

From THE DEPARTMENT OF NEUROBIOLOGY, CARE
SCIENCES AND SOCIETY
Karolinska Institutet, Stockholm, Sweden

**ENABLING AT-HOMENESS FOR OLDER PEOPLE DESPITE
THEIR SEVERE ILLNESS AND IMPENDING DEATH**

Lotta Saarnio



**Karolinska
Institutet**

Stockholm 2018

All previously published papers were reproduced with permission from the publisher.

Published by Karolinska Institutet.

Printed by E-print AB 2018

© Lotta Saarnio, 2018

ISBN 978-91-7676-974-4

ENABLING AT-HOMENESS FOR OLDER PEOPLE DESPITE THEIR SEVERE ILLNESS AND IMPENDING DEATH

THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

Lotta Saarnio

Huvudhandledare:

Professor Joakim Öhlén
Göteborgs Universitetet, Göteborg
Sahlgrenska akademien
Institutionen för vårdvetenskap och hälsa

Fakultetsopponent:

Docent Karin Josefsson
Högskolan i Borås, Borås
Akademien för vård, arbetsliv och välfärd
Sektionen för vårdvetenskap

Bihandledare:

Docent Anne-Marie Boström
Karolinska Institutet, Stockholm
Neurobiologi, vårdvetenskap och samhälle
Sektionen för omvårdnad

Betygsnämnd:

Professor Gerd Ahlström
Lunds Universitet, Lund
Medicinska fakulteten
Institutionen för hälsovetenskaper

Professor Petter Gustavsson
Karolinska Institutet, Stockholm
Institutionen för klinisk neurovetenskap
Sektionen för psykologi

Docent Pernilla Hillerås
Rödakorsets högskola, Stockholm
Hälsovetenskapliga institutionen

Medicine doktor Ragnhild Hedman
Ersta Sköndal Bräcke högskola, Stockholm
Institutionen för vårdvetenskap

Professor Bertil Axelsson
Umeå Universitet
Institutionen för strålningsvetenskaper

ABSTRACT

The overall aim of this thesis was to describe the phenomenon of at-homeness and how at-homeness could be enabled for older people with severe illness and impending death. The project comprises four studies and was guided by an interpretive description design. Data generation for studies I and II was through individual qualitative narrative interviews with older people who were severely ill or facing impending death and living in their ordinary homes or in long-term or short-term nursing homes. Data generation for study III was based on seven reflective group discussions with the nursing staff in a nursing home (III) and study IV was based on participant observations and directed interviews (IV) with both older people and nursing staff in long-term and short-term nursing homes. The studies were analyzed using phenomenological hermeneutic interpretation (I, II) and constant comparative technique (III, IV).

The results showed (I) that for the older people at-homeness meant being oneself and being connected, which were interpreted as agency and communion. The results of the older people's experiences of how the meanings of at-homeness were temporally and spatially shaped (II) showed that the phenomenon is interrelated, where at-homeness was shaped through relying on a familiar place and through continuous balancing between the past, present and future. The reflections of the nursing staff regarding how at-homeness was enabled for older people resulted in patterns such as (III) striving to get to know the older people, showing respect for the older people's integrity, creating and working in family-like relationships, helping to find a new ordinariness and preparing and making plans to ensure continuity for the older people. The last study (IV) explored how the nursing staff enabled at-homeness for older people in a nursing home who were at the end of life. The results showed that strategies used by the nursing staff to enable at-homeness were presenting themselves as reliable, respecting the resident's integrity, being responsive to the resident's needs, collaborating with the resident in decision-making and through nurturing comforting relationships.

This thesis shows that older people can experience at-homeness despite being severely ill and facing impending death. However, the results show that having time to be able to become familiar with new people and places is of importance for how older people experience at-homeness as are the older people's earlier experiences in life and how they come to terms with changes and losses. This thesis shows specifically that, through person knowledge, respect for integrity and nurturing comforting relationships, nursing staff can enable at-homeness for older people who are severely ill and facing impending death.

Keywords; *at-homeness, constant comparative technique, end-of life, interpretive description, narrative interviews, nursing homes, nursing staff, older people, ordinary homes, palliative care approach, participant observations, phenomenological hermeneutical interpretation, reflective group discussions, severe illness*

LIST OF SCIENTIFIC PAPERS

- I. Saarnio, L., Boström, A-M., Gustavsson, P. & Öhlén, J. (2016). Meanings of at-homeness at end-of-life among older people. *Scandinavian Journal of Caring Sciences*, 30(2), 312-319. doi: 10.1111/scs.12246
- II. Saarnio, L., Boström, A-M., Gustavsson, P., Hedman R. & Öhlén, J. Temporally and spatially shaped meanings of at-homeness among people aged 85 years and over with severe illness. *International Journal of Older People Nursing*.doi: 10.1111/opn.12165 (E-pub Aug 2017)
- III. Saarnio, L., Boström, A-M., Hedman, R., Gustavsson, P. & Öhlén, J. (2017). Enabling at-homeness for residents living in a nursing home: reflected experiences of nursing home staff. *Journal of Aging Studies*, 43, 40-45. doi: <https://doi.org/10.1016/j.jaging.2017.10.001>
- IV. Saarnio, L., Boström, A-M., Hedman, R., Gustavsson, P. & Öhlén, J. Enabling at-homeness for older people at the end of life: A participant observation study from nursing homes. (Manuscript)

CONTENTS

1	Introduction	1
2	Background.....	3
2.1	Being old.....	3
2.2	Living with severe illness and impending death	5
2.3	Older people’s dying and death	6
2.4	Palliative approach	7
2.4.1	A palliative care approach at older people’s end of life.....	8
2.5	The Home and nursing home as arenas for a palliative approach	9
2.6	Nursing staff in nursing homes	11
2.7	At-homeness, well-being and Health.....	12
2.7.1	Previous research on at-homeness	14
3	Rationale.....	16
4	Aim	17
5	Methods	18
5.1	Interpretive description.....	18
5.2	Settings and participants.....	20
5.3	Recruitment procedures.....	21
5.4	Data Generation and analysis.....	22
5.4.1	Studies I and II	22
5.4.2	Study III.....	24
5.4.3	Study IV.....	25
5.5	Ethical Considerations.....	26
6	Results.....	28
6.1	Summary of main results.....	28
6.1.1	Study I.....	28
6.1.2	Study II	28
6.1.3	Study III.....	29
6.1.4	Study IV.....	30
6.2	Synthesis of main results.....	31
6.2.1	At-homeness is enabled through coming to terms with changes in life	32
6.2.2	At-homeness is enabled through promoting safety	33
6.2.3	At-homeness is enabled through supporting agency.....	33
6.2.4	At-homeness is enabled through supporting communion.....	34
7	Discussion.....	36
7.1	Discussion of the results.....	36
7.1.1	At-homeness as an individual process and experience until death.....	36
7.1.2	The fundamentals of care supported by strategies that enable at- homeness	38
7.1.3	Relationship-focused strategies that enable at-homeness	39

7.1.4	At-homeness as a goal for a palliative approach for older people who are at the end of their lives	41
7.2	Methodological considerations	44
8	Conclusions and implications	47
9	Future research	48
10	Svensk sammanfattning/ Summary in Swedish	49
11	Aknowledgements	51
12	References	53

1 INTRODUCTION

This thesis concerns the need to research older people's well-being at the end of their lives, older people's experiences of at-homeness and how nursing staff could enable at-homeness for older people who are severely ill and dying. To make the text more readable, the shortened term older people will be used throughout this thesis to refer to older people who are severely ill and facing impending death.

Even though older people's living conditions and care have been in the focus of the media, society and researchers, there is little understanding of older people's end of life care and death, despite the large number of people who die at a high age. In 2016, there were 91000 deaths in Sweden and over 60 percent of all deaths occurred among older people aged 80 years or more (National Board of Health and Welfare, 2016A). The number of older people who will die at a high age is expected to increase in the future, since the number of older people who are 75 years or more will double until the year 2050. Although an increasing proportion of older people live an active life, the vast majority becomes in need of social and health care at the end of life. This means, therefore, that there will be an increased need for home care help and nursing home beds (The Swedish Agency for Health and Care Services Analysis, 2015). For several years it has been argued that there is insufficient research on older people's end of life and palliative care (Hallberg, 2004, National Board of Health and Welfare, 2006). Palliative care of older people has been less prioritized due to the need for highly qualified end-of-life care for younger people with cancer (cf. e.g. Sawatzky et al., 2016). However, older people's end of life has been viewed as a growing public health concern and interest in improving older people's end-of-life and palliative care needs is growing (Cohen & Deli ns 2012).

This project considers that human beings are capable of personal development throughout their whole life and that older people have the possibility to overcome difficulties and challenges in life up until death, which is similar to theories such as gerotranscendens (Tornstam, 2005) and the stages of human development (Erikson & Erikson, 1998). Recognizing older people's abilities for personal growth is important when exploring how older people who are severely ill and facing impending death experience at-homeness and how nursing staff can enable this.

The research on older people's at-homeness and how nursing staff may enable at-homeness has been carried out using a practice-oriented design, Interpretive Description, developed by Thorne (2016). This design allows research from a broad front, using techniques that are needed to generate the data required and through interpretations of the data to be able to understand the phenomenon of at-homeness, which is both metaphorical and abstract. Earlier studies on at-homeness throughout the life span show that experiences of at-homeness may differ throughout life. Small children, for example, described at-homeness as being with their mother and older people experienced at-homeness as being safe and comfortable (Zingmark, Norberg, & Sandman, 1995).

2 BACKGROUND

The background aims to provide a starting point in order to understand how at-homeness is enabled for older people despite their severe illness and being at the end of life. First, some theories and thoughts on being old are presented, followed by older people's experiences of living with severe illness and impending death and, finally, older people's dying and death will be described. Thereafter, the palliative approach and the palliative care approach at older people's end of life will be presented. The background will be continued with a presentation of the home and nursing home as arenas for palliative care, and of the nursing staff who work within the context of home care and nursing homes. Finally, at-homeness, well-being and health as concepts and previous research on at-homeness among older people will conclude the presentation of the background.

2.1 BEING OLD

Age and being old has been explained and theorized in many perspectives and, in this section, some of the perspectives which are of importance in the thesis will be presented. Age has been traditionally described from a chronological perspective which may be the most familiar way of explaining age, however its relevance as a marker for old age has been questioned, because the chronological age alone will not tell how ill a person is (Lindenberger & Baltes, 1997).

Another important theoretical perspective is to divide age from birth to being old into four ages and where old age is divided into a 3rd and 4th age. The 3rd age usually refers to younger old age and the 4th to older old age. Younger old age is an active period and is described as an age of physical and mental strength (Baltes & Smith, 2003; Laslett, 1989), productivity and being alert (Ågren Bolmsjö, 2008). In this age, people are at the top of their emotional intelligence and wisdom (Baltes & Staudinger, 2000). In high income countries, the transition from the 3rd to the 4th age usually occurs at around 85 years of age (Baltes & Smith, 2003). The 4th age is described as a period in life where the ability to learn becomes more difficult and the loss of cognitive abilities and degree of frailty, disability, and multiple illness increase (Baltes & Smith, 2003). Because of this knowledge that older people's physical and mental losses often occur around 85 years of age, this thesis will focus on older people at-homeness who are 85 years or more and living with severe illness and impending death.

Another popular theory called Successful Aging relates to the period of 3rd age, hence Successful Aging is a perspective of living with health and being able to live without disease and disability as well as maintaining high cognitive and physical functioning up to a high age (Rowe & Kahn, 1987); engagement in social and productive activities has also been regarded as a component in Successful Aging (Rowe & Kahn, 1997). Successful Aging has been criticized as being an approach that is not taking into account the nature of natural aging and

where being active and productive are highly valued up to old age (Liang & Luo, 2012). Successful Aging has also been regarded as an approach where aging well and without difficult health issues is an individual choice, where older people have responsibility for their own independence and for reducing the costs of care for older people (Rožanova, 2010). Therefore the Successful Aging approach becomes problematic when compared to the view of aging in this thesis, where the context is to study older people's end of life that is marked by decline, frailty and dependency, which the majority of older people go through before their death (this will be described in more detail in the next chapter). In addition, implementing models such as Successful Aging in care of older people could cause increased feelings of guilt and shame, since Successful Aging regards aging as the individual's responsibility and it is possible that older people are not able to retain their physical and mental strengths.

From a psychodynamic perspective through the whole lifecycle, Erikson & Erikson (1998) presented a theory with nine stages. Each stage is described as having development crises and it is a process that interplays between the person and society. The final two stages were described as stages of aging and where the eighth stage of aging is about a struggle between integrity and despair with the aim of finally achieving wisdom. However, the crisis may lead to a sense of disgust when one is nearing the end of life with increasing confusion and helplessness. If the crises are positively overcome, there is, as stated earlier, the possibility of reaching wisdom. The last stage of the theory, the ninth stage, can be said to start for people who become very old, somewhere between 80 and 90 years of age, when the body's weakness begins to become apparent and there is a risk of losing control of the body and becoming dependent on others. In addition, the sorrow of losing many significant others could also create a crisis in the older person's life. Therefore, retaining senses of trust and hope, that may have been concealed throughout the whole of life from being a new-born baby up to the moment when death is impending, could still help older people overcome their loss and create development where they feel safety, joy and increased wisdom.

Gerotranscendence is a theory of positive aging (Tornstam, 2005) and can also be used to show that being old can mean becoming less self-occupied and more careful in the choice of daily activities. Some of the aspects that define gerotranscendence are experiencing a close connection with younger generations, regarding material things to no longer be of interest and eventually re-evaluating life, death, time and space. Tornstam (2011) further stresses that this process of growing is dependent on others around the older people; being encouraged to participate in activities and other events or having their desire to talk about death diverted might be experienced by older people as demanding and this may therefore constrain positive aging. Instead, listening to older people's wishes about when and how they would like to participate in activities, creating the possibility for and being attentive to older people's needs for discussion about death and dying, and showing interest in the older people's earlier life could all be examples of how nursing staff could enable well-being for older people. These theoretical perspectives of aging from a developmental and positive viewpoint, where older people can experience wisdom, could be closer to the thoughts of at-homeness that this thesis

addresses and which older people could experience despite severe illness and impending death.

2.2 LIVING WITH SEVERE ILLNESS AND IMPENDING DEATH AS AN OLDER PERSON

In this thesis, severe illness is described as the experience of living with life-limiting illness, which means knowledge of life being limited due to the disease and that death will not necessarily occur immediately. Sometimes it is difficult to say when older people's end of life begins, however it has been stated that the last year of life could be the time period that may be referred to as older people's end of life (Seymour, Witherspoon, Gott, Ross, Payne & Owen, 2005).

Living with severe illness and/or being at the end of life as an older person has been described as an individual dynamic process (Krishnan, 2017). When the meaning of older people's life at its end was studied, it was recognized that older people created their meaning of life in relation to past and present, both through an inner dialogue and in communication with others (Dwyer, Nordenfelt, & Ternstedt, 2008). Despite older people having lived a long life and being of a high age, becoming severely ill was, according to a study by Whitaker (2010), an unexpected event that often affected the older people's whole life due to the changes and losses in their body (Whitaker, 2010; Österlind, Hansebo, Andersson, Ternstedt, & Hellström, 2011).

Losing control as a result of impairment and other bodily changes has been recognized as being a challenging time for older people and many older people also are living with losses other than those related to their body, such as those related to social relations and places (Nicholson, Meyer, Flatley, Holman, & Lowton, 2012). Older people suffering different types of losses in their lives has been recognized as leading to dependence on healthcare and persons close to the older people (Ågren Bolmsjö, 2008; B. Ternstedt & Franklin, 2006). Previous studies have shown that being dependent on others and not as mobile as they used to be can be difficult for older people to deal with and may cause existential loneliness (Sjöberg, Beck, Rasmussen, & Edberg, 2017). According to Franklin, Ternstedt and Nordenfeldt (2006), bodily changes and impairment may cause older people to have difficulties recognizing themselves in the same way as they used to and can violate older people's dignity. Similarly, Whitaker (2010) found that losing control of one's own body could evoke feelings of shame, frustration and indignity.

Older people who were severely ill experienced being alone and disconnected from the rest of the world and felt that they had no one to share their everydayness with (Sjöberg et al., 2017). It has also been recognized that older people with severe illness are unwilling to share their health problems with their relatives because of not wanting to worry them or become a burden to others (Andersson, Hallberg, & Edberg, 2008; Lloyd-Williams, Kennedy, Sixsmith, & Sixsmith, 2007).

Despite many bodily changes and losses due to disease and the aging process, older people with severe illness are not always aware of their condition, as seen by Klindtworth et al. (2015). In this study, old and very old people with severe heart failure and who were living in their ordinary homes were interviewed about their understanding of their illness and end of life issues, which found that they were not always aware of how ill they were or that they were dying (Klindtworth et al., 2015). Similarly, older cancer patients were not always aware they were dying (Lloyd et al., 2016). However, some studies have shown that older people were aware that they were at the end of their life, for example the interview study of older people living in nursing homes by Franklin et al., (2006). In addition, a study by Lloyd-Williams et al (2007) showed that older people over 80 years and living in their ordinary homes were found to be aware that their time left in life was limited and made preparations regarding their own death such as planning their funeral and sorting out belongings (Lloyd-Williams et al., 2007).

