.

Furthermore, our findings revealed that frailty reduced participants' abilities. Living with a partner or significant other was crucial, and they drew strength from each other. Albeit, at the same time, dependence. The importance of relying upon someone aligns with previous research, in which frail older people left the decision-making process to a partner or close family members for the benefit of the participants and helped balance the ever-changing function and the world around them (Combes et al., 2021). However, our study further highlights that the participants wanted to continue living together in their shared home, receiving support and help from someone knowing their story. The participants' strengths and values had changed from being a performer of practicalities to being conversation partners and tradition bearers of everyday rhythms and traditions of the home. These findings support previous research and emphasize the importance of everyday activities in familiar surroundings (Munkejord et al., 2018).

Nevertheless, participants who had lived alone in adulthood still experienced at-homeness as a commitment to their home. They described rituals and seasonal work performed in the home for generations, such as working with wood in the spring, as essential contributors to the experience of at-homeness. Earlier studies among older people support this: the home was a place that the older adults could not imagine living without, and it had become an integral part of living itself and was an intimate part of the older person's being (Hilli & Eriksson, 2019). Participants experience a unique atmosphere pervading their home, affected by its natural surroundings, reflecting their values, beliefs, personality and way of life. The ability to follow seasonal changes throughout the year by looking out the window or opening the door is paramount, and participants do not know whether this feeling is possible to obtain when away from home. Others describe the well-being experienced while being close to nature, with its silence, peace and tranquility leading to a feeling of at-homeness (Hemberg et al., 2020; Molony, 2010).

Our findings have similarities with previous studies describing the home as a person's innermost space, where people have continually shaped their homes, recognized by significant others, cherished possessions and everything that mattered to them

(Combes et al., 2021; Hilli & Eriksson, 2019; Molony, 2010). Participants described the home as a sanctuary they could return to, associated with familiar rhythms associated with lived life and its continuation. Once familiar and comfortable, participants perceived the home and body as less inviting and tried to adapt to their changing situation. Since participants could not maintain the house or their hygiene to their preferred standard or could not go out alone, the atmosphere in the home changed, and they may feel homeless in their own home. Hilli and Eriksson (2019) argue that one aspect of the home can be a place full of unmanageable duties, which parallels Pasveer et al. (2020), who state that the home can also be an extra burden that amplifies decay. This study emphasized that living with frailty meant that domestic duties became an overwhelming burden and participants' description of not being at home points to a double burden since they linked at-homeness to being at home. They have lost a lot due to ageing and frailty and therefore have doubts about leaving home, trying to create and recreate the feeling of at-homeness despite illness (Søvde et al., 2022).

The introduction of home health care was a relief, and the participants appreciated help with practical tasks and health care when frailty prevented them from doing it themselves. However, this was not sufficient to regain the feeling of at-homeness, and some participants perceived it as a warning that life at home would soon be over as they knew and appreciated it. Previous research shows that introducing health care providers can threaten the home's identity and integrity and negatively affect the participants' way of life (Gillsjö et al., 2011). Our findings have some similar findings, but moreover, participants expressed satisfaction with the care they received at home. However, our findings show that the participants' connection to the home, community, family and nature conflicted with their ability to perform daily activities: for instance, not being able to walk up and down stairs forced them to move to a nursing home while the house was adapted. These findings support Nilsen et al. (2021), who stated that people's desire to live in a familiar environment sometimes conflicts with the accessibility of the housing needed for mobility.

Interestingly, participants felt safer with more people around and more professional assistance available during the temporary stays at the nursing home. Nevertheless, fixed routines and reduced opportunities to go outdoors made them feel alienated. Our findings highlight that, in addition to new routines and rhythms of the nursing home, participants felt deprived of the natural rhythms that belonged to being outdoors, such as changes in daylight, temperature and weather throughout the day, from season to season. These rhythms had previously helped them

attune to nature and towards a feeling of at-homeness. These findings have similarities with previous research, showing that routines, loss of autonomy and inactivity negatively impact residents living in nursing homes (Cooney, 2012; Fæø et al., 2019; Paddock et al., 2019).

Moreover, participants found temporary stays necessary and acceptable. However, they feared moving there permanently and expressed resistance to being away from home, friends and family. They started to question their immediate future and foregrounded the idea of a permanent place in the nursing home. Previous research emphasizes that the home refers to the end as people follow their life path to find the ultimate destination for their existence. Existential issues, including their finitude, became more apparent, reinforcing a sense of limited time and moving to a nursing home mainly involved complex changes and losses that affected the individual's well-being and identity (Dekkers, 2009). Participants described the move permanently to a nursing home as embarking on the final journey in solitude for fear of leaving everything that made their lives meaningful. They were thrown into a situation impossible to escape. Participants' fears and opposition displayed an irreversible change of life for participants unavoidable yet experienced as an existential crisis. The strong desire to stay at home has similarities to the findings of Fæø et al. (2019) related to home-dwelling older people with dementia, describing the loss of autonomy and lack of homeliness at the nursing home followed by an aversion to moving there. Further, Fæø et al. described participants' strong desire to stay home, although knowing that nursing home admission would be necessary at some point and that they would have to accept it. Our findings support this to a certain extent but further deepen participants' ambivalent feelings towards moving away from home.

Participants' insight increased as their bodies weakened, and they feared losing their homes and shelters while losing themselves from illness and aggravation. Following Svenaeus (2010), illness is linked to not being at home in the body, while Hilli and Eriksson (2019) highlighted that feeling of not belonging to a place tends to alienate and threaten a person's existence. Nevertheless, the participants were not afraid of dying, and they described more concern about how their life would be and the urgent need to live well here and now. According to Vetlesen (2009), every human move towards their future and has ideas, hopes, and fears about it. Living with frailty was a condition that forced participants to choose what was essential in life by opting out of what was less crucial, ending up with existential conditions of human life, such as vulnerability, dependence and mortality (Heidegger, 1962). The participants

experienced these conditions as marginalized, making them feel not being at home. As their current situation developed, it became clear that life was not sustainable as they lived it. Their frailty, age, illness, and disability put life itself under pressure. Our findings show that life did not always turn out as the participants hoped after returning home from a short stay at the nursing home. The practicality of the home and care services foregrounded treatment and care for health issues, leaving existential issues in the background.

Previous research underscored that frail older people often experience multidimensional losses and are frequently affected by complex and increasingly burdensome symptoms, making achieving well-being more challenging (Andrew et al., 2012; Nieboer et al., 2018). Our study underscored that being in the transition between home and nursing home and a robust and frail body represents a uniquely significant experience for frail older people, highlighting existential issues that health-care providers need to address.

