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CONDITIONS FOR RELATIVES' INVOLVEMENT IN NURSING HOMES

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To my grandmother Ethel, who always encouraged me, acknowledged me, believed in me and showed me the way into academia

The world's problems can not possibly be solved by skeptics and cynics whose mental horizons are limited by obvious "facts". We need men and women who are able to dream of things that never have been possible before.

(John F. Kennedy)

ABSTRACT

The overall aim of this thesis was to describe and analyse how the involvement of relatives is conditioned in nursing homes from different critical perspectives. Gender perspectives, discourse analysis and intersectional theory are applied, based on social constructionist ontology. The thesis comprises three qualitative papers and data are based on ethnographically-focused fieldwork in three municipal nursing homes in the form of formal/informal interviews, participating observations and the analysis of documents.

Based on gender perspectives, the routines and reasonings among nursing staff were studied and thematically analysed in relation to how these conditioned the involvement of relatives in the daily caring activities (I). In the second study (II), the nursing staff were interviewed in groups to describe, discursively analyse and identify the biopolitical meaning in the “involvement discourse” that was collectively constructed in the speech of the nursing staff concerning the involvement of relatives. In the last study (III), interviews with relatives were thematically analysed in the context of intersectional theory about their involvement in the nursing homes.

The findings show that the conditions for relatives’ involvement were dynamic and constantly in re-negotiation, but also conservative and inflexible. This placed relatives in both privileged and unprivileged social positions in the nursing homes, which were relevant for their involvement. The relatives were considered to be “visitors”, which conditioned the characteristics and levels of involvement in the care of the residents and was linked to gendered notions of the division of labor, both within the groups of relatives and between nursing staff and relatives (I). The involvement of relatives was conditioned by the biopolitics of an “involvement discourse” that prevailed in the nursing homes. This built upon family-oriented rhetorics and metaphors that upheld and legitimised notions about relatives. The relatives were considered to be members of the “old” family in relation to the “new” family represented by the nursing staff (II). The relatives described how they were positioned in a *betweenship*, squeezed between different competing social musts from the older family members, the nursing homes as institutions and the nursing staff (III).

Inverting the prevailing picture of the involvement of relatives would make it possible to consider the nursing staff as pedagogical, professional and caring “visitors” in the nursing homes for the benefit of the residents and their relatives. This could be achieved through a constructive change management which emphasises the learning of nursing staff, their responsibility and the emotions of relatives, along with a focus on alternative notions of involvement, where relatives are included in the development of quality of care in Swedish nursing homes.

Key words: discourse analysis, focused ethnography, focus group interviews, gender perspectives, intersectionality, involvement, nursing homes, nursing staff, participant observations, qualitative interviews, relatives, social constructionism and thematic analysis.

LIST OF SCIENTIFIC PAPERS

This thesis is based on three scientific papers, presented below and referred to in the thesis by their roman numerals, I-III.

- I. Holmgren, J., Emami, A., Eriksson, L. E., & Eriksson, H. (2012). Being perceived as a “visitor” in the nursing staff’s working arena – the involvement of relatives in daily caring activities in nursing homes in an urban community in Sweden. *Scandinavian Journal of Caring Sciences*, 27(3), 677-685. doi: 10.1111/j.1471-6712.2012.01077.x
- II. Holmgren, J., Emami, A., Eriksson, L. E., & Eriksson, H. (2013). Replicating the family – the biopolitics of involvement discourses concerning relatives in nursing home institutions. *Aporia – The Nursing Journal*, 6(4), 19-29.
- III. Holmgren, J., Emami, A., Eriksson, L. E., & Eriksson, H. (2014). Intersectional perspectives on family involvement in nursing home care: rethinking relatives’ position as a betweenship. *Nursing Inquiry*, 21(3), 227-237. doi: 10.1111/nin.12046

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CLARIFICATIONS OF CONCEPTS

Although no abbreviations are used in this thesis, there are some recurring concepts that need to be clarified.