Older people living at the end of their life wanted to be free from pain and other symptoms (Krishnan, 2017) and felt it was important to have good connections with their relatives. They also felt that relatives and nursing staff were there for them (Andersson et al., 2008; Krishnan, 2017). Thus, having nursing staff that are mindful of older people's needs and wishes in a period of change and loss could indicate that older people with severe illness and living at the end of their lives may experience the enabling of at-homeness to be something positive in their lives. The time frame taken in this thesis for the older people who were severely ill and facing impending death is the older people's last year, months and sometimes few days of life.

2.3 OLDER PEOPLE'S DYING AND DEATH

The most common causes of death in the western world among people over 65 years of age were heart and circulatory diseases, respiratory diseases and cancer (WHO, 2008). In 2012, the most common causes of death among all the registered deaths in Swedish nursing homes were circulatory diseases, dementia and cancer (Smedbäck et al., 2017). However, it is common that older people suffer from more than one life-limiting illness, which together might contribute to death (Pal & Manning, 2014; WHO, 2011). As earlier described, the most common causes of death for older people in Europe and Swedish nursing homes, such as circulatory diseases, respiratory diseases, cancer and dementia, were also the diseases that participants in this thesis suffered from and what is referred to here as severe illness.

Older people's dying and death usually takes the form of a process over a period of time (Covinsky, Eng, Lui, Sands, & Yaffe, 2003; Ross, Fisher, & Maclean, 2000). A study of older people's dying and death found that most older people are disabled in their last year of life and common symptoms they might have are distress, pain, depression and confusion (Fleming et al., 2017). However, older people's deaths have been identified as being difficult to predict and a study by Barclay et al. (2014) found that, in a nursing home, being able to

recognize when an older person was dying varied from case to case. In some cases, the older person's dying was identified in time, which meant there was the possibility to initiate direct care activities including end of life care. However, in other cases, older people's deaths were difficult to predict and dying was described as uncertain and unexpected in cases where older people died suddenly (Barclay et al., 2014).

Since it has been regarded that older people's deaths can be difficult to predict and especially to identify, when the last period before death begins (Covinsky et al., 2003), instruments such as the conception of frailty have been developed. Comorbidities and disabilities have often been related to being part of the definition of frailty (Lekan, 2009) and it has been recognized that frail older people often have more than one life-limiting illness and are in need of care with a palliative approach (Pal & Manning, 2014). In addition, vulnerability and aging have been included as key elements in the concept of frailty; however there is a lack of mutual consensus surrounding this concept (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010).

Older people's dying and death have, to some extent, been described as unexpected and unknown and at the same time comorbidities and frailty have been recognized as markers predicting that older people might be near to death. Thus, it is not always clear for the older people that they are severely ill and facing impending death nor for the nursing staff who are taking care of them. There is therefore a need for an appropriate way for introducing older people at the early onset of end of life to a care form that would be appropriate until death and where a palliative care approach could possibly be beneficial for older people at the end of life.

2.4 PALLIATIVE APPROACH

A palliative approach is characterized by being a holistic vision (patient as a whole) supporting the person's dignity and well-being throughout life (European Association for Palliative Care, [EAPC], 2009; National Board of Health and Welfare, 2013) regardless of diagnosis or age (National Board of Health and Welfare, 2013). Palliative care is defined by the WHO (2002, pp 83) as an approach where death is regarded as a natural process and "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." The modern palliative approach was founded by Cicely Saunders who, in 1967, started a hospice in London as a movement against the over-medicalization of people severely ill with cancer (Clark & Seymour, 1999).

The development of palliative care is ongoing. The palliative approach, in a Swedish context, follows the international definitions and has been further defined by using four key concepts to guide palliative care at the end of life: wholeness, nearness, empathy and knowledge (Regional Co-operative Cancer Centers, 2012). In Sweden, palliative care is regarded as having two phases during the disease process: an early phase and a late phase. The early

phase can be long and its goals are to ensure that life-prolonging treatments are appropriate for the specific patient and to promote actions that give a higher quality of life during such treatments. The late phase can often be short and focuses on relieving suffering and promoting as high well-being and quality of life as possible for the patients and their close relatives. The time point at which the early phase turns into a late phase can be vague. Since it can be difficult to determine the change from an early to a late phase of palliative care, this may affect the approach to care at the end of life (National Board of Health and Welfare, 2013). However, when the medical decision has been made and the transition to the late phase of palliative care begins, this often gives or is meant to give, the patients and their relatives the opportunity to prepare to live close to death (Regional Co-operative Cancer Centers., 2012).

Besides palliative care being divided in two phases depending on where the patients are in their illness trajectory, the European Association of Palliative Care (2009) has divided palliative care into three levels of care: a palliative care approach, general palliative care and specialist palliative care. Specialist palliative care is a level of care given by services and healthcare professionals and other team members who have appropriate training in caring for patients with complex problems and care needs suffering from life-threatening incurable illnesses. General palliative care is for patients who are living with life-threatening illnesses and where the care is given by healthcare professionals in primary care. The healthcare professionals may have appropriate basic knowledge about palliative care, but may have other specialties as their main focus. A palliative care approach has a broader meaning and is where the principles of palliative care can be integrated into other care systems, such as in hospitals and nursing homes, and where the healthcare staff might have basic education and knowledge about palliative care (EAPC, 2009).

2.4.1 A palliative care approach at older people's end of life

From the start of the hospice movement, palliative care has been dedicated to the care of patients with incurable cancer diagnoses (Clark, 2007). However, in the past decades, the needs that older people have for palliative care have been identified and the palliative care and end of life care of older people have been recognized as lacking (Hallberg, 2004). The WHO (2011) have raised the need for the development of older people's end of life care in their publication "Better care for older people", in which palliative care for older people has been described as an *urgent public health priority*. Palliative care for older people is being described as a priority because of the rapidly increasing older population, (Cohen & Deli ns, 2012; WHO, 2011), and because older people's disease patterns are changing. The complex needs of older people are therefore also reasons for needing to make older people's palliative care a priority.

Both a palliative care approach and palliative care have the same basic perspectives whereby the person who is ill and their family are supported, and the focus is on the person as a whole

and not only the disease. A palliative care approach, as stated earlier, is a wider perspective than palliative care and should be given in the early phase of end of life, such as in comorbidities, frailty, cancer, dementia or heart diseases (Sawatzky et al., 2016) and one that could be integrated with, for example, geriatric care and the nursing of older people. Dekkers (2009) has identified at-homeness as a possible and relevant goal that is an integral part of palliative care and may help ensure that death is humane and dignified.

In this thesis, the focus will be on this wider perspective of a palliative care approach, which is seen as an appropriate way to develop older people's end of life care and where at-homeness could be a goal for a palliative care approach for older people with severe illness. There is, therefore, a need for further development of how at-homeness could be enabled for older people who are at the end of their life regardless of where they are living, since a palliative care approach has been considered suitable for older people living in their ordinary homes or in institutions such as nursing homes throughout the illness trajectory until death (HAS, 2016).

2.5 THE HOME AND NURSING HOME AS ARENAS FOR A PALLIATIVE APPROACH

Many older people with severe illness and at the end of their lives continue to live in their ordinary homes or in nursing homes, which are both regarded as being older people's homes (National Board of Health and Welfare, 2002). In Sweden older people who are living in their ordinary homes may receive help with their personal care or with domestic tasks. What kind of help the older person needs and who provides it is decided with the help of assessments of the older person's individual needs (Larsson, 2006). It has been described that older people who live in their ordinary homes experience more freedom and independence (Taube, Jakobsson, Midlöv, & Kristensson, 2016) compared to those who have moved to live in nursing homes (Riedl, 2011).

Older people may need to move into nursing homes because they do not feel safe or they feel lonely in their ordinary homes (National Board of Housing, Building and Planning & National Board of Health and Welfare, 2003). In a study by Westerbotn and colleagues, one of the main reasons for older people managing to live in their ordinary homes was that they had retained their cognitive capacity (Westerbotn, Fahlström, Fastbom, Agüero-Torres, & Hillerås, 2008). Health issues, the need for twenty-four/seven care and increased dependency due to severe illness and functional decline are other reasons why older people might need to move to nursing homes. Those living in Swedish nursing homes are often older people who have entered the 4th age and have extensive care needs and problems with being able to orientate themselves in their everyday lives (National Board of Housing, Building and Planning & National Board of Health and Welfare, 2003). It seems that many older people are suffering from severe illnesses and are late in their illness trajectory and at the end of life when they move into a nursing home, which means that older people are now living longer in

their own homes (Estabrooks et al., 2015). According to the figures from a Swedish context, there is a tendency for older people to live in their own homes for longer and then move into a nursing home when they have just a short time left to live. This shows that older people's length of stay in nursing homes is decreasing (Schön, Lagergren, & Kareholt, 2016); almost every third older person who moved into a nursing home died within six weeks and more than half of them died within ten months (Smedbäck et al., 2017).

The respective numbers of older people who are receiving home-help or living in nursing homes are changing and for several years there has been a tendency to decrease the number of nursing home places; in 2011 there were 94,000 older people living permanently in Swedish nursing homes and in 2016 there were 87,900. There is also a tendency for increased numbers of older people to receive care and home-help in their ordinary homes, which has increased from 211,000 older people in 2011 to 223,000 older people in 2016 (National Board of Health and Welfare, 2016B).

There have been major changes to and development of the care of older people in Sweden. In 1992, "ädelreformen" took place whereby the responsibility for the long-term care of people over 65 years of age was moved from the county councils to the municipalities and changed from being a medically-oriented long term care model to a more residential type of care with a homelike and social environment (Statistics Sweden, 2006), which I have chosen to call a nursing home. This is because older people who live in nursing homes usually have high basic care needs as well as the need for medical care and a homelike environment.

One of the reasons for introducing Ädelrefomen was to provide institutional care for older people in a single type of housing, called a nursing home, where care is provided 24 hours per day and is also a place that older people can call home. In this type of nursing home, older people live in rental flats with shower, toilet and a place to cook (SOU 2007:103). In addition to long-term nursing homes that are regarded as older peoples own homes, short term-nursing homes were also established in connection with Ädelreformen. These are intended for people who are in need of intermittent care, treatment, rehabilitation, a care place before moving into a long-term nursing home or care that is expected to be temporary such as care at the end of life. Short-term nursing homes follow the same principles as long-term nursing homes, where values of the home such as ordinary everydayness and the daily living of the older people are in the forefront, and medical and nursing care is provided based on needs, but is in the background (National Board of Health and Welfare, 2002).

A study of the place of death among older people with dementia in five European countries showed that this varied depending on the country where the older people died, age, gender and the availability of hospital and nursing home placement for people with dementia. The study showed that deaths in ordinary homes among people with dementia were rare; less than five percent in all the countries studied. Nursing homes were the most common place of death among people with dementia (Houttekier et al., 2010).

In general, the probability of dying in a nursing home increases with older people's age (Luta et al., 2016). A Swedish register study of all the registered deaths in 2012 showed that more than 60% of people over 90 years of age died in nursing homes (Håkanson, Öhlén, Morin, & Cohen, 2015) and the probability of dying in the ordinary home decreases with older people's increasing age (Hunt, Shlomo, & Addington-Hall, 2014). In general, institutions such as hospitals and nursing homes are increasingly the place of death for older people in Sweden and globally (Håkanson et al., 2015; Reyniers et al., 2015; Sarmiento, Higginson, Ferreira, & Gomes, 2016).

Nursing homes have become a place for a palliative care approach regarding older people's death and dying. However, there has been a lack of interest in researching older people in this context (e.g. Henoch et al 2016), which may also affect older people's possibilities of receiving palliative care to the same extent as younger people who are at the end of life (Österlind et al., 2011). Studies have shown, for example, that older people's preferred place of death is recorded to a lesser extent compare with younger people (Hunt et al., 2014) and, in Sweden, the nursing home deaths that were recorded showed that less than half of older people died in their preferred place (Smedbäck et al., 2017). Other studies have shown that the majority of people in general would prefer to die in their ordinary home rather than in a nursing home or hospital (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013).

2.6 NURSING STAFF IN NURSING HOMES

The nursing assistants and registered nurses are, together with occupational therapists and physiotherapists, responsible for most of the older people's everyday care in Swedish nursing homes (Törnquist, 2004). Nursing assistants often work closely with the older people and nursing assistants' job descriptions vary depending on the work-setting (Hewko et al., 2015). However, the usual working tasks of nursing assistants in a Swedish context have been described as nursing care, social intercourse, and household, medical and administrative tasks (Törnquist, 2004). The nursing assistants' work has been described as complex and demanding, both physically and mentally (Nielsen & Glasdam, 2013), and it has been recognized that burnout among nursing assistants is not an uncommon phenomenon. (Estabrooks et al., 2015).

In a study by Karlsson, Ekman & Fagerberg (2009), the work of registered nurses in nursing homes was described as being a consultant concerning older people's medical issues and everyday care and also having a formal role as a leader (Karlsson, Ekman, & Fagerberg, 2009). Similar results were found in a study by Josefsson & Hansson (2011) where registered nurses described that organizational conditions were often uncertain with regard to leadership, for example regarding how and where decisions were made. The same study stressed that a large number of registered nurses were leaders for at least a small group of nursing assistants. Another study by Karlsson, Ekman & Fagerberg (2008) presented the point of view of nursing assistants as expecting the registered nurses to be

equal team members but that the registered nurses had the main responsibility for the care of older people living in nursing homes. It has also been identified that nursing assistants can feel that their awareness and experience were not appreciated by other team members when taking care of older people who were dying (Fryer, Bellamy, Morgan, & Gott, 2016).

In a study by Dwyer and colleagues (2009), nursing assistants taking care of older people at the end of life have stated that there are problems with finding nursing assistants who are interested in working with older people at the end of life (Dwyer, Andershed, Nordenfelt, & Ternestedt, 2009). Another problem with taking care of older people at the end of life seen in a study by Österlind et al. (2011) was that nursing assistants in nursing homes did not speak very much about death and dying with the older people because of their own fear of death (Österlind et al., 2011). One possible reason for this, as described by Fryer et al., is that education about palliative and end-of-life care has been recognized as lacking by many nursing assistants (Fryer et al., 2016; Goddard, Stewart, Thompson, & Hall, 2013). The nursing staff wanted end-of-life care education, and identified that they needed more knowledge to be able to give appropriate end-of-life care (Goddard et al., 2013). They preferred to receive education that was more practical and given by their colleagues rather than a conventional style of education (Fryer et al., 2016).

In spite of the many barriers to working as a nursing assistant in nursing homes and taking care of dying older people, it has been acknowledged that nursing staff often valued their own work (Estabrooks et al., 2015). Major positive aspects regarding their work was the relationships between the nursing assistants and the older people and the older people's loved ones (Eldh et al., 2016; Fryer et al., 2016), and the relationship with their team members, which enabled personal and professional growth (Eldh et al., 2016).

2.7 AT-HOMENESS, WELL-BEING AND HEALTH

The relationship between the concepts of health, well-being and at-homeness will be briefly clarified, since it might help in understanding the concept of at-homeness, which is the main focus of this thesis. However, although at-homeness is the main focus, I will start with the umbrella concept of health that the WHO (1946) describe as follows: "Health is a state of physical, mental and social well-being and not merely the absence of disease and infirmity.". Further development has been given to emphasis on the holistic view of health, which means that a person is considered as a whole and where well-being has been regarded as the experience of health (cf. Nordenfelt, 2006; Dahlberg, Todres, & Galvin, 2009). Well-being has its starting point in a person's subjective experiences and feelings (Eriksson, 1984; Sarvimäki, 2006), in this respect, can be regarded as similar to the concept of at-homeness, and where the metaphorically opposite meaning, homelessness, could be described as being close to the experience of illness. According to Öhlén and colleagues, at-homeness has been described as a part of well-being and that (Öhlen, Ekman, Zingmark, Bolmsjö, & Benzein, 2014) there is a pendulum between the opposite poles of at-homeness and homelessness. The

pendulum of well-being is described by Dahlberg et al. (2009) as a vital capacity between movement and peace.

According to Dahlberg et al. (2009), the central concepts of well-being for a person are movement, peace, vitality and goals in life related to the world around them such as time, place and other persons. Some similarities with this view of well-being were found in an earlier work by Zingmark, Norberg and Sandman (1995) who studied the experience of being at home through the life span of ages from two to 102 years and found that the experience of being at-home was related to other people, places, things, activities and to the person themselves (Zingmark, Norberg, & Sandman, 1995).

There is a variety of terms and concepts that are similar to that of at-homeness, such as home, being at-home and a sense of home. Sometimes these concepts are explained similarly to at-homeness and sometimes their meanings differ. When research on at-homeness among older people is presented here, I will use the concept of at-homeness in cases where findings and knowledge contribute to the study of at-homeness among older people with severe illness and impending death, even though some studies may use other concepts with similar meanings to at-homeness.

However, it seems that at-homeness may be understood in two ways. Firstly, there is knowledge generation of at-homeness where place and environment is regarded as the midpoint for the experience of at-homeness. At-homeness has, for example, been defined as something that is related to an environment with familiar surroundings, objects, settling and stillness (Galvin & Todres, 2011), in both a literal and/or metaphorical way, which also includes social and cultural elements. The environmental relations of at-homeness have been related to older people moving from their ordinary home to assisted places such as nursing homes and where older people are facing the need for a new place integration (Rowles, 2013). A metasynthesis of the meaning of home has been performed by Molony (2010) who studied people aged 65 years and over with the purpose of creating therapeutic environments during the transition to a residential home. At-homeness was described as place-based experiences that were related to the older people's place integration, relationship to oneself and to other people who were important to them and, when the integration faced problems, there was the possibility of existential homelessness (Molony, 2010).