Methodological considerations

We conducted this study with frail older people in rural x. We used clear inclusion criteria with a well-known frailty model to ensure that the participants were frail. The findings have similarities with previous studies, indicating that the essential meanings highlighted might be relevant across cultural settings. Nevertheless, the cultural settings should be considered regarding the transferability of findings. Trustworthiness is essential throughout the entire research process, and this means asking how valid the knowledge is and whether it offers new knowledge about the phenomenon under study (Shenton, 2004). To ensure rigour and trustworthiness in our study, we aimed for a varied sample to increase the findings' dependability, transferability, credibility and confirmability (Lincoln & Guba, 1985). To increase the credibility, the first author used her clinical experience when planning and preparing the interviews, preparing the interview guide, and all authors read and participated in the analysis. Variation in the sample was required to strengthen the dependability (Shenton, 2004). Consequently, we aimed to reach participants with different backgrounds. A reflexive attitude was maintained throughout the research process to safeguard confirmability. This means that we were aware of our role in interaction with the participants, empirical data, theoretical perspectives and pre-understanding that the researchers brought into the project. Regarding the transferability (Shenton, 2004), the informants were recruited from two inpatient clinics and were given care from different care contexts; this may strengthen the transferability. The limited number of participants might have limited the range of experiences described in this article. However, we consider our findings strong because we had a varied sample and rich data we have analysed to

describe the essentials of a complex phenomenon. These aspects add strength to validity according to well-established criteria for validity in qualitative studies (Creswell & Creswell Báez, 2020). One strength of our study is giving voice to a vulnerable group of older people on the verge of managing at home and their perception of at-homeness, which is unique.

Conclusion

Our study provides insight into the lived experiences with frailty related to at-homeness. Older people described the experience of frailty as an existential feeling of not being at home, emerging as inevitable reality participants have to face in their near future. The experience of being lost in transition represents a uniquely significant experience for frail older people, foregrounding existential issues and carrying the potential of at-homeness.

Relevance for clinical practice

To unleash frail older people's potential for at-homeness, healthcare professionals must address and meet the needs of frail older people individually. This means that planning and caring for frail older people involves more than medical decision-making and care, indicating that going beyond signs and symptoms is crucial to understanding what living with frailty is like. Understanding people's concrete, everyday experiences is helpful in supportive care. Healthcare providers need to address existential needs and provide more holistic care than today. Our study highlighted that frail older people prefer to live well here and now instead of planning future care. However, being aware of frail older people's potential for sudden deterioration and fluctuating health, healthcare providers should have conversations with patients about how they envisage their near future, aiming to enhance the feeling of at-homeness independent of where and how frail older people live their lives.

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Author contributions

BES, AMS, and JD designed the study. The first author collected the data, and all the authors read and analysed the data. Finally, the first author drafted the manuscript, and all authors contributed to the final manuscript.

Data availability statement

The data is not publicly available due to privacy and ethical restrictions.

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Appendix 1 Review of the literature

Author/Year/Country	Theme	Inclusion/Exclusion criteria	No. of participants/ studies (review)	Main findings
To, T.-L., et al. 2022, Taiwan.	Transitions of self-management behaviors and frailty status among community-dwelling older adults: a national longitudinal population-based cohort study	Community-dwelling older adults aged 65 years and older without cognitive impairment were recruited. Frailty was defined based on Fried's frailty phenotype.	1283 participants	Maintaining body weight and frequent physical exercise increased the ratio of frailty stability among individuals 65–74 years old. Increasing exercise behavior is the only factor to improve their frailty status among older adults aged 75 years and over. Older adults should be encouraged to perform adequate physical exercise and maintain a healthy body weight to maintain the frailty status in younger old aged 65–74 years, and especially perform more frequent exercise to improve frailty status in older old over 75 years.
Suikkanen et. al 2021, Finland	Changes in the Severity of Frailty Among Older Adults After 12 Months of Supervised Home-Based Physical Exercise: A Randomized Clinical Trial	Home-dwelling older adults aged ≥65 years who were frail (meeting 3-5 criteria) or prefrail (1-2 criteria) according to frailty phenotype criteria.	299 participants	The severity of frailty can be reduced through 12-month supervised home-based exercise training. Exercise should be included in the care of older adults with signs of frailty.
Laukli, Ingerid et. Al. 2021; Norway	Frailty assessment of older adults, first-time applicants of public home care service in Norway	116 older adults >65 years applying for public home care service for the first time. An adapted version of the Fried Frailty Phenotype assessed frailty.	116 participants	The prevalence of frailty among older adults, first-time applicants of public home care services in Norway is major. Screening for frailty should be considered before older adults apply for public home care service for the first time. Gait speed at a cut point at 0.8 m/s may be an appropriate screening tool for frailty.
Gotaro Kojima1 Affiliation: 1Japan Green Medical Centre, London, United Kingdom	Frailty as a Predictor of Nursing Home Placement Among Community-Dwelling Older Adults: A Systematic Review and Meta-analysis.	Any cohort studies examining associations between frailty and subsequent nursing home placement risk among community-dwelling older adults published from 2000 to July 2015 were potentially eligible.	5, 3528 participants	Frailty and prefrailty are significant predictors of nursing home placement among community-dwelling older adults.
Suikkanen et . al, 2019 Finland	Effects of Home-Based Physical Exercise on Days at Home and Cost-Effectiveness in Pre-Frail and Frail Persons: Randomized Controlled Trial.	≥65 years, meeting at least 1 of the frailty phenotype criteria, Mini-Mental State Examination score ≥17.	299 participants	Over 12 months, the exercise group gained 0.04 quality-adjusted life-years and maintained the baseline level, while the score in the usual care group deteriorated. Physical exercise did not increase the number of days spent at home.