The term *involvement* is used throughout the thesis. In this thesis, the understanding of the involvement of relatives is based on Andershed's (1998) description within a palliative care context. According to her, involvement is being a part of something, to have the knowledge, to be included and to be engaged. Andershed emphasises that the involvement of relatives is an issue that should be taken into account in order to provide the best possible care to a sick and perhaps old person. Even though this definition of involvement is based on a palliative care research context, it is relevant and applicable in the nursing home context. Wallerstedt and Andershed (2007) argue that it is not the relatives who should be made to be involved, it is the nursing staff, as professionals, who should strive to make themselves involved by showing respect, openness, honesty and confirmation in relation to the relatives. However, Wallerstedt and Andershed raise the point that if nursing staff are not provided with the proper organisational prerequisites, such as a caring philosophy, a set of values, and time and support from policy makers, it makes it difficult for them to get involved and also to include relatives.

The *relatives* in this thesis should be considered as persons closely related to the residents who lived in the nursing homes. In most cases, the relatives and the residents had family ties to each other. The choice of the term *relative* as a concept is based on the denomination used in the nursing homes, both by the relatives themselves, and also by the nursing staff. According to some nursing staff, next of kin may have been the politically correct term to use. However, the term was rarely or seldom used in the everyday talk about the relatives in the nursing homes.

Nursing staff includes heads of units, registered nurses, enrolled nurses and nursing assistants. The nursing staff and relatives are sometimes referred to as *informants*, in the sense that they communicated information about the nursing home culture.

Residents refer to the persons who lived in the nursing homes based on municipal assistance decisions. Sometimes the residents were called "pensioners" by some nursing staff, but in this thesis I use the term *residents* because it appeared more commonly in the daily discourse in the nursing homes. The residents are also called *older family members* in order to get a more varied language. In this text the concept of older persons has been used to prevent the reproduction of ageism.

The *nursing homes* were three municipal-run special housings for persons with considerable care needs according to the description on the municipality's website. These facilities did not care for older persons who had been diagnosed with dementia diseases.

1 INTRODUCTION

The overall aim of this thesis is to describe and analyse how the involvement of relatives is conditioned in nursing homes. The focus is on relatives and their involvement, studied from various critical perspectives, based on a constructionist stance.

The research questions in this thesis grew out of my experience as a registered nurse at an emergency care department. In my profession, I often had cause to reflect on how relatives had to adapt to and subordinate themselves to institutional structures and routines. It could be about visiting hours, the number of relatives who were allowed to visit at any one time, round procedures, communication practices, whether the relatives would be allowed to sleep over, and even food and coffee routines in the ward. This experience led me, in turn, to reflect on relatives' involvement and the social positions created for them in health care institutions.

I study the involvement of relatives in the context of nursing homes, where there is probably more continuity and a longer timespan than in acute care. Because relatives may visit older family members in nursing homes over a longer period, the structures and routines of the nursing homes should reasonably have time to condition those relatives' own forms of involvement in care, whatever they were to begin with. The degree to which relatives have a right or an obligation to be involved in the care of older family members is an issue without a clear public consensus today. That older persons have the right to be involved in their own care is given, but how and to what extent should relatives be involved in the nursing home care?

Even though my previous experiences in the care of older persons are indeed limited, as a young grandchild to grandmothers and grandfathers, I realise that I and many others will care for older family members in the future. This is a situation that concerns me, both as a woman with aging parents and also as a mother of three half-grown children with different needs. Will the conditions for my involvement be similar to those of the relatives that I met on the emergency ward? Will they be quite stringent and restrictive, or welcoming and flexible? Based on what I have experienced as a nurse in somatic emergency care, there is justification to study the conditions for relatives' involvement more closely.

2 BACKGROUND

In order to obtain an understanding of the conditions for relatives' involvement in nursing homes, a background about informal caregivers' situations in relation to care for older persons in Swedish society will be provided. Thereafter, nursing homes and nursing homes as workplaces will be presented. The background section will end with a review of previous research on relatives' involvement in nursing homes. Altogether, this constitutes the starting point for this thesis.