In this thesis, the understanding of at-homeness is regarded from a wider interpretation of the concept, where at-homeness may be understood through the person's whole life and not merely through place and environment. Öhlen et al. (2014) have called this a metaphorical way of understanding at-homeness, regardless of people being severely ill, and where environment is a part of the older people's at-homeness. Here again, Zingmark, Norberg and Sandman (1995), who investigated the experience at-homeness through the life span of ages from two to 102 years (Zingmark et al., 1995), also saw that being at home was experienced in many ways such as "*safety, rootedness, harmony, joy, privacy, togetherness, recognition, order, control, possession, nourishment, initiative, power and freedom*". Earlier research,

presented below, will focus on the wider perspective of at-homeness, which has also been the way at-homeness has been understood in this project.

The experience of at-homeness or homelessness could also be in relation to a person's own body and the illness experience. The philosopher Svenaeus (2011) studied at-homeness philosophically in relation to illness as an unhomelike being-in-the-world experience, where illness could be understood as *otherness*, and where the person is not familiar with illness and is therefore experiencing themselves as an outsider in life (Svenaeus, 2011). Svenaeus further proposed that suffering chronic pain could make life as a whole unhomelike (Svenaeus, 2015). However, as described earlier, it is possible to experience at-homeness whilst having disease as is shown in a review by Öhlén et al., (2014); at-homeness in spite of illness lies on a continuum between the poles of at-homeness and homelessness where aspects of being *safe, connected and centered* were recognized. Four processes were identified between the poles of at-homeness and homelessness: (I) expanding - limiting experiences of disease and time, (II) uniting - segregating ways to relate to others, (III) recognizing - not recognizing themselves, and (IV) being given space by others - being taken away by others. These aspects and processes were mostly based on age-specific studies.

2.7.1 Previous research on at-homeness

Previous studies on at-homeness that specifically researched older people with severe illness, older people who were at the end of their life and/or who lived in nursing homes will now be presented. According to a study by Andersson et al. (2008), older people who were at the end of life and living in a nursing home experienced at-homeness when they felt inner confidence in their life situation (Andersson et al., 2008). Another aspect of at-homeness was feeling safe, which was recognized as being related to the experience of at-homeness among older people in nursing homes (Edvardsson, 2008). Older people who lived in their ordinary homes also related at-homeness to the possibility of providing safety to others such as family members (Moloney, 1997).

In a case study by Ekman, Skott and Norberg (2001) where one person, an older woman, was studied both in her ordinary home and later in a nursing home, the aspects at-homeness and homelessness were both identified; at-homeness was identified as relating to the body and, when she had learned to live with the illness, homelessness was related to worries about becoming dependent on others such as nursing staff (Ekman, Skott, & Norberg, 2001).

Being able to make their own choices and being involved in their own care in nursing homes has been related to older people's experiences of at-homeness or sense of home (Molony, Evans, Jeon, Rabig, & Straka, 2011; Rijnaard et al., 2016). Another aspect of being at-home and experiencing a sense of home was being able to continue with daily routines (Andersson et al., 2008; Rijnaard et al., 2016).

Relationships to others and to nursing staff were also regarded as aspects related to older people's at-homeness (Andersson et al., 2008; Edvardsson, 2008; Moloney, 1997; Rijnaard et al., 2016) as were being known and affirmed by others (Rijnaard et al., 2016). When loneliness among older people was studied, the results showed that older people experienced loneliness either as devastating, which was interpreted as homelessness, or enriching, which was interpreted as at-homeness (Graneheim & Lundman, 2010). According to a study by Andersson et al. (2008), loneliness meant that older people who were at the end of their lives did not have any connection to other residents or nursing staff and this was interpreted as homelessness (Andersson et al., 2008).

Place and environment are important and there is a relational aspect between the nursing staff and older people. Edvardsson (2008), for example, found that a therapeutic environment was something that was related to at-homeness and to how nursing staff behaved and acted in nursing homes. Other studies have also identified that place as an aspect of at-homeness was related to older people having their own belongings with them when moving to a nursing home (Andersson et al., 2008; Rijnaard et al., 2016).

3 RATIONALE

Aging is an individual process, however somewhere between the ages of 80 and 90 years the majority of older people become more frail and dependent on others, may suffer from multiple diseases and, for many, it is the time when dying and death occur. Many older people die in nursing homes and after only having lived there a relatively short time, which may mean that older people risk experiencing loneliness whilst dying. Earlier studies have also shown that nursing staff do not always have the knowledge and resources to take care of older people who are dying and in need of palliative care.

At-homeness and homelessness for older people at the end of their lives have previously only been studied as part of other research questions or have come up as incidental findings in broader research. These previous studies have shown that at-homeness among older people involves several aspects such as feeling safe, that at-homeness and homelessness are related to the older people's bodies, feeling confident, the environment, loneliness and to relational aspects with other people, such as nursing staff and others.

Older people's experiences of at-homeness at the end of life are important to study because of the bodily, relational and environmental changes that often occur. To be able to experience at-homeness despite these changes is an important goal for the palliative care of older people. Studies of what at-homeness means for older people who are at the end of life are few and, to the best of my knowledge, there are no studies of how nursing staff could enable at-homeness, even though it appears as one of the most important areas in older people's palliative and end-of-life care.

4 AIM

The overall aim of the thesis is to describe the phenomenon of at-homeness and how at-homeness could be enabled for older people with severe illness and impending death. The specific aims are:

- I. To illuminate meanings of at-homeness among older people over 85 years with advancing illnesses.
- II. To illuminate how meanings of at-homeness are temporally and spatially shaped by older people with severe illness.
- III. To explore nursing home staff's experiences of how to enable at-homeness for residents living in a nursing home.
- IV. To explore how nursing staff enable at-homeness for residents in a nursing home being cared for at the end of life.

5 METHODS

Older people's at-homeness and how to enable at-homeness were studied from the perspective of older people with severe illness and/or living at the end of life, and from the perspective of nursing staff caring for older people with severe illness and/or living at the end of life. The studies have been performed in chronological sequence and are referred to as I, II, III, and IV, which will also be used when each specific study is discussed.

5.1 INTERPRETIVE DESCRIPTION

This thesis is qualitative in its overall design and informed by the approach of interpretive description (Thorne, 2016), an approach that aims to generate knowledge from complex practices, which can be useful for practice fields such as nursing and the care of older people. This methodology adds to our understanding of experiences in health and illness and how nurses could improve people's experiences of health and illness (Thorne, Kirkham, & MacDonald-Emes, 1997). In my opinion, therefore, interpretive description is a suitable design to explore older people's at-homeness and how to enable it, since at-homeness is indeed one way to understand and approach people and their health and well-being. Another reason to apply an interpretive description design for the overall thesis was because the study context was severely ill older people receiving home care or nursing home care, and is therefore a practice-oriented field which is regarded as the main context for using the interpretive method (Thorne, 2016).

The interpretive description design was developed to help nurse researchers and nurses in the healthcare field, where the methods traditionally used in qualitative studies such as Ethnography, Grounded theory and Phenomenology were not always regarded as sufficient through the whole research process and where the use of a single research approach may not have been applicable in nursing practice (Thorne, 2016). Instead, as mentioned earlier, interpretive description is an inductive way of expressing people's subjective accounts of a specific phenomenon. The interpretation springs from socially constructed truths and where interpretive description seeks to find, amongst other themes, relationships and patterns from the nursing practice (Thorne, 2016; Thorne, Kirkham, & O'Flynn-Magee, 2004).

In this design, the researcher needs to be explicitly aware of the field and surrounding theories before entering the field and where the researchers themselves are tools throughout the actions and interpretations in an inquiry. The strength of the design is being able to explore unknown but relevant areas of the studied phenomenon that contribute varied interpretations and make the understanding of the area more fulfilled (Thorne, 2016).

Interpretive description gives an opportunity to research the phenomenon at-homeness among older people at the end of their lives. The project is also practice-oriented so this design also supports the possibility of making interpretations, which is necessary since at-homeness is a

concept that can be considered abstract and the experiences might be imbedded in the studied context.

Studies I and II were based on a phenomenological hermeneutical method (Lindseth & Norberg, 2004), which is especially suitable for researching the meanings of phenomena. The aims of these studies were to illuminate older people's meanings of at-homeness and how meanings of at-homeness are temporally and spatially shaped. The data-gathering methods for the two studies were narrative interviews with older people with severe illness and /or who were at the end of their lives. Studies III and IV were based on Interpretive description (2016) and the studies' aims were to explore nursing home staff's experiences of how to enable at-homeness for residents living in a nursing home and how the nursing staff enable at-homeness for the residents who are at the end of their lives. Data generation for study III was based on group discussions (Bengtsson, 1993; Bengtsson, 1995) with nursing staff in a nursing home and for study IV on participant observations with formal and informal interviews (Mulhall, 2003; Thorne, 2016) with both older people at the end of their lives and with nursing staff. Data analysis for studies I and II was based on phenomenological hermeneutical interpretation (Lindseth & Norberg, 2004) and constant comparative technique (Thorne, 2016) was used for studies III and IV.

Tabel I. Overview of the studies

Study	Aim	Sample and informants	Data generation	Data analysis
I	To illuminate meanings of at-homeness among older people over 85 years with advancing illnesses	20 men and women aged 85 years or more with severe illnesses.	Individual qualitative narrative interviews	Phenomenological-hermeneutical interpretation
II	To illuminate how meanings of at-homeness are temporally and spatially shaped by older people with severe illness.			
III	To explore nursing home staff's experiences of how to enable at-homeness for residents living in a nursing home	10 nursing staff	Reflective group interviews	Constant comparative technique
IV	To explore how the nursing staff enable at-homeness for the residents who are at the end of their lives.	Two units with a total of 14 nursing assistants and 13 residents	Participant observations and interviews	

5.2 SETTINGS AND PARTICIPANTS

All four studies were conducted in three larger cities in Sweden and in the context of nursing homes and home care, which are common housing forms for older people with severe illness and who are at the end of their lives. It was also important that the older people who participated in the study had some basic care needs in order to make sense of how nursing staff could enable at-homeness.

Initially, settings from long-term and short-term nursing homes, and home care organizations were contacted for participation in the study. In addition to those that initially decided to participate in this project, contacts with new settings were also made to obtain as much variety in settings and participants as possible. In order to achieve greater variation in settings and participants, purposeful sampling principles were employed to obtain representation which, according to Thorne (2016), is about obtaining varied descriptions of data. Diversity was sought regarding characteristics of participants (older people and nursing staff) such as age, gender and country of birth and type of housing and care organization. Except for the participants living in their ordinary homes, data generation was conducted both in long-term nursing homes and in short-term nursing homes, which was in total seven public, private and non-profit-driven organizations. Long-term nursing home units were general nursing home units where the main reason for participants being cared for in a nursing home was having a somatic illness. One short-term nursing home unit cared for people with somatic illnesses or disability and another short-term nursing home for people with somatic illnesses, disability or palliative care needs. All long-term nursing homes had single rooms with a small kitchen, toilet and shower. In short-term units, the older people's rooms also had a toilet and shower, however were not equipped with a small kitchen and one of the short-term nursing homes had both double and single rooms. All nursing home units had a larger social area with shared kitchen for preparation of meals, dining tables and chairs and an area for sofas and TV. All nursing home units had nursing assistants who were responsible for the older people's everyday living and basic nursing care, and registered nurses who were responsible for the older people's medical care. Occupational therapists, physiotherapists and physicians also visited and contributed to the older people's care on a consultation basis.

Older people who lived in their ordinary homes all lived alone in a house or a flat. They all received home-help from nursing assistants such as cleaning, cooking, going out or help with their daily hygiene. In this thesis, the participants in the study were both older people with severe illness and/or living at the end of their lives in their ordinary home or in a nursing home and nursing staff who worked in nursing homes.

In total, the participants were 33 older people aged 85 years or over and all had at least one severe life-threatening illness and/or were receiving palliative care. The inclusion criteria for participating in this project was being 85 years or over, having been diagnosed with progressive or chronic life-threatening conditions, multimorbidity and/or receiving palliative care or end-of life care, and an ability to communicate in Swedish or Finnish, since my native language is Finnish. As mentioned earlier, data generation was followed by purposeful

principles, where variation in, for example, living place, age, gender and nationality have been sought.

Table II. Demography of the included older people

Gender	N	Age years	N	Housing	N	Country of birth	n	Walking ability	n
Women	21	85-90	20	Ordinary home	4	Sweden	26	Independent	4
Men	12	91-96	8	Short-term	12	Rest of Northern Europe	5	With walker	19
		97-103	5	nursing home		Rest of Europe	2	With wheelchair/bed-ridden	10
				Nursing home	17				

In total, 17 nursing staff from a nursing home unit and a short-term unit participated in the study and the nursing staff were between 18 and 61 years of age. Nursing staff who worked in a nursing home participated in study III and some of the nursing assistants also participated in study IV. The inclusion criterion for the participation of nursing staff was that they were taking care of older people on a regular basis and could communicate in Swedish.

Table III. Demography of the included nursing staff

Gender	n	Country of birth	n	Work place	N	Education in the field	n	Working experience	n
Women	14	Sweden	8	Short-term	7	None	1	0-3 years	3
Men	3	Rest of Northern Europe	2	nursing home		Receiving education	1	4-10 years	6
		Out of Europe	7	Nursing home	10	Nursing assistant	13	11-20 years	2
						Registered nurse	1	21-36 years	6
						Occupational therapist	1		

5.3 RECRUITMENT PROCEDURES

The recruitment of participants was conducted in connection with the data gathering for the studies. Studies I and II involved the same data gathering and the participants were recruited from one medium-sized city and from two larger-sized cities in Sweden. The managers of long-term and short-term nursing homes were contacted as were the managers of home-care organizations. After a first contact with the managers by email or phone, information about the project was given and plans were made for how to involve staff and older people who would eventually be asked to participate. The managers of each organization engaged and informed the staff who would then help inform and ask older people who met the study criteria if they were interested in receiving more information about the study and meeting the researchers. Once the older people had given their agreement, the researchers met the pre-participants to give more information about the study. Informed consent was obtained from

the older people who decided to participate once the researcher was sure that they fully understood what participation would involve.

In study III, two planned information meetings about the study were held with the nursing staff to inform them that their participation was voluntary and informed consent was obtained during these meetings. Nursing staff who had not had the opportunity to participate in these information meetings were given information and signed informed consent forms before attending the group discussion occasions.

There were two separate recruitment processes for study IV. The first recruitment process was in 2015 in a long-term nursing home unit and the second was in 2017 in a short-term nursing home unit. In both recruitment processes, the nursing staff were informed about the study and that participation was voluntary. The researcher who conducted the field work obtained informed consent from the nursing staff who cared for older people at the units with severe illness and/or were at the end of life. Informed consent was also obtained from the older people during the fieldwork. The nursing staff also had a key role in recruiting older people who were cared for in each of the nursing homes. Firstly, the nursing staff informed the older people briefly about the study and asked if the researcher could give them more information about the study. Informed consent was obtained from the older people, either in writing or orally depending on the older person's ability to hold a pen and write.

5.4 DATA GENERATION AND ANALYSIS

Data generation has been conducted through individual qualitative narrative interviews (I, II), reflective group discussions (III), participant observations and directed interviews (IV) and the analysis of the studies was conducted through phenomenological hermeneutic interpretation (I, II) and constant comparative technique (III, IV).

5.4.1 Studies I and II

The purpose of these two studies was to illuminate the phenomenon of at-homeness among older people who were severely ill and at the end of life. In total, ten women and ten men over 85 years who were severely ill and at the end of life were interviewed for the study by using individual narrative interviews. The analyses were based on the phenomenological hermeneutical interpretation according to Lindseth & Norberg (2004).

In studies I and II, the data generation method chosen was individual narrative interviews, partly to capture the phenomenon of at-homeness as experienced by older people and also because the narrative interview is regarded as part of the phenomenological hermeneutical method (Lindseth & Norberg, 2004). The narrative interviews were planned to be conducted with the purpose of making two studies with different aims.

Narrative interview is regarded as a method where human stories are in focus (Riessman, 2008). An interview is conducted with two active participants who, together, create the story and its meaning. According to Riessman (2008), narrative interviews focus on obtaining rich and detailed stories rather than short answers and general statements. Using the narrative interview technique (Riessman, 2008), one open-ended question was used to start the interviews: *'Could you please tell me about situations when you feel or have felt at-homeness or homelessness?'*. In this method it is important to let the participants speak freely without being disturbed, which was fulfilled during the interviews. Some probes (Price, 2002) were used during the interviews with follow-up questions such as: "What does that mean to you?, How did it feel?, Tell me more about this"; these were asked by the interviewer to develop the participant's narration together.

Data analyses for studies I and II were based on phenomenological hermeneutical interpretation (Lindseth & Norberg, 2004). The interpretation theory according to Ricoeur, 1981) has been further developed by Lindseth and Norberg (2004) to an empirical phenomenological hermeneutical method. The method has been described as an ongoing movement between the whole text and parts of the text, and as moving between distancing from and appropriating the text.

Data from studies I and II were interpreted successively using the phenomenological hermeneutical method. The narrative interviews were interpreted in relation to the first aim followed by manuscript preparation for study I, and then the same interview set was interpreted in relation to the second aim followed by manuscript preparation for study II. Both study I and study II were interpreted using the same analytical steps, thus the interpretations varied depending on the aim and because of the possibility of reaching a deeper understanding of the phenomenon in the second interpretation in study II. Phenomenological hermeneutical interpretation is structured in three analytical phases: naive understanding, structural analysis and comprehensive understanding (Lindseth & Norberg, 2004) and these were followed during the interpretation process in both studies.