Zhao et. al, 2019, China	Relationship Between Loneliness and Frailty Among Older Adults in Nursing Homes: The Mediating Role of Activity Engagement.	Residents (N = 370; aged ≥60 years; 220 female, 150 male) were from 33 nursing homes in China.	370 participants	The prevalence of frailty was 29.2% among Chinese older adults living in nursing homes. Results suggest that it is not loneliness in general that affects frailty but actively engaging in activities. Activity engagement mediated the association between loneliness and frailty.
Mckay et. al, 2022, USA	Factors associated with the risk for falls in PACE participants.	Nursing home eligible older adults ≥55 who live in the community	84 participants	Frailty and fear of falling were significant predictors of the risk for falls. When controlling for sociodemographics, frailty, fear of falling, and incontinence were significant predictors for the risk for falls.
Verver et. al, 2019, Netherlands	A cross sectional study on the different domains of frailty for independent living older adults.	Independent living older adults of 65 years and over who are member of a welfare organisation	1768 participants	68.9% of the respondents was frail on one or multiple domains and 51.6% of the respondents was frail based on the total score on the TFI. Social frailty (18.4%) was most often present followed by 10.3% for frailty on all three domains of the TFI. All variables tested, except for income, showed significant differences between the different domains of frailty.
Cegri et. al, 2020, Spain	The impact of frailty on admission to home care services and nursing homes: eight-year follow-up of a community-dwelling, older adult, Spanish cohort.	Community-dwelling individuals aged ≥70 years in home care programmes (HC) and nursing homes (NH)	616 participants	Prognostic models based on comprehensive geriatric assessments can predict the need for the commencement of HC and NH admission in community-dwelling older adults. Multivariate models for a HC and NH showed that the risk of a HC entry was associated with older age. An increased risk of being admitted to a NH was associated with older age and social risk.
Combes et. al, 2021, UK	The importance of living well now and relationships: A qualitative study of the barriers and enablers to engaging frail elders with advance care planning	Frail elders and family members using a community based older peopsn`s service urban UK hospice	18 participants	Advance care planning is unclear, in terms of meaning and the language used; Lack of relevance, with frail elders preferring to focus on living well now; and the importance of family, relationships and home, and the influence of relationship on end of life decision-making. Engagement strategies included preparing the frail elder for advance care planning conversations and using a gentle, honest, individualised approach.
Pérez-Ros, Pilar, et al Spain	A home-based exercise program focused on proprioception to reduce	70 years or over	564 participants	These results suggest that a home proprioception program may be a viable alternative to complex multicomponent exercise

	falls in frail and pre-frail community-dwelling older adults.			programs in settings where these are not feasible, since home proprioception can reach a larger population at a lower cost, and it affords clear benefits.
Moody et. al 2022, Australia	Out-of-pocket expenses related to aging in place for frail older people: a scoping review.	Sources that reported on the financial expenses incurred by older people (60 years or older) with frailty living in the community, or on the expenses incurred by their family and friend caregivers, were eligible for inclusion in the review	42 sources, two policy papers, 40 research papers	Categories of out-of-pocket expenses found in the literature included home care, medication, cleaning and laundry, food, transportation, medical equipment, respite, assistive devices, home modifications, and insurance. Five sources reported on out-of-pocket expenses associated with people who were frail and had dementia, and seven reported on the out-of-pocket expenses for caregivers of people with frailty. While seven articles reported on specific programs, there was very little consistency in how out-of-pocket expenses were used as outcome measures. Several studies used measures of combined out-of-pocket expenses, but there was no standard approach to reporting aggregate out-of-pocket expenses.
Ris et. al. 2019, Switzerland	An integrative review on family caregivers' involvement in care of home-dwelling elderly.	Studies written in German or English between 1996 and 2017 focusing on FCs' caring for home-dwelling older adults together with home care nurses were included and critically appraised.	26 studies	The findings illustrate that involvement in care is an interactional process, which provides the basis for collaborative practices with the home care nurses for family caregivers. Family members often want to be part of the healthcare team, and nurses need contextual factors that allow providing their full range of skills and knowledge to involve family caregivers accordingly.
Yuan et al, 2021 USA	Physical frailty and cognitive impairment in older nursing home residents: a latent class analysis.	U.S. nursing homes. It is conducted at admission and periodically during the nursing home stay, collecting data on residents' demographic and clinical characteristics, including physical functioning, cognitive functioning, bladder and bowel conditions, nutritional status, pain, diagnoses, and receipt of medications	871, 801	Findings indicate the heterogeneous presentations of physical frailty in older nursing home residents and additional evidence on the interrelationship between physical frailty and cognitive impairment.
Overbeek, et. Al, 2019 Netherlands	Low patient activation levels in frail older adults: a cross-sectional study.	Community-dwelling adults who received home care and residents of care homes.	200 participants	Most of this frail and very old study population, especially those with a lower health-related quality of life, may be unable to self-manage their health and healthcare to the expected level. The increasing population of frail older

				adults may need help in managing their health and healthcare.
Duppen et al. 2019, Netherlands	Meaning in Life for Socially Frail Older Adults.	Participants were recruited in the Flemish speaking area of Belgium and the city of Brussels. Belgium, using snowball sampling and the help of five home-care organizations. Participants were excluded from the study in cases of hospitalization, when the older participant or the informal caregiver indicated that the older adult was unable to participate, or when the interviewer noted that the older participant was unable to provide adequate answers	56 participants	Socially frail older adults experience meaning in life in different dimensions.. There is a need for meaningful activities in organizations that ameliorate social connectedness for community-dwelling older adults.
Joddrell et. al, 2021 UK	Continuous in-home walking speed monitoring in older people with a low-cost ambient sensor: Results of a feasibility study.		20 participants	There was a high degree of variance to the number of walking speed measurements recorded by each participant's sensor. Where regular measurement was achieved, the results indicate that walking speed might be better viewed as a distribution rather than a single figure, taking into account the natural variation to walking speed in daily life.
Hemberg, Jessica et. al. 2019; Finland	"Homeless in life" – loneliness experienced as existential suffering by older adults living at home: a caring science perspective.	The inclusion criteria for study participation was being aged 65 years or older, being able and willing to give informed consent, and wanting to share experiences.	17 participants	The findings resulted in one main category and three subcategories. The main category was as follows: Being homeless in life—loneliness expressed and primarily stemming from existential suffering. The subcategories were as follows: Loss of communion with one's partner or other loved ones, Loss of meaningful social activities due to isolation and Loss of health due to frailty and vulnerability. All categories were described and implications for practice discussed.
Morkisch, et. al , 2020 Switzerland	Components of the transitional care model (TCM) to reduce readmission in geriatric patients: a systematic review.	The review included geriatric patients explicitly older than 65 years with comorbidities in order to comply with the European Union of Medical Specialists definition of a geriatric patient [4] and who were hospitalized due to an acute or chronic health condition.	Three articles	High intensity multicomponent and multidisciplinary interventions are likely to be effective reducing readmission rates in geriatric patients, without increasing cost.
Silva et. al, 2020, Brazil	Physical and psychological states interfere with health-related quality of life of	Inclusion criteria required elderly to assimilate the methodological tools and agree to participate in the study	125 participants	The median of HRQoL of institutionalized elders was 64. Multivariate regression models showed that retirement, frailty and depression were