2.1 SWEDISH WELFARE, CARE FOR OLDER PERSONS AND RELATIVES AS INFORMAL CAREGIVERS

People are living longer today in Sweden as in the rest of the Western world (Lagergren, 2002). This places great demands on a well-functioning system of care for older persons that can provide older persons and their relatives with quality care as part of effective welfare. The Swedish welfare policy is historically characterised by the thought of solidarity. This has meant that the citizens in Swedish society are more or less entitled to public care, financed by tax revenues regardless of their social background or income. Swedish care for older persons is one important area in society that has been influenced by the dynamic and complex changes in the welfare policy through the decades (Parker, 2001).

Historically, in the agricultural society of Sweden in the 1800s, the care for older persons was mainly the concern and responsibility of the family and those who did not have a family to care for them were referred to the poorhouse. Much later, during the 1950s and 1960s, the responsibility for providing care to the older persons in need of specialised care was considered to belong to the state. The first modern public older persons' care institutions were built and the relatives were supposed to be able to rely and trust the state to care for their older relatives. From this point until the 1990s, care for the older person flourished and developed and older persons received the practical and direct care support they needed, either in their home or in an institution, from the state without great difficulty. However, due to the launching of the Swedish so-called "elderly care reform act", Ädelreformen, in 1992, there was a significant turn in the history of modern care for the older person (Trydegård, 2000). The public older persons' care that had previously been the responsibility of the county councils now became the responsibility of the municipalities. This meant that care for older persons was legally guided by both the Health and Medical Services Act and the Social Services Act (Carlström, 2005). During this period, Sweden was facing a recession which resulted in cutbacks in public finances which, in turn, influenced the older persons' care sector negatively. This was the beginning of a shift from the state's responsibility based on solidarity back to the family as informal caregivers. At this point, the "aging in place" principle was well established in Swedish society and had an even greater impact when the number of older persons' care institutions decreased. This meant that relatives took on a much greater level of responsibility as informal caregivers, caring for a family member at home (Lagergren, 2002).

Because of the financial restructuring and the decentralisation from the county councils to the municipalities, the relatives have gradually been taking on more and more responsibility until now, when caring for their older family members is a significant complement to the public provision of care for older persons. Today, it is mostly the frailest older persons who are granted institutional care, as there is no room for anything else in the public older persons' care finances. Relatives thus play a key role as informal caregivers to make the system of care for older persons work effectively (Johansson, Long, & Parker, 2011). In light of this background, the involvement of relatives in Swedish society has been highlighted increasingly, both in public debate, and politically and legally, mainly over the past two decades. Shortcuts made in the public older persons' care sector have affected the conditions of relatives' involvement and the situations they face as informal caregivers. Altogether, these factors have led to a situation where the social position of relatives as informal caregivers has been highlighted and problematised (Johansson et al., 2011; Sand, 2005; Trydegård, 2000). As a consequence of the growing attention, national family-focused organisations, such as the Swedish Family Care Competence Centre and Carers Sweden, have been established with the aim of promoting relatives' rights.

Since 2009 there has been a change of law in the Social Services Act (SoL, SFS 2001:453) which dictates that municipalities should not only support relatives as informal caregivers, but must also provide support and facilitate the well-being of relatives when they are caring for older persons (Socialstyrelsen, 2013). In relation to this legislative change, the National Board of Health and Welfare in Sweden have conducted a pilot study (Socialstyrelsen, 2012) and a follow-up study (Socialstyrelsen, 2014a) regarding the social consequences for relatives as informal caregivers. It was found that 1.3 million Swedes cared for, helped and supported a family member or someone close. This meant that every fifth adult was an informal caregiver of whom 100,000 persons have had to reduce their percentage of employment or resign from their job, to be able to function in their roles as informal caregivers. Every third relative provided a family member or friend practically, psychosocially and/or with care every day and two thirds of the informal caregivers are women. The involvement of relatives thus constitutes both a socio-economic and a significant care conceptual platform in Swedish society. The pilot study also showed that both men and women were responsible for the informal care of older family members given the time and frequency. However, men focused more on practical and financial support while women engaged in intimate care work. In the follow-up study it was concluded that the informal caregivers not only constituted a complement to care for older persons, but they were also a socio-bearing function. Most of the informal caregivers believed that the state held the formal care responsibility, even though they took on great informal care responsibilities themselves. In the studies, it was concluded that the informal caregivers need an understanding of their situations by the care for older persons and health care sectors and the provision of individualised, flexible and early support.