The narrative interviews were first read several times to obtain an understanding of the studied phenomenon; for study I this was to illuminate meanings of at-homeness among older people at the end of life and, for study II, to illuminate how meanings of at-homeness are temporally and spatially shaped by older people. During the process of creating a naive understanding, two specific questions were generated and further guided the next phase, the process of structural analysis of the interpretations. In study I, these two questions were: "What does at-homeness mean in relation to oneself? What does at-homeness mean in relation to others?". The questions for study II were: "How might aspects of familiarity of places shape meanings of at-homeness? How might biographical aspects of the past, present and future shape meanings of at-homeness?".

Next, the parts of the narrative text that answered these questions were discerned and then divided into meaning units and condensed. The condensed meaning units were selected according to the questions, which formed two structural analyses in study I and two structural

analyses in study II. In both studies, the two structural analyses were performed in parallel and this analytical phase implied a movement back and forth between the parts of the narrative text as a whole, the meaning units and the condensed meaning units, which were arranged into subthemes and further into themes.

In the last phase, a comprehensive understanding was created together with the research group through critical reflection by using our pre-understandings together with literature that could enrich the understanding of the structural analyses and the naive understandings.

5.4.2 Study III

Reflective group discussion with nursing staff from one nursing home unit was chosen for the second data generation. This was both a data-gathering method and a development process to learn more about at-homeness and how nursing staff could explicate knowledge on how to enable at-homeness for the residents. According to Bengtsson (1993), reflective group discussions provide an opportunity for professionals to attain distance through dialogue and thus articulate experience (Bengtsson, 1993).

Seven group discussion sessions were held with nursing staff. The moderator had a planned focus for each session and these were 1) The phenomenon of at-homeness among older people, 2) Promoting at-homeness for residents, 3) Promoting at-homeness for the residents, 4) Strategies to enhance at-homeness for residents, 5) Deepen earlier understandings of at-homeness among the residents, 6) Strategies to enhance at-homeness, 7) Deepen earlier understandings of at-homeness among the residents. The group sessions all followed the same structure. The moderator had prepared coffee and cake for each session and the sessions started with an introduction followed by the working process and ended with feedback for improving the next group session. A descriptive summary was written after every session for the participants who were not able to attend.

Interpretive description is suitable for research in clinical practice (Thorne, 2016), such as in study III which is seeking and developing knowledge from the nursing staff's and resident's reality. Data generation and analysis are regarded here as parallel processes. The research question that guided the analysis was: how at-homeness could be enabled for the residents with severe illness and who are at the end of life.

A constant comparative technique was applied for the analysis (Thorne, 2016) and the initial analyses started alongside data gathering, since the design gave the possibility to make improvements and any necessary corrections in data gathering (Thorne, 2016). What was discussed during the group discussions and the way it was discussed were evaluated after the first two and then after five discussion group occasions. This was to enable any improvements in how and what was discussed and, therefore, be sure that the data gathering was in line with the aim of the study. After the data gathering, the material was analyzed broadly and inductively to seek patterns, similarities and differences within the studied

material. Memos on the possible patterns and some preliminary interpretations were written up. After this phase, the researcher also read relevant literature related to at-homeness at the end of older people's lives which could enrich the analyses and the interpretations. The next phase was to perform similar rounds where the gathered material was read, the new memos were shaped if necessary and some alternative interpretations were made and tested. This ongoing process of going back and forth was repeated until there was an indication that how to enable at-homeness was fully researched.

5.4.3 Study IV

Data generation through participant observations and interviews about the observed situations was used in the interpretive description design (Thorne, 2016) that guided study IV.

Participant observations were conducted in two settings, initially in a long-term nursing home, and then in a short-term nursing home with six patient rooms that were reserved for people with palliative care needs. Observations in the long-term nursing home were important for the researcher's development of the participant observations before the second observations were carried out in the short term nursing home. As a result, the researcher understood that more participation by the researcher was needed in nursing care situations to be able to observe in more detail how nursing staff enable at-homeness for the residents.

Unstructured field notes concerning observed situations were documented electronically in the nursing homes living and kitchen area. Both what happened in a nursing care situation and reflections on the situation were documented (Mulhall, 2003). Directed interviews were held after the observed situations with the residents or the nursing staff. The questions were related to the observed situation and the researcher asked different questions depending on whether the participant was a nursing assistant or a resident, however the questions were related to wellbeing, at-homeness and how to enable at-homeness.

Constant comparative technique was used as an analysis method, similar to study III, and similarly, data generation and analysis were also parallel processes where the research questions guided the analysis of how at-homeness could be enabled for the residents. Grounded in participant observations (IV), however, the initial analyses started alongside data gathering and were analyzed and improved during the field-work. First the participant observations were evaluated and some corrections were made, such as the researcher finding that observations should be carried out in the residents' rooms to enable richer observations of how nursing staff enabled at-homeness. During the participant observations period, the material was analyzed to find if there were situations or other aspects that the researcher should focus on to gain greater understanding of the field.

After the field-work, the material was analyzed broadly and inductively to seek patterns, and similarities and differences within the studied material. In both studies, memos on the possible patterns and some preliminary interpretations were documented. After this phase, the

researcher also read relevant literature related to at-homeness at the end of older people's lives which could enrich the analyses and the interpretations. The next phase was to perform a similar round where the gathered material was read, the new memos were shaped, if necessary, and some alternative interpretations were made and tested, which meant that alternative interpretations were tested throughout the whole material. This ongoing process of going back and forth was repeated until there was an indication that how to enable at-homeness was fully researched.

5.5 ETHICAL CONSIDERATIONS

Older people who are severely ill and at the end of their lives is an understudied group and there is a presumption that taking part in research would be burdensome to them. On the contrary, taking part in research could also be potentially therapeutic and enrich the participant's life (LeBlanc, Wheeler, & Abernethy, 2010). However, older people with severe illness and at the end of life are often in a vulnerable position which is why great attention has been given to ethical principles in this project; the ethical principles for research according to declaration of Helsinki (World Medical Association, 2013) on vulnerable groups and individuals has been taken into consideration during the whole project. One of the principles is that research should be responsive to the needs and priorities in vulnerable groups and individuals. As stated earlier in this thesis, this group of people are under-researched and there is a lack of knowledge about how to improve older people's well-being at the end of life.

The project was granted ethical approval before the start of the project and additional approval was later received, both from the regional Ethics Committee in Stockholm (2013/252-31/5 and 2014/1494-32).

The older people and the nursing staff were informed about the study both orally and in writing. There was always the possibility for participants to ask questions about the study. The informed consent was voluntary and was obtained in connection with the data gathering in each part of the project. Informed consent was signed by all the nursing staff who decided to participate and by those older people who were able to sign. Informed consent was obtained orally from older people wanting to participate who had some bodily impairment and were not able to use their hands or to see. Some of the older people who participated in studies I, II, and IV had problems with memory loss.

The nurses initially asked the older people about whether they wanted to participate in the study and this was the first way of assessing if the older people understood what participation meant when giving consent. Then, whilst giving information about the study, as a researcher, I continuously processed if the older people understood what it meant to participate in the study. However, in the middle of the interviews some older people did ask why I was interviewing them and, in those cases, I told the participant why and what I was doing and asked again if they would like to continue. None of the older people in these cases wanted to

end the interview. During the interview and the observations I also tried to be aware of whether participants had shown that they were tired, feeling discomfort or indicated in other ways that they might not want to continue the interview or observation. Repeated informed consent (Seymour & Ingleton, 2005) was also applied in group discussions (III) and in participant observations (IV). Hence, these data gatherings were repeated and the participant's decision to participate could be changed. Above all, the older people who were at the end of life could have become increasingly affected by their illness or their life situation, which could have influenced the older people's voluntary decision to participate in the study.

6 RESULTS

In this section, the most significant results will first be presented for each study as short summaries of the main results. After this, a synthesis of the results from all studies will then be presented. The results relate to meanings of at-homeness and strategies for how at-homeness could be enabled by the older people themselves and by the nursing staff. However, experiencing at-homeness and enabling at-homeness are complex processes where multiple aspects and strategies are interrelated.

6.1 SUMMARY OF MAIN RESULTS

The four studies that constitute the results of this thesis will be presented separately as studies I, II, III and IV.

6.1.1 Study I

The meanings of at-homeness among older people who were severely ill and at the end of their lives are described in two main themes, *Being oneself* and *Being connected*.

Being oneself was regarded as older people's need to continue to be themselves and to manage despite losses and changes, which were understood as being in relation to bodily changes and relational changes in the older people's lives. Being oneself was also understood in relation to older people being able to perform tasks that were of benefit to themselves and others.

Being connected was described as relationships with others that were important for older people's at-homeness, for example that the older people had close relationships with their significant others such as relatives, old friends and neighbors. In addition, relationships with the nursing staff and other residents in the nursing homes were important for older people's at-homeness, since it was in these kinds of relationships that the older people could be affirmed as persons, which also meant at-homeness for them. Being in a safe dependency was also interpreted as being connected, which meant that the older people could rely on nursing staff helping them in a way and at the time they wished. In a comprehensive understanding, the two main themes were related to two main interrelated human forces; being oneself was interpreted as agency and being connected was interpreted as communion.

6.1.2 Study II

The second study on older people's experiences of how meanings of at-homeness are temporally and spatially shaped resulted in two main themes: *Shaping at-homeness through*

relying on a familiar place and Shaping at-homeness through continuous balancing between the past, present and future.

Shaping at-homeness through relying on a familiar place was related to the place where older people were able to recognize themselves. This meant that the older people's at-homeness was shaped when older people were familiar with their environment, surroundings and daily routines, and with the people around them. For the experience of at-homeness, time influenced being able to become familiar with the environment and older people's ability to decide when and where they would move from their ordinary homes. Experiences of at-homeness were also related to a place where older people felt that they were known and seen by nursing staff and other residents/neighbors.

Shaping at-homeness through continuous balancing between the past, present and future meant that older people's at-homeness was both a result of accepting some change in their lives over time, and a process where older people had not come to terms with the change and instead may experience homelessness. However, if older people had accepted a change or loss in their life there was also the possibility for reorienting and finding new meaning and content in their life.

6.1.3 Study III

Nursing staff's experiences of how to enable at-homeness for older people living in nursing home resulted in five patterns: *Striving to get to know the resident, Showing respect for the resident's integrity, Creating and working in family-like relationships, Helping to find a new ordinariness and Preparing and making plans to ensure continuity.*

Striving to get to know the resident was a strategy that nursing staff regarded as a basis for learning about the new resident and in order to get to know a new resident the nursing staff needed several encounters and care situations.

Showing respect for the resident's integrity was another strategy through which nursing staff thought they could enable at-homeness. This meant that they were fully present in the nursing care situation, residents' wishes were respected regarding when and how care situations would be performed and they assumed a position as a guest when they were in the resident's room.

Creating and working in family-like relationships referred to near relationships which were created between the nursing staff and the residents they had the main responsibility for on a daily basis. This was a relationship where residents were able to show and talk about how they felt at the moment and where nursing staff showed interest in the resident's life. Also giving hugs and holding a resident's hand were strategies that enabled at-homeness according to nursing staff.

Helping to find a new ordinariness was something that nursing staff discussed and they recognized that residents' being able to come to terms with life changes was a process. The nursing staff tried to show their acceptance of the residents and also discussed with the residents about their change or loss, often related to their body or to life in general, and tried to normalize the changed situation, which could enable at-homeness for the residents.

Preparing and making plans to ensure continuity was about how nursing staff guided the residents through a nursing care situation so that residents could experience safety. In addition, this was about making plans together for coming events and nursing care situations that residents often wished to do with the nursing staff member who was responsible for their care.

6.1.4 Study IV

A participant observation study of how at-homeness was enabled by nursing staff disclosed five strategies: *Nursing staff presenting themselves as reliable*, *Respecting the resident's integrity*, *Being responsive to the resident's needs*, *Collaborating with the resident in decision-making* and through *Nurturing comforting relationships*.

At-homeness was enabled through *Nursing staff presenting themselves as reliable* which was a strategy where the behavior of the nursing staff in a care relationship could enable, for example, the older people to feel trust and to feel safe. Nursing staff presenting themselves as reliable was something that happened in real-time and was not only dependent on how long the nursing staff and older person had known each other. However, nursing staff had the possibility to prepare by getting to know as much as possible about the older people before they met for the first time, which helped the nursing staff to present themselves as reliable.

At-homeness was enabled through *Respecting the resident's integrity* where nursing staff showed respect for older people's private sphere and older people could feel safety and comfort in nursing care situations when no more of their body was visible than necessary.

At-homeness was enabled through *Being responsive to the resident's needs* which occurred when nursing staff were open-minded to the needs the older people had and responsive to the older people's verbal and nonverbal signals. They were also able to make changes depending on what the older people needed and wished.

At-homeness was enabled through *Collaborating with the resident in decision-making* which was about nursing staff inviting older people to make their own choices and decisions about their life, for example the meals and mealtimes that older people could decide upon, and where nursing staff were flexible about letting the older people make decisions concerning themselves and their care needs.

At-homeness was enabled through *Nurturing comforting relationships*, which meant that the nursing staff were interested in the older people and their lives, there was the possibility to

express feelings of happiness and sadness in a safe atmosphere and the nursing staff affirmed the older people as persons.

6.2 SYNTHESIS OF MAIN RESULTS

In this results presentation, aspects that have been experienced from the older people’s perspective, the nursing staff’s perspective and as a result of the fieldwork have been interpreted as one result. This synthesis resulted in four patterns where firstly, the presentation shows that at-homeness could be enabled through the individual coming to terms with life changes and, further, how at-homeness is enabled by promoting safety, supporting agency and through supporting communion to individual older people. In this synthesis, the concept enable has been seen as an umbrella for the concepts of promoting and supporting; when nursing staff are promoting at-homeness this means that they are more responsible for securing the aspects that shape the care relationship, and when nursing staff are supporting at-homeness, this is more about working together with the older people, where the nursing staff connect with the older people to reach this.

The main strategies that are found in the synthesis of results have been presented in a table (Table IV) showing how at-homeness and how to enable at-homeness interrelate. Some of the strategies are presented twice in the table since they have seen been regarded as important strategies in more than one pattern of how to enable at-homeness.

Table IV. Strategies of how at-homeness could be enabled

<p>Coming to terms with changes in life</p> <ul style="list-style-type: none"> • Letting time pass • Discussion about life changes • Showing acceptance of the person as they are 	<p>Supporting agency</p> <ul style="list-style-type: none"> • Getting to know older people • Listening to and helping older people with their wishes and needs • Involving older people in decision-making • Affirming the person as they are
<p>Promoting safety</p> <ul style="list-style-type: none"> • Presenting oneself as reliable • Getting to know the older people • Maintaining continuity • Preparing nursing care situations and events • Respecting older people’s privacy 	<p>Supporting communion</p> <ul style="list-style-type: none"> • Giving time for care relationship • Showing engagement in older people’s interests • Maintaining continuity • Joking and chatting in the way of older people • Touches and hugs

6.2.1 At-homeness is enabled through coming to terms with changes in life

At-homeness was interpreted as a dynamic process, where older people's experiences and thoughts about past, present, future and death were interwoven with their experiences of their body and bodily changes, with the experience of the environment they were living in and with the people they were connected to (II).

Being an older person with severe illness and living at the end of life meant facing a multitude of changes, not only bodily changes and experiences of disease and impairment, but also changes related to longing and loss of family members, friends, a limited social life and changes related to place of living. These changed living conditions that the older people needed to deal with were often related to increased dependency on other people and nursing staff. These changes and losses were referred to in both the older people's narratives and in the aspects that nursing staff identified as changes and losses in the older people's lives (I-IV).

At-homeness that was enabled through coming to terms with life changes was both an individual process experienced by older people (II) and a process where nursing staff could influence the older people's process or aspect of coming to terms with the changes in their life (III). The nursing staff recognized that the older person's individual process moved forward a bit at a time (III). In this process of coming to terms with life changes, there was the possibility that older people were still feeling loss due to the changes in their lives but this did not always constrain the experience of at-homeness. Instead, the change or loss had been a part of the older people's lives that they had accepted. There was variation regarding the experience of coming to terms with a changed life situation and there was also the possibility that not all older people accepted such changes, which could mean that they did not experience at-homeness and had difficulty moving forward with their lives. This was interpreted as an experience of homelessness, which was both related by the older people and discussed by the nursing staff (II, III).

One aspect that enabled the older people's individual process of coming to terms with life changes was time. Letting time pass after the change had occurred, such as for example a bodily impairment or a move to a nursing home, until it became familiar or getting used to surroundings, nursing staff, older people or routines all contributed to older people being able to accept the new life situation (II). The nursing staff in a nursing home discussed how they supported the residents in moving on with their changed life through having conversations about the new situation or condition, and that they tried to help by showing their acceptance of the resident for the other residents (III).

Older people also related that, after coming to terms with the changed life situation, there was a possibility for reorienting their life and finding a new meaningful everydayness that could enable older people's at-homeness. As in the example of a woman who found a new meaning through singing for other residents in a nursing home after her husband had died (II).

6.2.2 At-homeness is enabled through promoting safety

The older people who participated were vulnerable and had an increased dependency in their everyday lives which could cause them to feel unsafe, and this was interpreted as being related to the experience of homelessness (I, II, IV). Older people's safety was promoted by nursing staff in different ways and in different situations related to the care (I, III, IV).