	institutionalized elderly: a cross-sectional study.			statistically associated with poor HRQoL ($p < 0.05$). Not-frail elderly and less depressed were more likely to present higher HRQoL scores. Lower HRQoL of institutionalized elderly is associated with decline of physical and psychological states.
Ryuichi Ohta et. al, 2021 Japan	Predicting factors of elderly patients' discharge to home after rehabilitation in rural Japan: a retrospective cohort study.	over 65 years with frailty and multimorbidity who were admitted with acute diseases and underwent active rehabilitation at a rural community hospital	783 participants	This study showed that elderly patients' motor aspect of ADL after rehabilitation in rural community hospitals might predict discharge to home in rural settings. Rehabilitation in rural community hospitals can be effective in rural elderly patients with frailty and multimorbidity.
Bloemhoff et. Al , 2020, Netherlands	Older persons are frailer after an emergency care visit to the out-of-hours general practitioner cooperative in the Netherlands: a cross-sectional descriptive TOPICS-MDS study.	The study focused on older persons (65+ years) who depend on the GPC for out-of-hours primary care.	39, studies, 32149 participants	Compared to the reference group, older persons with GPC contact were frailer in the domain of comorbidity and they reported less emotional wellbeing and experienced a lower quality of life. Moreover, older persons more often reported limited social functioning and limited perceived health. Finally, older persons with GPC contact more often used home care or were more often admitted to the hospital .Older persons with out-of-hours GPC contact for an emergency care visit were significantly frailer in all domains and more likely to use home care or to be admitted to the hospital compared to the reference group. Potentially frail older persons seemed to require adequate identification of frailty and support (e.g., advanced care planning) both before and after a contact with the out-of-hours GPC.
Rand et. al, 2022 Israel.	The Contribution of Frailty to Participation of Older Adults.	age 75 or older; community dwelling; able to hear, understand, and speak the language; able to ambulate independently within their homes (with or without a walking device); do not have a diagnosis of dementia in their medical record.	121 participants	Older adults aged 75 to 91 years were included. Older adults demonstrated full to restricted participation. Frailty was identified in 39 (32%). A negative moderate significant correlation was found between participation and frailty. The variance of participation was significantly explained by frailty, 31.5%, and basic ADL, 5.6% (after controlling for age and cognition); the total model explained 44.6% ($F = 23.29$, $p < 0.001$).

				Frailty is significantly associated with participation restriction. Since participation has many health benefits, understanding which factors are associated to participation is central to developing interventions for older adults.
Zimmermann J; et. Al, 2021 Germany.	Home environment and frailty in very old adults.	Community-dwelling individuals and nursing home residents aged ≥80 years. Using phenotype criteria	1557 participants	Of the very old individuals, 24.3% were robust, 57.0% were prefrail, and 18.7% were frail. Adjusting for relevant sociodemographic and health characteristics, being not closely attached to the HE was linked with an increased probability of being prefrail and frail. An improvement of the residential area was associated with a decrease in odds of being frail. Living in communities with less than 50,000 and with 100,000-499,999 inhabitants decreased the odds of being frail. Frailty prevalence is shown to be higher in the very old population than in the younger age groups in Germany. Early identification of frailty and tailored interventions focused on improving objective and subjective attributes of the HE are needed to reduce the risk of frailty.
Krogseth M. et al. 2021, Norge	Frailty among older patients receiving home care services.	65 years or over receiving home care services on a weekly basis	210 participants	When compared to severely frail patients, those with mild degrees of frailty were less frequently hospitalised (hazard ratio (HR) 0.33; 95 % confidence interval (CI) 0.19-0.60). During the two-year observation period, 63 (30 %) patients died. The mortality rate was highest in patients with severe frailty. In an adjusted Cox regression, increasing age was associated with a higher risk of death, but not with acute hospitalisation. Older patients with home care nursing services have a high degree of frailty, which is associated with increased risk of hospitalisation and death.
Weeks LE; et . al, 2021 Canada.	Health service experiences and preferences of frail home care clients and their family and friend caregivers during the COVID-19 pandemic.	We invited home care clients and their caregivers to respond to our COVID-19 related questions either during regularly scheduled interviews as part of our larger pragmatic randomized controlled trial or during a separate interview.	29 participants	Many participants were affected drastically by eliminating or reducing access to services, highlighting the vulnerability of home care clients and their caregivers during COVID-19. This took an emotional toll on home care clients and increased the need for family/friend

					caregiver support. While many participants expressed reduced desire to utilize residential long-term care homes, some caregivers found that passive remote monitoring technology was particularly useful within the COVID-19 context.
Zimmermann J; et. al., 2021, Cologne, Germany	Individual characteristics associated with the utilization of nursing care in the very old population: a cross-sectional study.	Community-dwelling individuals and nursing home residents aged ≥80 years.	1577 participants		Individual need factors dominated in explaining opNNU, suggesting that the very old population in NRW may have equitable access to these services. As social structure, region, and social resources explain inNNU, this type of care may be inequitably accessible.
Overbeek A; et. al. 2018 Netherlands	Low patient activation levels in frail older adults: a cross-sectional study.	The study population consisted of both community-dwelling older adults who received regular care from a home care organisation, such as assistance with activities of daily living (ADL), self-care or domestic help, and older adults residing in one of 16 residential care homes of a large long term care organisation in Rotterdam, the Netherlands.	200 participants		The majority of this frail and very old study population, especially those with a lower health-related quality of life, may be unable to self-manage their health and healthcare to the level expected from them. The increasing population of frail older adults may need help in managing their health and healthcare.
Dollard J; et. al. 2018, Australia	Older People Who Are Frequent Users of Acute Care: A Symptom of Fragmented Care? A Case Series Report on Patients' Pathways of Care.	Of 17 patients from the 61 patients identified in step 2. These patients represented a spread of ages (60-74, 75-84, ≥85 years), gender (male/female) and living arrangements (community/Residential Aged Care Facility (RACF)).	17 participants		Frequent users of acute care can experience untimely hospital communication and may require more coordinated care provided in the community to assist self-care and manage chronic conditions.
Yip O et. al, 2022, Switzerland.	Health and social care of home-dwelling frail older adults in Switzerland: a mixed methods study.	Quan:The current study included a sub-sample of frail older adults from the INSPIRE population survey in the parent study. Qual:Eight homedwelling older adults with multimorbidity, defined as the occurrence of two or more chronic diseases, using health services provided by at least two care organizations, or three or more different health services provided by one organization. Indicated frailty based on the PRISMA-7 frailty screening assessment.	2314 quantitative 7 qualitative		Support from health and social, formal and informal caregivers is diverse and anticipated to increase (e.g., for 'care and assistance at home' and 'meal services'). Most participants (93.5%) perceived their overall support to meet their needs; however, findings suggest areas (e.g., assessment of overall needs) which merit attention to optimize future care. Informal caregivers fulfilled various roles and while some older adults strongly relied on them for support, others feared burdening them.
Matarse, M., et. al. (2022). United States	Experiences of health care personnel with promoting a sense of home for older	qualitative studies that explore the experiences of health care personnel in promoting a sense of home for people aged 65 years and over living in	7 studies		The promotion of residents' sense of home in residential care facilities is influenced by i) the built environment, including private, single