In conclusion, more than 1 million Swedes are informal caregivers and care for a family member or someone close on a weekly or daily basis. Some of them care for older persons who have great care needs. According to the law, relatives have the right to individual

support and respite care, which may be in the form of daytime activities, short-term care, or permanent special housing for older persons. What I have noticed when I have looked deeply into the situations of relatives, is that it seems that the main societal focus is on relatives who care for someone living at home. This is probably related to the current “aging in place” principle in Sweden, where most of the older population is cared for at home. Noteworthy is also that a move to a nursing home seems to be considered a relief and a final solution to relatives’ informal caregiving responsibilities. However, those factors that condition the involvement of relatives in nursing homes as previously highly-involved relatives seem to be overshadowed.

2.2 NURSING HOMES

In Sweden, about 90,000 persons over the age of 65 live in special housings, spread over 2,100 facilities around the country (Socialstyrelsen, 2014b). Nursing homes are a form of special housings, organised to provide residents with care around the clock. Since the 1990s, the care for older persons in the municipality setting has been competitive. About 20 percent of the care for older persons is operated by private corporations in Sweden (Trydegård, 2012). Today it is the oldest and most vulnerable persons who live permanently in nursing homes. This is due to the financial recession of the state economy a few decades ago (Lagergren, 2002). As a result of the late admissions of older persons to nursing homes, two thirds of the residents pass away within the first year after moving. Based on this development, the nursing homes have, in some sense, turned into palliative care institutions (Riksrevisionen, 2014).

In response to Ädelreformen, over the decades, nursing homes have transformed from being institutional settings with a medical character to more home-like spaces. The nursing homes have been reconstructed and turned into leased apartments where each resident can consider the apartments as their own private homes, even if they are situated in institutional buildings (Trydegård, 2000). Historically, several residents shared rooms with little regard for the privacy and integrity of each person, based on institutional ideals. Today, the apartments in nursing homes are furnished and decorated with the residents’ own belongings to achieve a sense of home, with the exception of the ergonomic bed that is uniformly provided (Falk, Wijk, Persson, & Falk, 2013).

The nursing homes are often built according to two different architectural designs, in the form of an “L” or in the form of a “T”. Where ordinary houses have connecting stairwells between the apartments, the apartments in the nursing homes are interconnected through corridors. A kitchen for shared use is located in the middle of the nursing homes, as the hub of all activities. Even other shared spaces, such as the dining room and day room, are designed for the use of the residents, the nursing staff and relatives for socialising. There are also spaces in the nursing homes that may be considered as more private areas. The residents’ apartments, the coffee room for the nursing staff, the nursing staff stations, the office of the head of the unit and the locker rooms for staff are examples of such spaces. The exterior of the nursing homes are characterised by blocks of flats, divided into several floors. The façade is often in

bright tones and equipped with balconies or a terrace connecting to a garden. The area in front of the nursing home is paved to facilitate the transport of goods and mobility services (Andersson & Malmqvist, 2014).