One of the main findings of how to enable at-homeness through promoting safety was related to the older people's experiences of being safe despite dependency (I). This was shaped in a care relation through the older people being able to rely on being helped in a way they wished and needed, and at the right time (I). Strategies for how older people's experience of safety in relation to trust could be promoted was reflected by nursing staff who stated that, when taking care of older people, it was important to get to know the older people and their needs and wishes (III, IV). Another aspect was that nursing staff presented themselves as being reliable in a care situation, which was regarded as another strategy to promote safety and meant that older people could rely on the nursing staff knowing how to care for them so that they could put themselves in the hands of the nursing staff (IV).

According to nursing staff, preparing older people for nursing care situations and coming events by discussing and planning together with the older people how, when and with whom the upcoming situation was to be conducted was here interpreted as a strategy that promoted safety. To give older people a chance to predict and be prepared by knowing what was going to happen and with whom, both in a shorter and a longer perspective, promoted older people's safety and therefore also enabled at-homeness (III).

According to nursing staff, safety was promoted by respecting the older people's privacy which could minimize older people's vulnerability, such as for example through knocking or ringing a bell before entering the older people's rooms or in nursing care situations where nursing staff covered the body parts that were not being cared for at that moment (III, IV).

6.2.3 At-homeness is enabled through supporting agency

Agency influenced the experience of at-homeness among older people who were at the end of life. In older people's experiences of at-homeness, agency was interpreted as being related to continuing to be themselves despite dependency. Dependency was caused by older people's changes and losses related to their body and mind, and also other areas of the older people's lives (I). Older people also discussed the importance of the environment where they lived, which has been interpreted as supporting agency, for example if the older people felt familiar with the place, which was often a result of them having lived in a particular place for some time. Other aspects that influenced older people's agency were daily routines, people and familiar furniture, because these aspects helped older people to recognize themselves after moving to a new place (II).

When older people described that it was important that they were able to continue to be as independent as possible in performing everyday tasks this was also interpreted as at-homeness and sometimes this was enabled through different kinds of aids and resources, for example a walker, hearing aids or a security alarm. Another aspect that was related to at-homeness was when older people described that it was important for them to perform tasks that were of benefit, both to themselves and others. This meant that older people needed to have something to do such as watering the flowers or making a bed. Also helping other people in different ways supported the older people's agency (I).

The aspects of agency were being able to continue to be themselves, being independent and being beneficial and these were reflected in the strategies of how to enable at-homeness that may support agency. The strategies that were interpreted as enabling agency were nursing staff trying to get to know the older people (III), listening to and helping the older people with their wishes and needs (III, IV) and involving older people in decision-making about themselves and their care (II, IV). This supports older people in feeling that their wishes were important and that they were being taken seriously, which could also enable at-homeness (II, IV).

6.2.4 At-homeness is enabled through supporting communion

Older people experienced at-homeness when they were in a close relationship with other people (I-IV). The other people could be a family member, friend, neighbor (I, II), other resident (I, II, III) or nursing staff (I-IV). Communion was related to being close to significant others which were often relationships that the older people had had for a longer time, sometimes many decades (I). Sometimes older people made close and meaningful contacts with other residents in the nursing homes (I, III). One strategy that nursing staff discussed was how they could help older people to make contact with their significant others and the residents in the nursing homes (III).

The care relationships between the older people and the nursing staff have been described in this thesis as affirming friendships (II), family-like relationships (III) and nurturing comforting relationships (IV) which could all describe the meaning of communion. In care relationships between the nursing staff and the older people, at-homeness was enabled by affirming the older people as persons (III, IV), which could also mean that the nursing staff treated the older people as equals (I) and created an atmosphere of kindness and friendliness (I) that older people have expressed as important aspects of care relationships.

Fundamental strategies supporting communion and ones that could enable at-homeness were that nursing staff made time for the older people (IV), and that there was continuity in the form of the same nursing staff and nursing care actions (III).

For development of communion, besides the fundamental strategies named above such as time, continuity and getting to know the older people, both nursing staff and older people

discussed the care relationship between the nursing staff and the older people, for example making jokes and having fun together (III, IV), having everyday conversations and being engaged in who the older people were and what their interests in life had been. Other strategies that developed the care relationship were related to physical contact such as holding hands and giving hugs (III, IV), which were interpreted as strategies that enabled at-homeness through communion.

7 DISCUSSION

In this section, the most significant results and methodological considerations will be discussed.

7.1 DISCUSSION OF THE RESULTS

First and foremost, at-homeness and homelessness are individual experiences that may vary over time in older people's lives. In addition, in the care of older people who are living with severe illness, at-homeness could be enabled in spite of their impending death. Both at-homeness as an experience and how at-homeness could be a goal in the care of older people who are at the end of their life will be discussed. It seems that the experiences of older people are ongoing between the poles of at-homeness and homelessness and could change with the situations the older people are living with and how they are dealing with them. At-homeness may be enabled by nursing staff through supporting the older people during the changes they are going through, their agency and communion as well as through promoting older people's safety.

7.1.1 At-homeness as an individual process and experience until death

Enabling at-homeness for older people at the end of their lives has, in this project, mostly focused on at-homeness and the possibility of experiencing this in spite of severe illness and up until death (Öhlén et al. 2014). This is one explanation for why at-homeness is the focus, even though the older people who participated in this project were considerably affected by their illness and impending death. During this project, situations and narratives that were related and observed could also have been interpreted as illness, lack of well-being and even homelessness and in studies I and II there are situations that showed that the experience of homelessness was also present in several of the participants lives.

The ability to be independent, perform tasks that are of benefit to oneself and others (I), and being familiar with the surroundings and the people close to the older person (II) could help the older people continue to be themselves. Having the possibility to continue to be oneself is important for older people who are living at the end of their life, as similarly discussed in a review by Öhlén, et al. (2014) who found that at-homeness despite illness meant being centered and was described as an inner place of comfort, where people had the possibility to be who they wanted to be. In this thesis, an inner place of comfort could mean being able to continue to use one's own body and perform ordinary everyday tasks. However, there is a small difference compared with Öhlén et al. (2014) who stated that people may be who they want to be, which in our result was about continuing to be the person they have been. This is understood as the older people not longing to be something new, but instead wanting to continue to have the same life situation and the same abilities to live as they had at the present time. This was because they were aware that they might experience changes and losses

related to their body, relations and environment that may affect their ability to continue to be themselves and do what they wanted to do.

Most of the narratives also included both situations that were interpreted as at-homeness and as homelessness. Some unfinished situations that older people had not resolved or accepted from their past, present or future evoked homelessness, which in some cases was, in a metaphorical sense, like an open wound that was still bleeding. Some wounds were scarred and some were healed or accepted (II) giving an opportunity to experience at-homeness. It seems that the same person could experience both homelessness and at-homeness and it may be that the experiences that were most recent in the older person's life could influence whether the older person experienced at-homeness or homelessness at the present time. Similarly, an earlier study on people in hospice care and who were dying showed that being at-home was an everyday struggle because of bodily decline, which was one of the threats which may result in homelessness (Rasmussen, Jansson, & Norberg, 2000). The struggle for at-homeness could also be understood from a perspective of developmental theory through all ages; all phases involve crisis where the last phase will often start when body weakness becomes apparent and the older person becomes dependent on others, which could turn into a crisis in an older person's life (Erikson & Erikson, 1998). This is a similar process to being in crisis, since bodily changes could be seen in the older people's experience as being interpreted as homelessness and, through managing to overcome the crisis, there was the possibility of at-homeness.

An earlier case study showed that an older woman who previously lived in her own home and had been fulfilled with at-homeness, felt homelessness after moving into a nursing home and this was related to becoming dependent on nursing staff since her body caused her to feel insecurity and distress (Ekman et al., 2001). Our results show that one strategy for how nursing staff could enable at-homeness for older people is having conversations with the older people about their changed body as well as nursing staff showing their acceptance of the older people and their weaknesses. This could also enhance the older people's agency, or what Nolan et al. 2004 calls sense of significance and, through this, the nursing staff could show the older people that they are valued as persons.

The experience of at-homeness was also regarded as a process over time, meaning that the older people with severe illness often needed time to get used to or accept the new life situation that was related to changes in their body, mind or environment such as after moving from their ordinary home to a nursing home. The results show that time and letting time pass had an effect that helped older people to become at-home in a new life situation (II). However, letting time pass could be a problem, since many older people had quite a short stay in nursing homes before dying, which occurred both in this project and has also been shown earlier (Smedbäck et al., 2017). This means that there might not always be enough time to experience at-homeness in a new place with new nursing staff and other residents. As the results of this project show, older people being in a place where they felt familiarity was related to their experience of at-homeness (II) and, on the contrary, Österlind and colleagues

found that loneliness was a problem for older people who lived in a nursing home that was unfamiliar to them (Österlind, Ternstedt, Hansebo, & Hellström, 2016). Another study on the loneliness of very much older people who lived in their ordinary homes found that loneliness could be devastating and this was interpreted as homelessness (Graneheim & Lundman, 2010). A short length of stay before older people's deaths in nursing homes could mean homelessness for older people. However, the ways in which the care relationships could enable at-homeness even when older people only stay a short time in a nursing home before their death will be discussed later.

7.1.2 The fundamentals of care supported by strategies that enable at-homeness

Since the experiences of at-homeness and homelessness occur in older people's everyday lives, it seems that the strategies for how to enable at-homeness could also support the fundamentals of care. These are described by Kitson et al. (2010) as basic care needs and factors related to nursing care situations, for example a safe environment, eating and drinking, elimination, dying, rest and mobilization as well as taking care of hygiene and getting dressed (Kitson, Conroy, Wengström, Profetto-McGrath, & Robertson-Malt, 2010). However, it has also been stated that giving the fundamentals of care can be demanding, since there is a risk of a "task and time" oriented care culture. Instead, according to Kitson and colleagues (2014), there is a need for relationship-focused care where "thinking and linking" should be the focus when the fundamentals of care are provided for the patients (Kitson, Athlin, Conroy, & Int Learning, 2014). As we saw in the results regarding strategies, this occurred in the relationships between the older people and nursing staff and the strategies that enabled at-homeness were relationship-focused strategies preferably tailored to the older people's basic care needs. In this thesis, the strategies where nursing staff were joking, chatting or discussing with the older people meant forming nurturing comforting relationships in the older people's ways and in the things that the older people were interested in as part of their ordinary everyday life. It seems that strategies to enable at-homeness can be practiced by nursing staff in nursing care situations as part of the older people's ordinary everyday life.

For a deeper understanding of how at-homeness could be enabled in nursing care situations that occur in older people's everydayness related to place, our results also show a link between the place and the people in the environment. This project showed that places where older people were known and knew other people such as nursing staff and other residents were of importance for older people's experiences related to place. Place as a physical and psychosocial place related to at-homeness in palliative care has been studied by Rasmussen and Edvardsson (2007) who described at-homeness as an atmosphere where older people could experience hospitality, where they were welcome and accepted as they were and where the nursing staff were generous. Safety was also regarded as influencing an atmosphere where care philosophy and possibilities for being alone and being together were important. An atmosphere of everydayness was also important, in that the environment was not

institutionalized and there were instead everyday symbols such as flowers and paintings, and the possibility to have contact with significant others and maintain one's own rhythm of living.

Another concept similar to everydayness is ordinariness as described by Taylor (1994) who introduced this concept in nursing, which means that nursing staff become themselves in a nursing care relationship. In nursing care actions where older people's illness and disability may become visible and make them vulnerable, the nursing staff could help the older people to reduce their feeling of illness by trying to make the nursing care situations as ordinary as possible and not seeing them as something awkward. This is where the nursing staff relate as one person to another, show that they are genuine and where they learn to understand the patient and their care needs and, at the same time, maintain the professional skills of nursing (Taylor, 1994). Having a care relationship in this way could also enrich the strategies for how at-homeness could be enabled for older people who are facing impending death and could make it possible for older people to continue to live the way they used to before they needed help with their basic needs. It has also been argued that people living at the end of their life tend to die in the way they have lived (National Board of Health and Welfare, 2006; Weisman, 1972). Therefore, if nursing staff are able to support older people and have encounters with them so that they are able to live the way they used to, this could also enable at-homeness among older people at the end of their lives. As the strategies that enable at-homeness occur in care relationships, the next discussion will more specifically elaborate on the key strategies in care relationships that could enable at-homeness.

7.1.3 Relationship-focused strategies that enable at-homeness

Several of the strategies that enable at-homeness could be defined as fundamental or essential in the care of older people who are at the end of their lives. However, it can also be seen that the strategies for how to enable at-homeness for older people who are at the end of their lives are based on relationship-centered care which, for example, Nolan and colleagues (2006) have been working on. Earlier studies have also regarded relationships as being an important aspect of at-homeness (Andersson et al., 2008; Edvardsson, 2008; Moloney, 1997; Rijnaard et al., 2016).

The results regarding strategies that enabled at-homeness seem also to be built, at least partly, on other strategies such as time and continuity, which are both required to be able to get to know the older people. The strategy of maintaining continuity was about having the same nursing staff helping the older people as well as similar daily routines that made life predictable and enabled a feeling of security. Similarly, Nolan et al (2004) stress the importance of continuity for older people, which could mean establishing a relationship with the older people as well as them being cared for by a known person.

The strategy of making time for the older people and, in this way, also time for the caring relationship to grow could be understood as banal, since if the nursing staff are not with the

older people it would hinder the nursing staff from getting to know them in a way that is needed. However, it seems to be difficult for nursing staff to give the time the older people would like to have, as seen by Beck and colleagues (2012) who found that nursing staff were more focused on practical care activities and had difficulty focusing on just being with the older people who were at the end of their life and receiving palliative care. Despite nursing staff describing that they had a wish to focus more on the relationships, they felt that it was difficult because of the expectations on them from the managers, the older people's significant others and from the registered nurses (Beck, Törnquist, Broström, & Edberg, 2012). Harnett (2010) also found that limited time was one of the aspects as to why nursing staff in nursing homes did not always help with the needs and wishes of the older people.

One of the main findings of how to enable at-homeness is the strategy that nursing staff need to get to know older people and older people's needs and wishes; this strategy is important and essential for nursing staff to try attain in their everyday encounters with the older people. Earlier studies on at-homeness have also identified that knowing the older people and caring about their wishes was important for older people's experiences of at-homeness (Rijnaard et al., 2016). As discussed earlier, time and continuity were conditions for getting to know the older people. The needs and wishes that older people had were often in relation to issues that were possible for the nursing staff to meet, wishes related to everyday living such as meals, clothing, going outdoors or help with contacts with others. Similarly, according to Dewar & Kennedy, 2016 and Dewar & Nolan, 2013, person knowledge is important in relationship-oriented care, where it is the little things that are important for the older people and that nursing staff should not assume that they know how the older people would like to be cared for. To do the opposite, that is to not get to know the older people or their needs and wishes, could risk the care becoming inappropriate and routinized, and the older people becoming excluded and experiencing homelessness in care relations where nursing staff focus on their own duties and routines. This has been seen by Harnett (2010) who showed that nursing staff will not always answer the older people's needs and wishes because of the limited time they have, or because the older people's wishes are too banal, or because of organizational issues such as routines.

The care relationships between the older people and the nursing staff have been described in this thesis in various ways such as affirming friendships (II), family-like relationships (III) and nurturing comforting relationships (IV). All these ways reflect a close and meaningful relationship between the older people and significant others or nursing staff. In the studies in this thesis, it could be seen that affirming friendships were described by the older people as being the care relationships that would be best for achieving at-homeness. Family-like relationships were viewed by nursing staff as the care relationships that enabled at-homeness, and nurturing comforting relationships were considered to enable at-homeness by nursing staff, older people and by myself, who was the person who carried out the observations. One reflection when comparing how the older people and the nursing staff expressed the care relationship could be that this tells us something about the power relationships between the older people and the nursing staff. When older people were describing the care relationships

as friendships they can be regarded as equal relationships, thus concealing the ways that older people as care receivers were dependent on staff and the power structures related to professional regulation and institutionalization of the care of older people. When the nursing staff regarded the relationships as family-like this could be empowering, however there is also a risk for unequal relationships, such as in a relationship between a child and a parent who is responsible for them and makes decisions above the child's head but who is at the same time caring and loving.

The results of this thesis show that several strategies were regarded as enabling at-homeness such as involving older people in decision making, affirming the person as they are, showing engagement with the older people's interests, joking and chatting in the way of older people as well as hugging and touching. In this thesis, these are called nurturing comforting relationships, which could be understood to be what Dewar and Nolan (2013) called compassionate relationships-centered care, in which the strategies are similar to the findings in this thesis of how to enable at-homeness through nurturing comforting relationships. For example, the strategy of affirming the person as they are could be understood in Dewar and Nolan as asking how people are experiencing their life at the moment, about their feelings regarding an event and giving or taking feedback. Another example from the results of this thesis is involving older people in decision-making, which was instead articulated by Dewar and Nolan (2013) as "working together to shape the way things are done" indicating both involving and empowering people. Being curious was also an aspect found by Dewar and Nolan, which meant that nursing staff should ask about feelings and experiences regarding how to care for people, and our results show that showing engagement for older people's interests enabled at-homeness. The difference might be that results in this thesis are based on older people who stay longer in a specific nursing home, where Dewar and Nolan have studied people in a hospital ward, where their stay might not be as long as that of older people in nursing homes. However, being curious is instead relevant in strategies for trying to get to know the older people and the older people's wishes and needs.