	adults living in residential care facilities: a qualitative systematic review	residential care facilities, including, but not limited to, nursing homes, residential care homes, retirement homes, assisted-living facilities, and skilled nursing facilities.		rooms with bathrooms, homelike-domestic spaces, personalization of residents' rooms, homelike interior and exterior design, and non-hospital-like environment; ii) the national and local policy and regulations, and work organization, as well as leadership of managers and directors; and iii) the facilities' care culture, including philosophy of care, maintaining autonomy of residents and ties with the community, participation in domestic and recreational activities, and family relationships. Based on the ConQual scores, the confidence level in the synthesized findings was graded as low. According to health care personnel, the physical environment, interpersonal and social aspects, regulations, work organization, and the facilities' care culture can contribute to creating a sense of home for older adults in residential care facilities.
Liu, S., et. al. (2021), China	Trajectory and Correlation of Intrinsic Capacity and Frailty in a Beijing Elderly Community.	The inclusion criteria were: (1) aged over 75 years old and (2) lived in the CCRC active area. The exclusion criteria for the participants were as follows: (1) acute conditions including acute heart failure, acute coronary syndrome, acute exacerbation of chronic obstructive pulmonary disease, and acute pneumonia, and (2) severe cognitive impairment diagnosed by a neurologist.	230 participants	IC impairment and frailty overlap and co-exist in older adults. IC impairment, especially new impairment in locomotion and vitality are associated with the transitions from non-frail to frail status. It is important that geriatricians tightly monitor IC trajectory and find the new impaired domains to take early action to minimize the public health burden of frailty.
Tao A; Ho KHM; Yang C; Chan HYL (2023), Hong Kong	Effects of non-pharmacological interventions on psychological outcomes among older people with frailty: A systematic review and meta-analysis. [Review]	Eight electronic databases, including PubMed, MEDLINE, EMBASE, CINAHL, APA Psycinfo, Cochrane Library, CNKI and WANFANG were searched from inception to 14 November 2022. Randomised controlled trials and clinical controlled trials of non-pharmacological interventions on psychological outcomes in older people with frailty were included. The quality of the included studies was assessed using The Cochrane Risk of Bias Tool v2. Meta-analysis was performed using the RevMan5.3. The certainty of the evidence was evaluated by GRADE approach.	13 articles from 11 studies	Psychological outcomes in older people with frailty are understudied. Limited evidence shows the effects of complementary and alternative medicine on improving psychological outcomes. More rigorous trials are needed to examine the effects of non-pharmacological interventions on psychological outcomes among older people with frailty. Group-based physical exercise could be a strategy to reduce depressive symptoms among older people with frailty.

<p>Voie KS et. al (2023) Norway</p>	<p>Professional home care providers' conceptualisations of frailty in the context of home care: A focus group study.</p>	<p>Four focus group discussions with 14 home care professionals working in municipal home care in northern Norway analysed the data using thematic analysis.</p>	<p>14 participants</p>	<p>Home care professionals conceptualised frailty diversely, as moving along a continuum between cure and care. Diverse conceptualisations of frailty might be necessary if nurses are to meet the changing and varying care needs of older persons who live in their own homes and need health and care services.</p>
<p>Munkejord et. al (2018), Norway</p>	<p>Home best? A thematic analysis of older peoples stories about care and safety in own home</p>	<p>In-depth interviews living in rural areas highlighting different dimensions with living at home.</p>	<p>28 participants</p>	<p>Older people's housing preferences vary. The location and condition of one's original home come into play, but also dimensions such as one's physical and mental health, access to informal care from relatives, and one's own social networks and relationships. Moving can be a big step, but for some older people, moving to, for example, a care home or an adapted apartment centrally located in the municipality can contribute to well-being, security and improved physical and psychosocial health.</p>
<p>Martinsen et. al (2022), Norway and Denmark</p>	<p>The experience of dependence on homecare among people ageing at home</p>	<p>Individual in-depth interviews were used to explore 15 Danish and Norwegian homecare receivers' experiences of dependence on homecare.</p>	<p>15 participants</p>	<p>According to the voices of the older people in this study, future homecare should be accommodated in an organisational set-up that prioritises stability and continuity in the relation between the homecare receiver and the homecare staff. The presence of homecare staff in the participants' homes could entail a change where the participants experienced losing control over their surroundings. Also, it is significant that homecare staff do not have a task-oriented approach to their job and are sensitive to the values of the homecare receivers.</p>

<p>Spang, et. al (2023), Sweden</p>	<p>Experiences of Close Relatives of Older Adults in Need of a Nursing Home: It Is We Who Manage Their Fragile Daily Life</p>	<p>A qualitative approach was used, where fifteen relatives of nursing home applicants in central Sweden were interviewed using a study-specific interview guide. The interviews were analysed using thematic analysis</p>	<p>15 participants</p>	<p>Participants managed the older adults' life situation and acted as representatives in contact with health and social care. They tried to offer support in their daily life but experienced a breaking point over time when ageing in place was no longer sustainable, resulting in a nursing home application. The rationale for a nursing home application was often a combination of the older adult's wishes and that their relatives felt a combined need for extensive care and physical proximity to staff, which cannot be provided in ordinary housing. Sometimes the decision to apply was also based on relatives no longer having the capacity to continue managing an older adult's fragile situation.</p>
<p>Bjerkmo et. al. (2022), Norway</p>	<p>Experiences of Being Significant Others to Older Adults with Frailty Living Alone in Rural Arctic Norway: A Qualitative Study</p>	<p>Thematic analysis of semistructured interviews with ten persons identified as significant others by older adults in rural Arctic Norway.</p>	<p>10 participants</p>	<p>Experiences of being the significant other involve a continuous balancing act affected by the older adult's life situation, the significant other's life, and the rural Arctic context in which the older adult lives. Our study adds to previous conceptualizations of frailty as both a bodily and a relational phenomenon framed by materialities, the understanding of frailty as also a situated phenomenon</p>

Appendix 2 Interview guide Study 1

Intervjuguide

Studie 1: Korleis erfarer eldre som lever med store og samansette behov relatert til frailty kvardagen sin, og korleis opplever dei tenestene dei mottar?

Store og samansette behov

1. Kan du fortelje litt om deg sjølv og dine behov for ulike tenester?
2. Ein del av dei som har hjelp av heimetenestene har mange plager som påverkar kvarandre. Dersom du opplever det same, kan du fortelje litt om det?
3. Kva kunne gjere det lettare for deg å leve lengst muleg heime med dine plager?
 - a. Kven er viktige
 - b. Kva er viktig

Brukarmedverknad

1. Korleis opplever du å få hjelp heime?
 - a. Kva synest du er vanskeleg?
 - b. Kva synes du går greitt?
2. Kan du seie noko om kven som hjelper deg heime?
3. Kva er viktig for at du skal kunne klare deg best muleg i kvardagen?
4. Synes du hjelparane dine tek omsyn til kva du ønskjer?
5. Føler du at du blir tatt med på råd?

Samhandling

1. Kan du fortelje litt om dine besøk på sjukehus eller sjukeheim?
 - a. Korleis var det for deg?
2. Korleis opplevde du samarbeidet mellom dei som skulle hjelpe deg?
3. Har du nokre tankar om korleis dei ulike helsetenestene (feks sjukehus – heimesjukepleie- fastlege) kan samhandle slik at din situasjon blir betre?

Appendix 3, Interview guide study 2

Store og samansette behov

1. Korleis er ein vanleg dag for deg?
2. Kan du fortelje litt om korleis du erfarer å vere pårørande?
3. Kva kunne gjere det lettare for deg å la din (mann/kone/far/mor) bu lengst muleg heime?
 - a. Kven er viktige
 - b. Kva er viktig

Brukarmedverknad

1. Korleis opplever du å få hjelp frå heimetenestene?
 - a. Kva synes du er vanskeleg?
 - b. Kva synes du går greitt?
2. Kan du seie noko om kven som hjelper dykk heime?
3. Kva er viktig for at du og kona di skal kunne klare dykk best muleg i kvardagen?
4. Kan du fortelje korleis hjelparane dine tek omsyn til dine og kona di sine ønskjer?
5. Korleis opplever du at hjelpa du og kona di imøtekjem dine behov og ønskjer?

Samhandling

1. Kan du fortelje litt om din (mann/kone/far/mor) sine besøk på sjukehus eller sjukeheim?
 - a. Kan du seie noko om korleis du opplevde denne situasjonen?
2. Korleis opplevde du samarbeidet mellom dei som skulle hjelpe dokke?
 - a) Kva synest du var vanskeleg?
 - b) Kva synest du gjekk greitt?
3. Opplever du at du får tilstrekkeleg informasjon?
4. Dersom du skulle gje råd til dei som arbeider i helsevesenet, kva råd ville du gje?



Høgskulen
på Vestlandet



Vil du delta i forskingsprosjektet

” Korleis kan helsetenesta best ivareta og følgje opp heimebuande eldre med store og samansette behov?”

Dette er et spørsmål til deg om å delta i et forskingsprosjekt der formålet er å utvikle ny kunnskap kring omsorg for heimebuande over 65 år med store og samansette behov. Du har som brukar av tenestene viktige erfaringar og kunnskap å bidra med, og ditt synspunkt er viktig i arbeidet med å utvikle tenestene vidare. I dette skrivet gir vi deg informasjon om måla for prosjektet og kva deltaking vil innebere for deg.

Formål

I denne studien vil brukarar, pårørende og helsepersonell knytt til heimebuande eldre med store og samansette behov bli intervjuet for å få meir kunnskap om erfaringar og opplevingar dei har i sin praktiske kvardag. Det vil vere om lag førti personar som vert intervjuet i prosjektet til saman, medrekna 10 til 15 brukarar.

Tittel: Korleis kan helsetenesta best ivareta og følgje opp heimebuande eldre som lever med store og samansette behov?

Forskingsspørsmål:

Korleis erfarer eldre som lever med store og samansette behov kvardagen sin, og korleis opplever dei tenestene dei mottar?

Kven er ansvarleg for forskingsprosjektet?

Prosjektet er ein del av mitt doktorgradsarbeid som utgår frå Universitetet i Bergen og er finansiert av Høgskulen på Vestlandet.

Kvifor får du spørsmål om å delta?

I denne studien vil brukarar, pårørende og helsepersonell knytt til heimebuande eldre med store og samansette behov bli intervjuet for å få meir kunnskap om erfaringar og opplevingar dei har i sin praktiske kvardag.

Kva inneber det for deg å delta?

I ditt tilfelle vil det bli gjennomført eit intervju med deg, enten i heimen din, eller ein stad i nærleiken som passar for deg. Intervjuet vil vare i om lag 1 time. Underteikna vil intervjuet deg, og samtalen vil bli tatt opp på lydopptakar. Lydopptaket vil bli lagra på passordbeskytta PC som berre eg har tilgang til.

Mulege fordelar og ulemper

Mulege fordelar ved å delta i studien er at du kan bidra til ny kunnskap om korleis det vert opplevd å bu heime med store og samansette behov, og korleis du opplever å få hjelp av helsepersonell. Du vil få mulegheit til å uttrykke kva som er viktig for deg. I intervju med pårørende vil dei kunne uttale seg om din situasjon som pasient. Mulege ulemper er at du kan oppleve ein times intervju som krevjande, og du kan ha behov for hjelp under intervjuet. Sidan du er mottakar av heimetenester vil eg, dersom du godkjenner det, avtale med leiaren av tenesta eller ein av dine pårørende kven som skal kontaktast

dersom du har behov for hjelp. Om du ønskjer det, kan vi ta ein pause undervegs i intervjuet. Det vil ikkje medføre utgifter å delta i prosjektet.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Dersom du ønskjer å delta, underteiknar du samtykkeerklæringa på siste side, og eg vil etter ei kort tid kontakte deg på telefon. Du kan når som helst og utan å gje nokon grunn trekkje samtykket ditt, utan at det får nokon konsekvensar for deg eller dine tenester.

Ditt personvern – korleis vi oppbevarer og bruker dine opplysningar

Vi vil berre bruke opplysningane om deg til formåla vi har fortalt om i dette skrivet. Vi behandlar opplysningane konfidensielt og i samsvar med personvernregelverket.

Alle opplysningane vil bli behandla utan namn og fødselsnummer eller andre direkte gjenkjennande opplysningar. Ein kode knyter deg til dine opplysningar gjennom ei namneliste. Prosjektleiari har ansvar for den daglege drifta av forskingsprosjektet og at opplysningar om deg vert behandla på ein sikker måte.

Kva skjer med opplysningane dine når vi avslutta forskingsprosjektet?