7.1.4 At-homeness as a goal for a palliative approach for older people who are at the end of their lives

At-homeness could possibly enrich the lives of older people who are at the end of life and could possibly be considered as a goal for palliative care. As discussed earlier, at-homeness meant, among other things, continuing to be oneself and strategies included trying to get to know the older people and meeting the older people's need and wishes as well as forming relationships with their significant others. Nursing staff could also use strategies such as affirming the older person, joking and chatting which could confirm the positive sides of life when older people are nearing death and, since older people who are at the end of life are often severely ill and struggling from other changes, at-homeness could enrich older people's end of life. Similarly, Dekkers (2009), who proposed that at-homeness could be a goal for palliative care, stated that being at home or coming home could enrich the patient's way of

living during the process of dying. That a patient's end of life could be understood as a positive period of life has been stated by Saunders, who established the modern palliative care statement "the last stages of life should not be seen as defeat, but rather as life's fulfillment" (Saunders, 1965 pp.70).

In this thesis, at-homeness could be a goal for a palliative approach and the strategies for how nursing staff could enable at-homeness at the end of an older person's life could be practiced from earlier in the illness trajectory until death. This could also enable older people's at-homeness so that older people are familiar with the way of being cared for and where at-homeness is supported as part of a palliative approach when they become severely ill and when death is near. Similarly, it has also been proposed that a palliative approach be given to older people at the beginning of their illness trajectory, which, according to the WHO (2011), could be started early with interventions that suit the older person's illness trajectory and which could become the main care with impending death. However, recommendations for starting interventions in an early stage of palliative care for older people with severe illnesses might be difficult from the viewpoint of enabling at-homeness for older people living in their ordinary homes who then need to move to a nursing home. The results show that it might take some time to experience at-homeness after moving into a nursing home and older people might need to come to terms with the changes that the move has incurred. In addition, older people are often very ill and struggle with functional decline when they move into a nursing home and most of them will die shortly after (Smedbäck et al., 2017).

Dekkers (2009) has stated that people who are receiving palliative care experience being at-home in their ordinary homes and people who have been taken into an institution, such as a nursing home, to receive care should return to their ordinary homes as soon as possible. However, as we know, it is not always possible or the older people themselves do not always want to move back to their ordinary homes. Dekkers (2009) also continues that the modern hospice movement in Britain has been linked with home care and this could be one solution for the big change that moving from one's ordinary home to a nursing home involves. This is confirmed by the results from this project that show that when older people were forced to move from their ordinary home to a nursing home they were not familiar experiences of homelessness were evoked for some of the older people. If older people who are receiving home care could already be linked to a nursing home, similar to that of British hospice care, the move from the ordinary home could be organized step by step and hopefully, when the older person wishes to move or no longer has the possibility to stay in their ordinary home, the change will be less dramatic because the older people already know the nursing home and the nursing staff. This could mean the nursing home is experienced as familiar in a shorter time which, hopefully, could also enable older people to experience at-homeness more quickly. This would be of importance particularly in light of the results of this thesis that also found that time influences how familiar older people felt in relation to place. Letting time pass influenced how at-homeness was shaped and it is this process that could become shorter if the place and people were familiar to the older people when they moved permanently into a nursing home.

Before the care of older people who are severely ill and facing impending death can be organized as desired and proposed, there are issues that need to be solved. There are severe problems in the ability of municipalities to fulfill their responsibility to arrange nursing home placements for older people who are in need of them. It has been shown that many older people who have applied to move into a nursing home need to wait before a place becomes available, which may in some cases take several months depending on the municipality in Sweden. (National Board of Health and Welfare, 2016). To have to wait for a place in a nursing home when it is needed could be a difficult time for older people, who might experience feelings of insecurity, since they don't know when they will move and where they will move to. In addition, there would be an increased need of help by home care staff and significant others, which could increase older peoples' experiences of homelessness. In a report on the future demands for older peoples' care, an increased need for individual housing with support has been highlighted. This is housing that can be offered between a person's ordinary home and a nursing home that could solve the future increased needs of older people who are still able to live independently to some degree and have only small functional limitations in managing their everyday life (The Swedish Agency for Health and Care Services Analysis, 2015). However this kind of housing is, in many cases, a planning stage and would not affect the fact that older people still might need to move again from individual housing with support to a nursing home and experience yet another change that could lead to homelessness. One solution is that sheltered housing and nursing homes could be built as single units in the same building and with the same nursing staff, which could help the process when the older people need move into the nursing home.

At-homeness and enabling at-homeness for older people could enrich the Swedish approach to palliative care. In recent years there have been developments in this field both with policy documents such as "*A national knowledge-based guidance for end of life palliative care*" (NBHW, 2013) and the Care model for palliative care with a person-centered approach (6S:n) (Ternstedt, Österlind, Henoch, Andershed, Aceby, 2012). The Care model for person-centered palliative care considers concepts such as self-image, self-determination, social relationships, symptom relief and contexture (Ternstedt, Österlind, Henoch, Andershed, Aceby, 2012). Several of these concepts could also be used to understand at-homeness, however there has been some criticism of person-centeredness, in general relating to older people's care. This is because there is a risk of objectification of the patients and where values such as individualism and independency could turn into barriers preventing nursing staff from being able to focus on the older people's experiences; relationship-centered care could instead overcome the obstacles that person-centered care might have (Nolan, Davies, Brown, Keady, & Nolan, 2004). Similarly, nurturing comforting relationships as a strategy to enable at-homeness could enrich the person-centered palliative care.

This project did not study to any large extent how older people's experience of at-homeness were influenced by their significant others and neither have existential issues been studied. However, these two aspects might be of great importance for older people's at-homeness and provide more knowledge for how nursing staff might enable at-homeness for older people

who are severely ill and facing impending death. In the WHO:s (2002) Statement on palliative care, these two aspects have been regarded as crucial in the care of patients at the end of life, and these aspects might also be of importance when giving care with a palliative approach to older people. There is a need for future research on how significant others influence at-homeness and also on existential issues and how these are shaped in relation to at-homeness and how nursing staff enable at-homeness. Also needed is further development and research concerning the process of how older people might become to terms with life changes at the end of their life in relation to at-homeness and the way at-homeness is shaped. Examples of this are how at-homeness could be enabled for older people who are just about to move or have moved into a nursing home, how bodily and mental changes influence at-homeness and how nursing staff could more specifically enable at-homeness.

From the results of this thesis, relational aspects seem to be significant for how at-homeness is enabled by nursing staff and the next phase could therefore be further development of how at-homeness could be enabled in a care relationship. For example, it would be useful to test which strategies would be suitable for further development for enabling at-homeness at the end of older people's lives. With evidence for suitable strategies, it might be favorable to implement these as part of a palliative care approach in nursing homes. However, in a recently published study on the readiness of nursing homes to implement palliative care, individual and organizational challenges were regarded as presenting difficulties in succeeding with the implementation of palliative care in nursing homes (Nilsen, Wallerstedt, Behm, & Ahlström, 2018). This shows the need for further development of palliative care in nursing homes, and that implementation strategies of at-homeness as part of a palliative care approach could face similar challenges. This is important to take into consideration if and when further studies on at-homeness and possible implementation projects in this area are planned.

7.2 METHODOLOGICAL CONSIDERATIONS

This thesis is based on four qualitative studies using an interpretive description design as described by Thorne (2016). Quality considerations regarding methodological aspects such as enhancing credibility, epistemological integrity, representative credibility, analytic logic, interpretive authority, moral defensibility and disciplinary relevance (Thorne, 2016) will be discussed in relation to this research project.

Epistemological integrity means that the whole research project, from assumptions to whole research project, is in line with the chosen epistemology. This was ensured by following the design of interpretive description (Thorne, 2016) where all the research steps, from the planning phase, the aim of data generation and the analyses, were continuously checked against the design. Further, epistemological integrity means that the decisions are in line with the ground assumption through the whole research process, which was taken into account in studies I and II through the phenomenological hermeneutical method (Lindseth & Norberg,

2004), and followed the method step by step from the narrative interviews to the analytical phases.

The question of how well the phenomenological hermeneutical method suits the design of interpretive description could be argued as follows. This whole research project was about exploring knowledge of how at-homeness could be enabled for older people who are at the end of their lives; this is in line with the purpose of the design of interpretive description, which is to seek knowledge from practice and develop practice. This fits well with study III which investigated the group reflections of nursing home staff and study IV which focused on nursing care situations involving nursing home staff and older people. However, the first two studies were narrative interviews with older people at the end of life. These interviews were regarded partly as practice-oriented, since the interviews were the starting point for conceptual clarity and thus an important foundation for further practice development, and partly as a means to understand the phenomenon of at-homeness, which was needed in order to progress with the questions concerning how at-homeness could be enabled. The design of interpretive description has been inspired by building upon and furthering qualitative methodologies such as ethnography, phenomenology and grounded theory.

Representative credibility, according to Thorne (2016), is about how theoretical issues are followed at all stages of the research project and maximal variation in sampling principles is one way to understand representative credibility. This was assured in studies I and II through focusing on variation of the participants with regard to age, gender, country of birth and type of housing. The diversity of participants in studies I and II was seen as a strength for representative credibility, since this gave the possibility to study a variety of experiences of at-homeness that are, hopefully, of relevance for older people who are at the end of life in Western/Northern countries. Another strength of the narrative interviews was that the interviews were conducted in Swedish and a couple of them in Finnish, which enabled the older people who had immigrated to Sweden from Finland to speak their native language. In this way their narrations were possibly richer than they might have otherwise been, since Swedish was not their native language.

In study III, representative credibility was ensured through the relationships that were created between the nursing staff and the moderator, which supported the nursing staff by providing a positive atmosphere in which they could express themselves. However, on one occasion, only two members of the nursing staff participated and the discussion did not flow. The moderator tried to encourage the discussion by going back to earlier occasions, which may affect the credibility of the study. There were also other occasions when only two participants were able to take part in the study. Although only nursing staff from one unit were included in study III, the nursing staff had varied backgrounds regarding age, gender, education level and country of birth, which could enhance the representative credibility.

One limitation related to the study's representative credibility could be that only two nursing home units (IV) were included in the participant observation study. However, when studying older people with severe illnesses and at the end of life there is a need to create relationships

with the participants so that they experience a sense of security in the participant observation situations. This may, therefore, have influenced participation in the study and what the researcher was able to observe.

Analytic logic was ensured by keeping the aims of the study clear from the planning phase through the data-gathering period in all four studies, as well as holding critical discussions with the members of the project group during the whole project period. However, more specific analytic logic was followed in the data gathering in order to obtain data that could be analyzed according to the techniques that were planned to be used. In the analytical phase of all four studies, the interpretations were tested by working through the research material several times, through discussions within the project group, and in research seminars with other research colleagues where critical discussions ensured that the analyses had been logical. Thorne (2016) also claims that analytic logic can be made visible by describing the studied context and thus helping the reader to make sense of the interpretations that have been made, which could have been described more clearly in the two first studies with narrative interviews and phenomenological hermeneutical interpretation. In studies III and IV, efforts have been made to describe the studied context in more detail.

Interpretive authority relates to the trustworthiness of interpretations (Thorne, 2016), which in this project was supported by using quotes and field notes to provide transparency of the interpretations of the researched material in each study. In all the studies, efforts have been made to be as open as possible to several interpretations and to continue to be open throughout the whole interpretation process. In addition, critical discussions about the interpretations were regularly held in the research group and in specific research seminars related to the project.

Moral defensibility should, according to Thorne (2016), be described to show that the research conducted in the project is necessary for the applied field and practice. This project will contribute significant knowledge regarding the older people's reality in relation to at-homeness and ways to enable at-homeness that could be implemented by nurses in their everyday practice with older people who are severely ill and at the end of life. Variation was seen in how older people experience the meaning of at-homeness and how at-homeness is shaped, and being aware of these variations may help nursing staff to work from the understanding of what at-homeness for the older people could be and how to enable it. The strategies for how at-homeness could be enabled could also help nursing staff in their everyday work. The results from the studies in this thesis could be transferable, at least to contexts similar to those where the studies were performed.

Disciplinary relevance, according to Thorne (2016), means that knowledge that is generated should be relevant to the knowledge area of a discipline, which in the field of nursing is the knowledge area involving issues of health and illness. Knowledge from research on older people's at-homeness and how to enable at-homeness lies in the area of palliative care and well-being, which can be regarded as being in line with the knowledge area of nursing.

8 CONCLUSIONS AND IMPLICATIONS

The experience of at-homeness-homelessness among older people with severe illness and/or who are facing impending death is an individual process, where the direction of the experience could change depending on the events that have happened or are happening in the older person's life. These events, together with older people's thoughts about their past, present and future as well as time, letting time pass, place and other people, all influence the experience. Older people may be living with loss and change, which could be related to their body, significant others and living space, which could also influence older people's experience of homelessness. Beyond coming to terms with life changes, other aspects that were regarded as relating to the older people's experiences of at-homeness were safety, agency and communion.

How nursing staff enable at-homeness is complex, hence strategies that enable at-homeness could influence more than one aspect of at-homeness and these aspects may be interrelated. However, nursing staff enable at-homeness mainly in the care relationship, which is why relationships-centered care could be a fruitful way to develop at-homeness. It also seems that at-homeness is related to ordinariness in a care relationship and that strategies that enable at-homeness occur in older people's everyday life. Since at-homeness is enabled in a care relationship between nursing staff and older people, the care culture also plays a role in how older people experience at-homeness.

At-homeness as a goal for palliative care, as proposed by Dekkers, (2009), could enhance older people's well-being at their end of life. A palliative care approach could, therefore, be used in nursing homes together with strategies for enabling at-homeness, giving the possibility for nursing staff to work with these strategies in older people's end of life. At-homeness could therefore be a goal for nursing staff who care for older people using a palliative care approach.

Older people with severe illness and impending death are often living longer in their ordinary homes before moving into a nursing home. It seems that the limited time they then have living in a nursing home may not support the possibility for the older people to experience at-homeness in a new place, since it might take some time for them to come to terms with the change. There is, therefore, the possibility that older people do not have enough time to become at-home before their death. The transition from the older people's ordinary homes to nursing homes should be given more focus and strategies should be developed that enable older people's at-homeness.

9 FUTURE RESEARCH

Since at-homeness and strategies for how to enable at-homeness so far have been explored to such a limited extent, there are several areas that warrant future research:

- Deepen the understanding of the strategies, explore whether there are additional strategies and research how these strategies could best enable at-homeness.
- Explore how these strategies could enable at-homeness in similar contexts and clarify the interrelating aspects and strategies.
- Research studies are required concerning the meaning of at-homeness and strategies for enabling at-homeness in other groups who are at-the end of life.
- Aspects such as existential issues and the importance of having close relationships with significant others need further research.
- Develop a questionnaire which can be used to explore what at-homeness means for older people with severe illness and/or who are facing impending death and how nursing staff could enable at-homeness.
- Further exploration of at-homeness as a part of a palliative care approach.
- Develop strategies for how municipalities and organisations could enable at-homeness for older people who are moving from their ordinary homes to nursing homes.

10 SVENSK SAMMANFATTNING/ SUMMARY IN SWEDISH

Hemmastaddhet kan beskrivas som ett metaforiskt begrepp och liknas med välbefinnande. Det kan upplevas trots närvaro av en allvarlig sjukdom och fram till livets slut. Det finns begränsad forskning kring hur äldre människor med allvarliga sjukdomar upplever hemmastaddhet och hur vårdpersonalen kan möjliggöra äldre människornas upplevelse av hemmastaddhet. Det övergripande syftet med avhandlingsprojektet var att beskriva hemmastaddhet som fenomen hos äldre människor med allvarlig sjukdom och med döden nära förestående samt hur hemmastaddhet kan möjliggöras för denna grupp av människor.

Avhandlingen har en design av tolkande beskrivning (Interpretive description) och består av fyra delstudier. Data generationen bestod av individuella narrativa intervjuer med äldre personer som var allvarligt sjuka och/eller befann sig nära döden, som var bosatta i sina ordinarie hem och vård -och omsorgsboende (I, II). Data generationen för studie III baserades på sju reflekterande gruppdiskussioner med vårdpersonalen på en vård -och omsorgsboende (III) och studie IV:s data generation baserades på deltagande observationer och riktade intervjuer (IV) med både äldre personer som vårdades på vård -och omsorgsboenden och vårdpersonal från boenden. Analyserna av studierna genomfördes genom fenomenologisk hermeneutisk tolkning (I, II) och konstant komparativ teknik (III, IV).

Syftet med studie I var att belysa innebörden av hemmastaddhet bland äldre människor med allvarlig sjukdom och/eller som befann sig i livets slutskede. De resulterade i två huvudteman; *att vara sig själv* och *att vara i kontakt*. Syftet med studie II var att belysa hur upplevelser av rumslighet och tidighet formade hemmastaddhet bland äldre människor med allvarlig sjukdom och/eller som befann sig i livets slutskede. Studien resulterade två teman; *forma hemmastaddhet genom att förlita sig på en välbekant plats* och *forma hemmastaddhet genom kontinuerlig balansering mellan förflutna, nutid och framtid*. Syftet med studien III var att utforska vårdpersonalens erfarenheter av hur hemmastaddhet möjliggjordes hos äldre personer som bodde på en vård -och omsorgsboende. Studien resulterade i fem mönster; *försöka lära känna den boende, visa respekt för de äldre människornas integritet, skapa och arbeta i familjeliknande relationer vilket innebar att vårdpersonal aktiverade sig genom att vara i nära relationer. Hjälpa till att hitta en ny vardaglighet samt förbereda och planera för att säkerställa kontinuitet för de äldre människorna*. Syftet med studien IV var att undersöka hur omvårdnadspersonal möjliggjorde hemmastaddhet för äldre människor i livets slutskede på vård- och omsorgsboende och det resulterade i fem strategier; *att vårdpersonalen presenterar sig som tillförlitliga, respekterar de äldre personernas integritet, att vara lyhörda till de äldre personernas behov, samarbeta med de äldre personerna kring deras beslutsfattande och genom att ha vårdande tröstande relationer*.

Hur äldre människor med allvarliga sjukdomar och som befinner sig i livets slutskede erfar hemmastaddhet handlar om deras egna processer i livet och hur de hanterar situationen efter förändringar i livet, tillsammans med hur vårdpersonalen möjliggör de äldre människornas hemmastaddhet. Möjliggörandet av hemmastaddhet sker i vårdrelationen där en relations-

centrerad process kan stödja möjliggörandet av hemmastaddhet ända fram till de äldre personernas död. Hemmastaddhet som mål för palliativ vård skulle också kunna berika det palliativa förhållningssättet hos äldre som befinner sig i livets slutskede.

Nyckelord: berättande intervjuer, deltagande observationer, fenomenologisk hermeneutisk tolkning, hem, interpretive description, konstant komparativ teknik, reflekterande gruppdiskussioner, vård -och omsorgsboende, vårdpersonal, äldre personer.

11 AKNOWLEDGEMENTS

Det har varit många på den här resan som jag innerligt vill tacka, ända från det att jag drömde om att bli doktorand till att jag nu är på målsträcket att bli klar med mina doktorandstudier. Speciellt vill jag rikta min tacksamhet mot:

Alla äldre människor och vårdpersonal som så generöst deltog i studien och delade med sig av sina berättelser och reflektioner samt lät mig vara en del av er vardag under en liten period. Utan er hade inte denna avhandling blivit av!

Sektionen för omvårdnad, institutionen för neurobiologi, vårdvetenskap och samhälle, vid Karolinska Institutet. Tack för möjligheten att kunna delta på er excellenta doktorandutbildning.

Palliativa forskningscentrum vid Ersta Sköndal Bräcke högskola. Tack för en uppmuntrande och kreativ arbetsmiljö.

Familjen Erling-Perssons Stiftelse för finansieringen av mina doktorandstudier vid Ersta Sköndal Bräcke högskola.

Min huvudhandledare, professor Joakim Öhlén. Tack för att du trott på mig och min förmåga att klara av doktorandstudierna och som generöst har introducerad och delat med dig av dina kunskaper inom forskningsområdet. Jag har uppskattat att du låtit mig ha min egen arbetsprocess men samtidigt har du alltid varit redo att hjälpa och handleda mig.

Min bihandledare, docent Anne-Marie Boström. Tack för givande diskussioner, uppmuntrande ord och för dina kunskaper inom forskningsområdet.

Min bihandledare, professor, Petter Gustavsson. Tack för givande diskussioner och för att du bidragit och utmanat mig till att se nya perspektiv i forskningen.

Min bihandledare, medicine doktor, Ragnhild Hedman. Tack för givande diskussioner, praktisk hjälp i slutfasen samt för ditt kunnande inom forskningsområdet.

Min mentor, docent Anne-Cathrine Mattiasson. Tack för allt generöst stöd och uppmuntran som jag fått av dig genom alla dessa år och för att du alltid har funnits och stöttat mig både inom forskningen och inom det privata.

Kollegorna vid sektionen för omvårdnad vid Karolinska institutet. Tack för all uppmuntran och stöd igenom alla dessa år.

Kollegorna på palliativa forskningscentrum vid Ersta Sköndal Bräcke högskola. Trots att jag har kommit och gått sporadiskt de sista åren, har jag alltid känt mig välkommen och ni har fått mig känna mig som en del av gruppen. Speciellt tack till professor Britt-Marie Ternestedt för all uppmuntran och kunskap om det vetenskapliga området och tack till doktorandkollegorna som jag påbörjade doktorandutbildningen ihop med; Tina Lundberg, Maja Holm, Susanne Lind och Viktoria Wallin.

Och ett varmt tack till mina vänner och familj...

Paula Gröhn, min vän som jag åkte över havet till Stockholm tillsammans med. Det är precis 17 år sedan vi strandade på vikingterminalen i Stockholm och startade våra karriärer som nyfärdiga sjuksköterskor i Stockholm. Du har blivit en vän som funnits vid min sida genom alla år oavsett vilken väg livet har tagit.

Jessica Holmgren, min vän och doktorandförebild. Tack för all den stöttning som du givit mig i alla dessa år! Tack för ditt unika sätt att mötas med ärlighet, klokhet och stor uppmuntran vad diskussioner än har handlat om.

Tack till alla mina vänner i Älta, mitt hem och andra familj, som jag ständigt längtar tillbaka till. Utan ert stöd och uppmuntran hade det inte varit möjligt för mig att påbörja och genomföra mina doktorandstudier. Speciellt tack Liza och Janne Jansson för den omsorgen som ni givit mig och tack för att ni så generöst lät mig sova hos er efter att jag flyttade från Älta. Tack till Helena och Peo Bengtsson, som troget funnits i mitt liv, stöttat mig och ryckt in och hjälpt till med både små och stora saker. Tack till Ulrika Tasev, som funnits för mig, lyssnat och stöttat. Tack till Kristina Sarkisian, som bjudit hem mig till god mat, erbjudit sovplats och många samtal med nya vinklar och härliga skratt! Tack Malin Brandefalk och Lena Pilheden, för att ni har varit medsyststrar i livets med- och motgångar.

Tack Maria, Malin och Jenny Huttu för all hjälp under dessa år. Tack för att ni troget tagit hand om våra barn när det har krisat och tack för alla trevliga stunder när vi har umgåtts, allt från svampplockning till resor. Tack Malin för granskningen av kappan. Tack till mina svärföräldrar, Reetta-Liisa och Aaro Huttu, för att ni vecka efter vecka har kommit hem till oss med hemlagad mat och hemmagjorda pannkakor. Allt detta har många gånger räddat oss från ett middagskaos.

Min familj i Finland, min syster Outi och systerdotter Anna. Tack för allt stöd och uppmuntran på vägen. Tack för att ni funnits där för mig när jag behövt någon att prata med. Jag känner att ni har stöttat mig många gånger under dessa år. Tack min mamma, Hanne, som alltid uppmuntrat mig, funnits där och lyssnat och låtit mig välja min egen väg.

Tack Peter, min man, för att du stått ut med mig och mina doktorandstudier. Vi träffades när jag precis hade blivit inskriven som doktorand och vi har hunnit med mycket sedan dess; flytta, gifta oss och skaffa barn. Jag vill speciellt tacka dig för att du så tålmodigt tagit hand om barnen och hållit allt flytande när jag behövt fokusera på avhandlingen. Tack våra barn, Molly, Felicia och Tyra. Ni fyllde ett tomrum i mitt liv som jag så länge hade saknat. Nu ser jag framemot att få spendera mera tid till att umgås med er och hitta på roliga saker att göra ihop.

Till min pappa, Timo, som trots all sjukdom, kanske var min främsta supporter. Jag upplevde att du var stolt över det jag hade lyckats med i livet och vad jag var på väg att bli. Jag är ledsen att du inte hann se mig bli klar med avhandlingen, denna stund hade jag så gärna velat dela med dig.

12 REFERENCES

- Andersson, M., Hallberg, I. R., & Edberg, A. (2008). Old people receiving municipal care, their experiences of what constitutes a good life in the last phase of life: a qualitative study. *International Journal of Nursing Studies*, 45(6), 818-828. doi:10.1016/j.ijnurstu.2007.04.003
- Baltes, P. B., & Smith, J. (2003). New frontiers in the future of aging: From successful aging of the young old to the dilemmas of the fourth age. *Gerontology*, 49(2), 123-135. doi: 10.1159/000067946
- Barclay, S., Froggatt, K., Crang, C., Mathie, E., Handley, M., Iliffe, S., . . . Goodman, C. (2014). Living in uncertain times: trajectories to death in residential care homes. *British Journal of General Practice*, 64(626), E576-E583. doi: 10.3399/bjgp14X681397
- Beck, I., Törnquist, A., Broström, L., & Edberg, A-K. (2012). Having to focus on doing rather than being—Nurse assistants' experience of palliative care in municipal residential care settings. *International Journal of Nursing Studies*, 49(4), 455-464. doi: 10.1016/j.ijnurstu.2011.10.016
- Bengtsson, J. (1993). Theory and Practice -2 fundamental categories in the philosophy of teacher-education. *Educational Review*, 45(3), 205-211. doi: 10.1080/0013191930450302
- Bengtsson, J. (1995). What is Reflection? On reflection in the teaching profession and teacher education. *Teachers and Teaching*, 1(1), 23-32. doi: 10.1080/1354060950010103
- Clark, D. (2007). From margins to centre: a review of the history of palliative care in cancer. *Lancet Oncology*, 8(5), 430-438. doi: 10.1016/s1470-2045(07)70138-9
- Clark, D., & Seymour, J. (1999). *Reflections on palliative care*. Philadelphia: Open University Press
- Cohen, D. J. & Deliéns, L. (2012). *Applying a public health perspective on end of life care*, In Cohen J. & Deliéns L. (eds). *A public health perspective on end of life care*. New York Oxford University press
- Covinsky, K. E., Eng, C., Lui, L. Y., Sands, L. P., & Yaffe, K. (2003). The last 2 years of life: functional trajectories of frail older people. *Journal of the American Geriatrics Society*, 51(4), 492-498. doi: 10.1046/j.1532-5415.2003.51157.x
- Dahlberg, K., Todres, L., & Galvin, K. (2009). Lifeworld-led healthcare is more than patient-led care: an existential view of well-being. *Medicine, Health Care and Philosophy*, 12(3), 265-271. doi: 10.1007/s11019-008-9174-7
- Dewar, B., & Kennedy, C. (2016). Strategies for Enhancing “Person Knowledge” in an Older People Care Setting. *Western Journal of Nursing Research*, 38(11), 1469-1488. doi: 10.1177/0193945916641939
- Dewar, B., & Nolan, M. (2013). Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, 50(9), 1247-1258. doi: 10.1016/j.ijnurstu.2013.01.008

- Dwyer, L. L., Andershed, B., Nordenfelt, L., & Ternestedt, B. M. (2009). Dignity as experienced by nursing home staff. *International Journal of Older People Nursing*, 4(3), 185-193. doi: 10.1111/j.1748-3743.2008.00153.x
- Dwyer, L., Nordenfelt, L., & Ternestedt, B. (2008). Three nursing home residents speak about meaning at the end of life. *Nursing Ethics*, 15(1), 97-109. doi: 10.1177/0969733007083938
- EAPC (2009). White paper on standards and norms for hospice and palliative care in Europe. Part I Recommendations from the European Association for Palliative Care. *European Journal of Palliative Care* 1, 278-289.
- Edvardsson, D. (2008). Therapeutic environments for older adults - Constituents and meanings. *Journal of Gerontological Nursing*, 34(6), 32-40. doi:10.3928/00989134-20080601-05
- Ekman, I., Skott, C., & Norberg, A. (2001). A place of ones' own. The meaning of lived experience as narrated by an elderly woman with severe chronic heart failure. A case-study. *Scandinavian Journal of Caring Sciences*, 15(1), 60-65. doi: 10.1046/j.1471-6712.2001.1510060.x
- Eldh, AC., van der Zijpp, T., McMullan, C, McCormack, B., Seers, K., & Rycroft-Malone, J. (2016). 'I have the world's best job' – staff experience of the advantages of caring for older people. *Scandinavian Journal of Caring Sciences*, 30(2), 365-373. doi: 10.1111/scs.12256
- Eriksson, K. (1984). *Hälsans idé. [In English;The Idea of Health]*. Stockholm: Almqvist & Wiksell
- Erikson, E. & Erikson, J. (1998). *The Life Cycle Completed (Extended Version)* New York: W.W. Norton & Company, Inc.
- Estabrooks, C. A., Hoben, Matthias, P., Jeffrey W., Chamberlain, S. A., Thompson, Genevieve N., Silviu, James L., & Norton, Peter G. (2015). Dying in a Nursing Home: Treatable Symptom Burden and its Link to Modifiable Features of Work Context. *Journal of the American Medical Directors Association*, 16(6), 515-520. doi: <http://dx.doi.org/10.1016/j.jamda.2015.02.007>
- Fleming, J., Calloway, R., Perrels, A., Farquhar, M., Barclay, S., & Brayne, C. (2017). Dying comfortably in very old age with or without dementia in different care settings – a representative “older old” population study. *BMC Geriatrics*, 17(1), 222. doi: 10.1186/s12877-017-0605-2
- Fryer, S., Bellamy, G., Morgan, T., & Gott, M. (2016). “Sometimes I’ve gone home feeling that my voice hasn’t been heard”: a focus group study exploring the views and experiences of health care assistants when caring for dying residents. *BMC Palliative Care*, 15(1), 78. doi: 10.1186/s12904-016-0150-3
- Galvin, K.T, & Todres, L. (2011). Kinds of well-being: A conceptual framework that provides direction for caring. *International Journal of Qualitative Studies on Health and Well-being*, 6(4), 10362. doi: 10.3402/qhw.v6i4.10362

- Gobbens, R. J., Luijkx, K. G., Wijnen-Sponselee, M. T., & Schols, J. M. (2010). Toward a conceptual definition of frail community dwelling older people. *Nursing Outlook*, 58(2), 76-86. doi: 10.1016/j.outlook.2009.09.005
- Goddard, C., Stewart, F., Thompson, G., & Hall, S. (2013). Providing End-of-Life Care in Care Homes for Older People: A Qualitative Study of the Views of Care Home Staff and Community Nurses. *Journal of Applied Gerontology*, 32(1), 76-95. doi: 10.1177/0733464811405047
- Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care*, 12, 7. doi: 10.1186/1472-684x-12-7
- Graneheim, U. H., & Lundman, B. (2010). Experiences of loneliness among the very old: The Umea 85+project. *Aging & Mental Health*, 14(4), 433-438. doi: 10.1080/13607860903586078
- Hallberg, I. R. (2004). Death and dying from old people's point of view. A literature review. *Aging Clinical and Experimental Research*, 16(2), 87-103. Doi: 10.1007/BF03324537
- Harnett, T. (2010). *The Trivial Matters. Everyday power in Swedish eldercare*. Dissertation Series. School of Health Sciences. Jönköping. Intellecta Infolog.
- HAS, The French National Authority for Health (2016). *Organisation of pathways, Essentials of the palliative approach*. Retrieved 12 december 2017 from https://www.hassante.fr/portail/upload/docs/application/pdf/201709/organisation_of_pathways_-_essentials_of_the_palliative_approach.pdf
- Hewko, S. J., Cooper, S. L., Huynh, H., Spiwek, T. L., Carleton, H. L., Reid, S., & Cummings, G. G. (2015). Invisible no more: a scoping review of the health care aide workforce literature. *BMC Nursing*, 14, 38. doi: 10.1186/s12912-015-0090-x
- Houttekier, D., Cohen, J., Bilsen, J., Addington-Hall, J., Onwuteaka-Philipsen, B. D., & Deliens, L. (2010). Place of death of older persons with dementia. A study in five European countries. *Journal of Applied Gerontology*, 58(4), 751-756. doi: 10.1111/j.1532-5415.2010.02771.x
- Hunt, K. J., Shlomo, N., & Addington-Hall, J. (2014). End-of-Life Care and Preferences for Place of Death among the Oldest Old: Results of a Population-Based Survey Using VOICES-Short Form. *Journal of Palliative Medicine*, 17(2), 176-182. doi: 10.1089/jpm.2013.0385
- Håkanson, C., Öhlén, J., Morin, L., & Cohen, J. (2015). A population-level study of place of death and associated factors in Sweden. *Scandinavian Journal of Public Health*, 43(7), 744-751. doi: 10.1177/1403494815595774
- Josefsson, K., & Hansson, M. (2011). To lead and to be led in municipal elderly care in Sweden as perceived by registered nurses. *Journal of Nursing Management*, 19(4), 498-506. doi: 10.1111/j.1365-2834.2011.01228.x