Prosjektet skal etter planen avsluttast 01.10.2022. Informasjon om deg vil bli anonymisert eller sletta seinast fem år etter prosjektslutt, innan 01.10.2027. Data vil bli lagra etter prosjektslutt for etterprøvarhet.

Dine rettigheter

Så lenge du kan identifiserast i datamaterialet, har du rett til:

- innsyn i kva personopplysningar som er registrert om deg,
- å få retta personopplysningar om deg,
- få sletta personopplysningar om deg,
- få utlevert en kopi av dine personopplysningar, og
- å sende klage til personvernombudet eller Datatilsynet om behandlinga av dine personopplysningar.

Kva gir oss rett til å behandle personopplysningar om deg?

Vi behandlar opplysningar om deg basert på ditt samtykke.

På oppdrag frå Universitetet i Bergen har NSD – Norsk senter for forskingsdata AS vurdert at behandlinga av personopplysningar i dette prosjektet er i samsvar med personvernregelverket.

Kvar kan eg finne ut meir?

Dersom du har spørsmål til studien, eller ønsker å nytte deg av dine rettar, ta kontakt med: Stipendiat Bente Egge Søvdde, e-post: bente.egge.sovde@hvl.no, telefon 57677605/90968253
Veileidar professor Jorunn Drageset, e-post: Jorunn.drageset@hvl.no, telefon 55588521
ved Universitetet i Bergen

- Vårt personvernombud: Janecke Helene Veim, e-post: Janecke.Veim@uib.no, eller telefon: 55 58 20 29
- NSD – Norsk senter for forskningsdata AS, på epost (personvernombudet@nsd.no) eller telefon: 55 58 21 17.

Med venleg helsing
Bente Egge Søvdde
Prosjektansvarleg
(Stipendiat)

Samtykkeerklæring

Eg har mottatt og forstått informasjon om prosjektet ” **Korleis kan helsetenesta best ivareta og følge opp heimebuande eldre med store og samansette behov?** ”, og har fått anledning til å stille spørsmål. Eg samtykker til:

å delta i intervju

Eg samtykker til at mine opplysningar vert behandla frem til prosjektet er avslutta, ca. (01.10.2022)

(Signert av prosjektdeltakar, dato)

(Telefonnummer eg kan kontaktast på)

Eg bekreftar å ha gitt informasjon om prosjektet

Stad og dato

Signatur

Rolle i prosjektet



Høgskulen
på Vestlandet



Helse Førde

Vil du delta i forskingsprosjektet

” Korleis kan helsetenesta best ivareta og følgje opp heimebuande eldre med store og samansette behov?”

Dette er et spørsmål til deg om å delta i et forskingsprosjekt der formålet er å utvikle ny kunnskap kring omsorg for heimebuande over 65 år med store og samansette behov. Du har som brukar av tenestene viktige erfaringar og kunnskap å bidra med, og ditt synspunkt er viktig i arbeidet med å utvikle tenestene vidare. I dette skrivet gir vi deg informasjon om måla for prosjektet og kva deltaking vil innebere for deg.

Formål

I denne studien vil brukarar, pårørande og helsepersonell knytt til heimebuande eldre med store og samansette behov bli intervjuar for å få meir kunnskap om erfaringar og opplevingar dei har i sin praktiske kvardag. Det vil vere omlag førti personar som vert intervjuar i prosjektet til saman, medrekna mellom åtte og 12 pårørande.

Tittel: Korleis kan helsetenesta best ivareta og følgje opp heimebuande eldre som lever med store og samansette behov?

Forskingsspørsmål:

Kva erfaringar har pårørande med å vere tett på heimebuande eldre som lever med store og samansette behov, og korleis opplever dei samarbeidet mellom ulike tenesteytarar?

Kven er ansvarleg for forskingsprosjektet?

Prosjektet er ein del av mitt doktorgradsarbeid som utgår frå Universitetet i Bergen og er finansiert av Høgskulen på Vestlandet.

Kvifor får du spørsmål om å delta?

I denne studien vil brukarar, pårørande og helsepersonell knytt til heimebuande eldre med store og samansette behov bli intervjuar for å få meir kunnskap om erfaringar og opplevingar dei har i sin praktiske kvardag.

Kva inneber det for deg å delta?

I ditt tilfelle vil det bli gjennomført eit intervju med deg. Intervjuet vil finne stad i heimen din eller i eit passende lokale i nærleiken av deg, etter nærare avtale. Intervjuet vil vare i omlag 1 time. Underteikna vil leie intervjuet. Samtalen vil bli tatt opp på lydopptakar. Lydopptaket vil bli lagra på passordbeskytta PC som berre eg har tilgang til.

Mulege fordelar og ulemper

Mulege fordelar ved å delta i studien er at du kan bidra til ny kunnskap om korleis det vert opplevd å vere pårørande til ein brukar med store og samansette behov som bur heime, og korleis du opplever

samarbeidet med helsepersonell. Det vil ikkje medføre utgifter å delta i prosjektet, og det vil ikkje få konsekvensar for tenestene brukar får ifrå helsepersonell.

Det er frivillig å delta

Det er frivillig å delta i prosjektet. Dersom du ønskjer å delta, underteknar du samtykkeerklæringa på siste side, og eg vil etter ei kort tid kontakte deg på telefon. Du kan når som helst og utan å gje nokon grunn trekkje samtykket ditt, utan at det får nokon konsekvensar for tenestene brukar får ifrå helsepersonell.

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Prosjektleiari har ansvar for den daglege drifta av forskingsprosjektet og at opplysningar om deg vert behandla på ein sikker måte.

Kva skjer med opplysningane dine når vi avslutta forskingsprosjektet?

Prosjektet skal etter planen avsluttast 01.10.2022. Informasjon om deg vil bli anonymisert eller sletta seinast fem år etter prosjektslutt, innan 01.10.2027. Data vil bli lagra etter prosjektslutt for etterprøvbarhet.