- Karlsson, I., Ekman, S-L., & Fagerberg, I. (2008). To both be like a captain and fellow worker of the caring team: the meaning of Nurse Assistants' expectations of Registered Nurses in Swedish residential care homes. *International Journal of Older People Nursing*, 3(1), 35-45. doi: 10.1111/j.1748-3743.2007.00084.x
- Karlsson, I., Ekman, S. L., & Fagerberg, I. (2009). A difficult mission to work as a nurse in a residential care home--some registered nurses' experiences of their work situation. *Scandinavian Journal of Caring Sciences*, 23(2), 265-273. doi: 10.1111/j.1471-6712.2008.00616.x
- Kitson, A. L., Athlin, A. M., Conroy, T., & Int Learning, Collaborative. (2014). Anything but Basic: Nursing's Challenge in Meeting Patients' Fundamental Care Needs. *Journal of Nursing Scholarship*, 46(5), 331-339. doi: 10.1111/jnu.12081
- Kitson, A., Conroy, T., Wengstrom, Y., Profetto-McGrath, J., & Robertson-Malt, S. (2010). Scholarly Paper: Defining the fundamentals of care. *International Journal of Nursing Practice*, 16(4), 423-434. doi: 10.1111/j.1440-172X.2010.01861.x
- Klindtworth, K., Oster, P., Hager, K., Krause, O., Bleidorn, J., & Schneider, N. (2015). Living with and dying from advanced heart failure: understanding the needs of older patients at the end of life. *BMC Geriatrics*, 15(1), 125. doi: 10.1186/s12877-015-0124-y
- Krishnan, P. (2017). Concept analysis of good death in long term care residents. *International Journal of Palliative Nursing*, 23(1), 29-34. doi: 10.12968/ijpn.2017.23.1.29
- Larsson, K. (2006). Care needs and home-help services for older people in sweden: does improved functioning account for the recution in public care? *Ageing & Society*, 26(03), 413-429. doi:10.1017/S0144686X05004496
- Laslett, P. (1989). *A Fresh Map of Life: The Emergence of the Third Age*: London: Weidenfeld and Nicolson
- LeBlanc, T. W., Wheeler, J. L., & Abernethy, A. P. (2010). Research in End-of-Life Settings: An Ethical Inquiry. *Journal of Pain & Palliative Care Pharmacotherapy*, 24(3), 244-250. doi: 10.3109/15360288.2010.493579
- Lekan, D. (2009). Frailty and other emerging concepts in care of the aged. *Southern Online Journal of Nursing Research*, 9(3), 15p-15p.
- Liang, J., & Luo, B. (2012). Toward a discourse shift in social gerontology: From successful aging to harmonious aging. *Journal of Aging Studies*, 26(3), 327-334. doi: <https://doi.org/10.1016/j.jaging.2012.03.001>
- Lindseth, A., & Norberg, A. (2004). A phenomenological hermeneutical method for researching lived experience. *Scandinavian Journal of Caring Sciences*, 18(2), 145-153. doi: 10.1111/j.1471-6712.2004.00258.x
- Franklin, L-L., Ternstedt B-R., & Nordenfelt. L. (2006). Views on Dignity of Elderly Nursing Home Residents. *Nursing Ethics*, 13(2), 130-146. doi: 10.1191/0969733006ne851oa

- Lloyd-Williams, M., Kennedy, V., Sixsmith, A., & Sixsmith, J. (2007). The end of life: a qualitative study of the perceptions of people over the age of 80 on issues surrounding death and dying. *Journal of Pain and Symptom Management*, 34(1), 60-66. doi: 10.1016/j.jpainsymman.2006.09.028
- Lloyd, A., Kendall, M., Carduff, E., Cavers, D., Kimbell, B., & Murray, S. A. (2016). Why do older people get less palliative care than younger people? *European Journal of Palliative Care*, 23(3), 132-137.
- Luta, X., Panczak, R., Maessen, M., Egger, M., Goodman, D. C., Zwahlen, M., . . . Clough - Gorr, K. (2016). Dying among older adults in Switzerland: who dies in hospital, who dies in a nursing home? *BMC Palliative Care*, 15(1), 83. doi: 10.1186/s12904-016-0156-x
- Moloney, M. F. (1997). The meanings of home in the stories of older women. *Western Journal of Nursig Research*, 19(2), 166-176. doi:10.1177/019394599701900203
- Molony, S. L. (2010). The Meaning of Home: A Qualitative Metasynthesis. *Research in Gerontological Nursing*, 3(4), 291-307. doi: 10.3928/19404921-20100302-02
- Molony, S. L., Evans, L. K., Jeon, S., Rabig, J., & Straka, L. A. (2011). Trajectories of At-Homeness and Health in Usual Care and Small House Nursing Homes. *Gerontologist*, 51(4), 504-515. doi: 10.1093/geront/gnr022
- Mulhall, A. (2003). In the field: notes on observation in qualitative research. *Journal of Advanced Nursing*, 41(3), 306-313. doi: 10.1046/j.1365-2648.2003.02514.x
- National Board of Health and Welfare (2002) *Särskilt boende för äldre under kortare tid*. [In English; *Short-term residential care facilities for older people*]. Stockholm: Socialstyrelsen
- National Board of Health and Welfare (2006) *Vård i livets slutskede. Socialstyrelsens bedömningar av utveckling i landsting och kommuner*. [In English; *Care at the end of life. An assessment by the Swedish National Board of Health and Welfare concerning the developments that have been made by county councils and municipalities*]. Stockholm: Socialstyrelsen
- National Board of Health and Welfare (2013) *Nationellt kunskapsstöd för god palliativ vård i livets slutskede: vägledning, rekommendationer och indikationer: stöd för styrning och ledning*. [In English; *A national knowledge-based guidance for end of life palliative care*.] Västerås: Edita Västra Aros
- National Board of Health and Welfare (2016 A). *Vård och omsorg om äldre. Lägesrapport 2016*. [In English; *Care and Wellfare for older people. Situation report 2016*]. Västerås: Edita Bobergs AB
- National Board of Health and Welfare (2016 B). *Färre äldre bor i särskilt boende, faktablad*. [In English; *Fewer elderly people live in residential care facilities, fact sheet*]. Retrieved 29 November 2017 from <http://www.socialstyrelsen.se/nyheter/2016>

- National Board of Housing, Building and Planning & National Board of Health and Welfare (2003). *Varför kan inte behovet av särskilda boendeformer tillgodoses?* [In English; *Why can't the need for special types of residential care facilities be met?*]. Stockholm: Socialstyrelsen.
- Nicholson, C., Meyer, J., Flatley, M., Holman, C., & Lowton, K. (2012). Living on the margin: Understanding the experience of living and dying with frailty in old age. *Social Science & Medicine*, 75(8), 1426-1432. doi: <http://dx.doi.org/10.1016/j.socscimed.2012.06.011>
- Nielsen, K. T., & Glasdam, S. (2013). Professional caregivers' work with the dying in nursing homes--a Foucault-inspired analysis of discourses in the last decade in a Danish context. *Scandinavian Journal of Caring Sciences*, 27(4), 983-993. doi: 10.1111/scs.12021
- Nilsen, P., Wallerstedt, B., Behm, L., & Ahlström, G. (2018). Towards evidence-based palliative care in nursing homes in Sweden: a qualitative study informed by the organizational readiness to change theory. *Implementation Science*, 13(1), 1. doi: 10.1186/s13012-017-0699-0
- Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of Clinical Nursing*, 13, 45-53. doi: 10.1111/j.1365-2702.2004.00926.x
- Nordenfelt, L. (2006). The concepts of health and illness revisited. *Medicine, Health Care and Philosophy*, 10(1), 5. doi: 10.1007/s11019-006-9017-3
- Pal, L. M., & Manning, L. (2014). Palliative care for frail older people. *Clinical Medicine*, 14(3), 292-295. doi: 10.7861/clinmedicine.14-3-292
- Price, B. (2002). Laddered questions and qualitative data research interviews. *Journal of Advanced Nursing*, 37(3), 273-281. Doi: 10.1046/j.1365-2648.2002.02086.x
- Rasmussen, B. H., & Edvardsson, D. (2007). The influence of environment in palliative care: supporting or hindering experiences of 'at-homeness'. *Contemporary Nurse*, 27(1), 119-131. doi: 10.5555/conu.2007.27.1.119
- Rasmussen, B. H., Jansson, L., & Norberg, A. (2000). Striving for becoming at-home in the midst of dying. *American Journal of Hospice and Palliative Care*, 17(1), 31-43. doi: 10.1177/104990910001700109
- Riedl, M. (2011). Psychophysical and social changes in elderly people after the entry into a residential home - a systematic literature research. *Pflegewissenschaft*, 13(5), 299-311.
- Regional Co-operative Cancer Centers (2012). *Nationellt vårdprogram för palliativ vård 2012–2014* [in English, *National Clinical practice guidelines for palliative care 2012-2014*]. Västerås: Regionala cancercentrum i samverkan

- Reyniers, T., Deliéns, L., Pasman, H. R., Morin, L., Addington-Hall, J., Frova, L., . . . Houttekier, D. (2015). International variation in place of death of older people who died from dementia in 14 European and non-European countries. *Journal of the American Medical Directors Association, 16*(2), 165-171. doi: 10.1016/j.jamda.2014.11.003
- Ricoeur, P. (1981). *Hermeneutics and the human science: essays on language, action and interpretation*. Cambridge: Cambridge University Press.
- Riessman, C., K. (2008). *Narrative Methods for the Human Sciences*. California: Sage Publications
- Rijnaard, M. D., van Hoof, J., Janssen, B. M., Verbeek, H., Pocornie, W., Eijkelenboom, A., . . . Wouters, E. J. M. (2016). The Factors Influencing the Sense of Home in Nursing Homes: A Systematic Review from the Perspective of Residents. *Journal of Aging Research, 16*. doi: 10.1155/2016/6143645
- Ross, M. M., Fisher, R., & Maclean, M. J. (2000). End-of-life care for seniors: the development of a national guide. *Journal of Palliative Care, 16*(4), 47-53.
- Rowe, J.W., & Kahn, R. L. (1997). Successful Aging. *The Gerontologist, 37*(4), 433-440. doi: 10.1093/geront/37.4.433
- Rowe, J.W., & Kahn, R.L. (1987). Human aging: usual and successful. *Science, 237*(4811), 143-149. doi: 10.1126/science.3299702
- Rowles, G. D. & Bernard, M. (2013). *Environmental gerontology: making meaningful places in old age*. New York: Springer.
- Rozanova, J. (2010). Discourse of successful aging in The Globe & Mail: Insights from critical gerontology. *Journal of Aging Studies, 24*(4), 213-222. doi: <https://doi.org/10.1016/j.jaging.2010.05.001>
- Sarmiento, V. P., Higginson, I. J., Ferreira, P. L., & Gomes, B. (2016). Past trends and projections of hospital deaths to inform the integration of palliative care in one of the most ageing countries in the world. *Palliative Medicine, 30*(4), 363-373. doi: 10.1177/0269216315594974
- Sarvimäki, A. (2006). Well-being as being well - a Heideggerian look at well-being. *International Journal of Qualitative Studies on Health and Well-being, 1*(1), 4-10. doi: 10.1080/17482620500518101
- Saunders, C. (1965). The last stages of life. *The American Journal of Nursing, 65*, 70-75. doi:10.1093/acprof:oso/9780198570530.003.0014
- Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., . . . Stajduhar, K. (2016). Conceptual foundations of a palliative approach: a knowledge synthesis. *BMC Palliative Care, 15*, 5. doi: 10.1186/s12904-016-0076-9

- Schön, P., Lagergren, M., & Kareholt, I. (2016). Rapid decrease in length of stay in institutional care for older people in Sweden between 2006 and 2012: results from a population-based study. *Health & Social Care in the Community*, 24(5), 631-638. doi: 10.1111/hsc.12237
- Seymour, J. E., & Ingleton, C. (2005). Ethical issues in qualitative research at the end of life...article reprinted from *International Journal of Palliative Nursing* 1999 5(2):65-73. *International Journal of Palliative Nursing*, 11(3), 138-146. doi: 10.12968/ijpn.1999.5.2.9919
- Seymour, J., Witherspoon, R., Gott, M., Ross, H., Payne, S. and Owen, T. (2005). *End-of-life care: Promoting comfort, choice and well-being for older people*. Bristol: Policy Press in association with Help the Aged
- Sjöberg, M., Beck, I., Rasmussen, B. H., & Edberg, A. K. (2017). Being disconnected from life: meanings of existential loneliness as narrated by frail older people. *Aging & Mental Health*, 1-8. doi: 10.1080/13607863.2017.1348481
- Smedbäck, J., Öhlen, J., Årestedt, K., Alvariza, A., Furst, C. J., & Håkanson, C. (2017). Palliative care during the final week of life of older people in nursing homes: A register-based study. *Palliative & Supportive Care*, 1-8. doi: 10.1017/s1478951516000948
- SOU (2007:103). *Bo för att leva - seniorbostäder och trygghetsbostäder*. [In English; *Residences for living well - retirement homes and sheltered housing*]. Retrieved 8 December 2017 from <http://www.regeringen.se/49b6a9/contentassets/8f4016d8c21d408fbbd9584465d7ec24/bo-for-att-leva---seniorbostader-och-trygghetsbostader-sou-2007103>
- Statistics Sweden, (2006). *Äldres levnadsförhållanden, Arbete, ekonomi, hälsa och sociala nätverk 1980–2003* [In English; *Living Conditions of the elderly, Work, economy, Health and social networks 1980–2003*]. Stockholm: SBU, Statens beredning för medicinsk och social utvärdering
- Svenaesus, F. (2011). Illness as unhomelike being-in-the-world: Heidegger and the phenomenology of medicine. *Medicine, Health Care and Philosophy*, 14(3), 333-343. doi: 10.1007/s11019-010-9301-0
- Svenaesus, F. (2015). The phenomenology of chronic pain: embodiment and alienation. *Continental Philosophy Review*, 48(2), 107-122. doi: 10.1007/s11007-015-9325-5
- Taube, E., Jakobsson, U., Midlöv, P., & Kristensson, J. (2016). Being in a Bubble: the experience of loneliness among frail older people. *Journal of Advanced Nursing*, 72(3), 631-640. doi: 10.1111/jan.12853
- Taylor, B., J. (1994). *Being Human: Ordinariness in Nursing*. Melbourne: Churchill Livingstone.
- Ternstedt, B- M., & Franklin, L-L. (2006). Ways of relating to death: views of older people resident in nursing homes. *International Journal of Palliative Nursing*, 12(7), 334-340. doi: 10.12968/ijpn.2006.12.7.21611

- Ternstedt, B-M., Österlind, J., Henoch I., Andershed B., Aceby I. (2012). *De 6S:n; en modell för personcentrerad palliativ vård*. [the 6:S A care model for palliative care with a person-centered approach] Lund: Studentlitteratur
- The Swedish Agency for Health and Care Services Analysis. (2015). *Hemtjänst, vård- och omsorgsboende eller mitt emellan? Ett kunskapsunderlag för planeringen av morgondagens äldreomsorg* [In English; *Home care, nursing and care homes or between?*]. Stockholm: TMG Sthlm.
- Thorne, S. (2016). *Interpretive description*. Walnut Creek, CA: Left Coast Press
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20(2), 169-177. doi: 10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I
- Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The Analytic Challenge in Interpretive Description. *International Journal of Qualitative Methods*, 3(1), 1-11. doi: 10.1177/160940690400300101
- Tornstam, L. (2005). *Gerotranscendence: A Developmental theory of positive aging*. New York: Springer Publishing company.
- Tornstam L. (2011). *Åldrandets socialpsykologi*, 8 uppl. [In English; *The social psychology of aging, 8th Edition*] Nordstedts akademiska förlag, Stockholm
- Törnquist, A. (2004). *Vad man ska kunna och hur man ska vara en studie – en studie om enhetschefers och vårdbiträdens yrkeskompetens inom äldreomsorgens särskilda boendeformer*. [In English; *What you should know and how you should be - a study of the professional skills of unit managers and care assistants within elderly residential care facilities for older people*]. Institutionen för samhälle, kultur och lärande. Akademisk avhandling. Stockholms universitet.
- Westerbotn, M., Fahlström, E., Fastbom, J., Agüero-Torres, H., & Hillerås, P. (2008) How do older people experience their management of medicines? *Journal of Clinical Nursing*, 17(5a), 106-115. doi: 10.1111/j.1365-2702.2007.02151.x
- Whitaker, A. (2010) The body as existential midpoint—the aging and dying body of nursing home residents. *Journal of Aging Studies*, 24(2), 96-104. doi: <http://dx.doi.org/10.1016/j.jaging.2008.10.005>
- WHO. (1946). *WHO Definition of Health*. Retrieved 14 December 2017 from <http://www.who.int/about/mission/en/>
- WHO. (2002). *National cancer control programs: policies and managerial programs*. Geneva: World Health Organization
- WHO. (2008). *The global burden of disease: update 2004*. Geneva: World Health Organization
- WHO. (2011). *Palliative care for older people; better practices*. Regional office for Europe, Copenhagen: World Health Organization.

- Weisman, A. (1972). *On Dying and denying. A Psychiatric study of terminality*. 1st edn. New York: Behavioral Publications
- World Medical Association (2013). *Declaration of Helsinki-ethical principles for medical research involving human subjects*. Retrieved 20 November 2017 from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>
- Zingmark, K., Norberg, A., & Sandman, P. O. (1995). The experience of being at home throughout the life span. Investigation of persons aged from 2 to 102. *International Journal of Aging & Human Development*, 41(1), 47-62. doi: 10.2190/N08L-42J5-31D2-JUQA
- Ågren Bolmsjö, I. (2008). End-of-life care for old people: a review of the literature. *American Journal of Hospice & Palliative Care*, 25(4), 328-338. doi: 10.1177/1049909108315910
- Öhlen, J., Ekman, I., Zingmark, K., Bolmsjö, I., & Benzein, E. (2014). Conceptual development of "at-homeness" despite illness and disease: a review. *International Journal of Qualitative Studies of Health & Well-being*, 9, 23677. doi: 10.3402/qhw.v9.23677
- Österlind, J., Hansebo, G., Andersson, J., Ternstedt, B-M, & Hellström, I. (2011). A discourse of silence: professional carers reasoning about death and dying in nursing homes. *Ageing and Society*, 31(4), 529-544. doi: 10.1017/S0144686X10000905
- Österlind, J., Ternstedt, B-M., Hansebo, G., & Hellström, I. (2016). Feeling lonely in an unfamiliar place: older people's experiences of life close to death in a nursing home. *International Journal of Older People Nursing*. doi: 10.1111/opn.12129