Dine rettar

Så lenge du kan identifiserast i datamaterialet, har du rett til:

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Veileidar professor Jorunn Drageset, e-post: Jorunn.drageset@hvl.no, telefon 55588521
ved Universitetet i Bergen

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Med venleg helsing
Bente Egge Søvdde
Prosjektansvarleg
(Stipendiat)

Samtykkeerklæring

Eg har mottatt og forstått informasjon om prosjektet ” **Korleis kan helsetenesta best ivareta og følge opp heimebuande eldre med store og samansette behov?** ”, og har fått anledning til å stille spørsmål. Eg samtykker til:

å delta i intervju

Eg samtykker til at mine opplysningar vert behandla frem til prosjektet er avslutta, ca. (01.10.2022)

(Signert av prosjektdeltakar, dato)

(Telefonnummer eg kan kontaktast på)

Eg bekreftar å ha gitt informasjon om prosjektet

Stad og dato

Signatur

Rolle i prosjektet

Bente Egge Søvdde
Postboks 6165
5892 BERGEN

Vår dato: 06.07.2018

Vår ref: 61202 / 3 / LH

Deres dato:

Deres ref:

Tilråkning fra NSD Personvernombudet for forskning § 7-27

Personvernombudet for forskning viser til meldeskjema mottatt 20.06.2018 for prosjektet:

61202	<i>Korleis kan helsetenesta best ivareta og følgje opp heimebuande eldre som lever med store og samansette behov?</i>
Behandlingsansvarlig	Universitetet i Bergen, ved institusjonens øverste leder
Daglig ansvarlig	Bente Egge Søvdde

Vurdering

Etter gjennomgang av opplysningene i meldeskjemaet og øvrig dokumentasjon finner vi at prosjektet er unntatt konsesjonsplikt og at personopplysningene som blir samlet inn i dette prosjektet er regulert av § 7-27 i personopplysningsforskriften. På den neste siden er vår vurdering av prosjektopplegget slik det er meldt til oss. Du kan nå gå i gang med å behandle personopplysninger.

Vilkår for vår anbefaling

Vår anbefaling forutsetter at du gjennomfører prosjektet i tråd med:

- opplysningene gitt i meldeskjemaet og øvrig dokumentasjon
- vår prosjektvurdering, se side 2
- eventuell korrespondanse med oss

Meld fra hvis du gjør vesentlige endringer i prosjektet

Dersom prosjektet endrer seg, kan det være nødvendig å sende inn endringsmelding. På våre nettsider finner du svar på hvilke [endringer](#) du må melde, samt endringsskjema.

Opplysninger om prosjektet blir lagt ut på våre nettsider og i Meldingsarkivet

Vi har lagt ut opplysninger om prosjektet på nettsidene våre. Alle våre institusjoner har også tilgang til egne prosjekter i [Meldingsarkivet](#).

Vi tar kontakt om status for behandling av personopplysninger ved prosjektslutt

Ved prosjektslutt 31.10.2022 vil vi ta kontakt for å avklare status for behandlingen av personopplysninger.

Se våre nettsider eller ta kontakt dersom du har spørsmål. Vi ønsker lykke til med prosjektet!

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

Vennlig hilsen

Marianne Høgetveit Myhren

Lise Aasen Haveraaen

Kontaktperson: Lise Aasen Haveraaen tlf: 55 58 21 19 / Lise.Haveraaen@nsd.no

Vedlegg: Prosjektvurdering



FORMÅL

"Det overordna målet med studien er å utvikle ny kunnskap kring omsorg for heimebuande eldre med store og samansette behov relatert til frailty syndromet."

UTVALG OG REKRUTTERING

Utvalget består av eldre over 65 år som har sammensatte behov og benytter seg av hjemmetjenester mer enn tre ganger i uken, samt pårørende og helsepersonell.

Pasienter og pårørende rekrutteres gjennom hjemmetjenesten med bistand fra eldremedisinsk poliklinikk og kardiologisk poliklinikk i Helse Førde. Det vil ikke opprettes kontakt mellom informantene og forsker før de har ytret ønske om å delta i prosjektet. Personvernombudet mener rekrutteringsformen er tilstrekkelig for konfidensialitet og at frivilligheten ved deltagelse ivaretas gjennom prosessen.

I meldeskjema opplyses det om at noen av deltakerne kan ha kognitiv svikt. I følge meldeskjema skal imidlertid kun personer med samtykkekompetanse inkluderes i prosjektet. Forsker har et eget ansvar for å vurdere samtykkekompetansen til den enkelte deltaker. Samtykkekompetansen kan vurderes i samråd med pårørende og/eller noen som kjenner vedkommende eller tilstanden godt (f.eks. helsepersonell).

INFORMASJON OG SAMTYKKE

Dere har opplyst i meldeskjema at utvalget vil motta skriftlig og muntlig informasjon om prosjektet, og samtykke skriftlig til å delta. Vår vurdering er at informasjonsskrivene til utvalget stort sett er godt utformet, men det må legges til informasjon om at pårørende vil uttale seg om situasjonen til pasientene i skrevet til pasienten.

Dersom pårørende skal uttale seg om situasjoner knyttet til andre pasienter enn de som deltar i prosjektet, må pasientene informeres om dette.

Vi ber dere om å sende det reviderte informasjonsskrivet til personvernombudet@nsd.no Husk å oppgi prosjektnummer. Prosjektet kan deretter starte.

METODE OG DATA

Det vil foretas personlige intervju med pasienter, og gruppeintervju med pårørende og helsepersonell.

I gruppeintervju er det spesielt viktig å tenke på om spørsmålene er utformet på en slik måte at de kan besvares i plenum (f.eks. dersom det er snakk om veldig personlige eller sensitive spørsmål). Det kan noen ganger være relevant at de som deltar undertegner en gjensidig taushetserklæring.

Det fremgår av meldeskjema at dere vil behandle sensitive opplysninger om helseforhold.

TAUSHETSPLIKT

Helsepersonell har taushetsplikt. Personvernombudet forutsetter at det ikke innhentes personopplysninger om enkeltpasienter eller pårørende, og at taushetsplikten ikke er til hinder for den behandling av opplysninger som finner sted.

INFORMASJONSSIKKERHET

Personvernombudet forutsetter at du/dere behandler alle data i tråd med Universitetet i Bergen sine retningslinjer for datahåndtering og informasjonssikkerhet. Vi legger til grunn at bruk av mobil lagringsenhet er i samsvar med institusjonens retningslinjer.

PROSJEKTSLUTT OG ANONYMISERING

Prosjektslutt er oppgitt til 31.10.2022. Det fremgår av informasjonsskrivet at data vil lagres frem til 01.10.2027 for etterprøvbarehet. Etter dette skal opplysningene anonymiseres.

Anonymisering innebærer vanligvis å:

- slette direkte identifiserbare opplysninger som navn, fødselsnummer, koblingsnøkkel
- slette eller omskrive/gruppere indirekte identifiserbare opplysninger som bosted/arbeidssted, alder, kjønn
- slette lydopptak

For en utdypende beskrivelse av anonymisering av personopplysninger, se Datatilsynets veileder:

<https://www.datatilsynet.no/globalassets/global/regelverk-skjema/veiledere/anonymisering-veileder-041115.pdf>

Vi legger til grunn at videre lagring av personopplysninger er avklart med behandlingsansvarlig institusjon.



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