2.3 NURSING HOMES AS WORKPLACES

Whitaker (2008) describes how the nursing home arena may be considered as a complex and contradictory space as it involves residents, relatives and nursing staff with separate needs, expectations and missions. While the nursing home functions as a home for the residents, it is also a workplace for nursing staff. From this point of view, it is organised and structured with the help of institutional routines, commissioned to provide good care in accordance with the Social Service Act (SFS 2001:453). The institutional features also condition the involvement of relatives, subject to the nursing home's structures and procedures (Whitaker, 2008). The nursing staff, as professionals, must follow the law of confidentiality and take responsibility for the security of the residents (SFS 2001:453). Both relatives and nursing staff have to take the autonomy of the residents into account. This conditions how and to what extent relatives may be involved in the everyday care, as the nursing homes are considered to be the residents' private homes (The National Board of Health and Welfare, personal communication, Nov 2014). At the same time, issues around the requirements for good treatment and cooperation between nursing staff and relatives have been raised in the discussions about the care for older persons (Whitaker, 2008). Today, although there is a law that should support relatives in individual municipalities (SFS 2001:453), there is no specific regulation that relatives should be involved in the care of their older family members in nursing homes. Relatives are not duly bound to care according to the Social Services Act. However, that law focuses on making individuals involved as support persons when planning interventions for older persons, for example in nursing homes (The National Board of Health and Welfare, personal communication, Feb 2015).

The majority of the nursing staff are women, of all ages. This is reasonably connected to and a reflection of the gender order in society at large, where caring is considered to be a natural female characteristic (Lill, 2010; Sörensdotter, 2008). That the majority of the nursing staff workforce are women may therefore appear quite "natural". Lill (2010) illustrates how this notion is reproduced and maintained in everyday talk, but also through the media and public discourse on care for older persons. Lill further suggests that much of the activities in nursing homes are based on a traditional division of labor where men and women are assigned tasks related to gender.

In a comparative study by Daly and Szebehely (2012), they found that 20 percent of Swedish nursing staff in nursing homes do not have the minimum level of education, which is defined as relevant secondary education with a specialisation certification in nursing care. This would reasonably influence the quality of care, particularly when caring for the oldest and most vulnerable persons in society. The conditions for the nursing staff may become even more complex as some of them, the residents and the relatives do not always share the same language and values that are based on cultural backgrounds (Olt, Jirwe, Saboonchi, Gerrish,

& Emami, 2014). The workforce in nursing homes is partly characterised by its gender homogeneity, poor education level and multicultural background. Additionally, as for other female professions in the public sector, the caring professions in older persons' care have a slow wage growth (Daly & Szebehely, 2012) and there is limited power to influence and improve the working conditions for nursing staff (Ericson-Lidman, Norberg, Persson, & Strandberg, 2013). Acknowledgement and improvement of the aforementioned working conditions for nursing staff may be considered to be one of the main organisational and structural challenges for the future of Swedish care for older persons. According to Johansson and colleagues (2011), the best support for relatives would be a well-functioning system of older persons' care. Reasonably, this condition assumes that the workforce in nursing homes should be provided with the relevant resources and support to be able to deliver quality care.

2.4 RESEARCH ON THE INVOLVEMENT OF RELATIVES IN NURSING HOMES

Some of the first publications regarding the involvement of relatives in nursing homes were published in the 1960s and 1970s and reflected the viewpoints of both relatives and nursing staff from multidisciplinary perspectives (Linn & Gurel, 1969; York & Calsyn, 1977). From that point until the beginning of the 2000s, relatively few studies have been conducted in this field of research. Hertzberg's (2000) thesis about the relationship and interaction between nursing staff and relatives in Swedish nursing homes may be considered as a classic in the field. Nolan, Grant and Keady (1996), Kellett (1999), Ryan and Scullion (2000), Gladstone and Wexler (2000) and Bauer and Nay (2003) are researchers who have contributed, and continue to, in this area of research. They have all described the involvement of relatives in nursing homes from different perspectives.

Based on my review of previous research regarding the involvement of relatives in nursing homes, published in English, and limited to ten years previous, I would like to highlight some general reflections. In the recent decade it seems as though the research has stalled slightly and reached a plateau. Out of 682 articles identified and indexed in PubMed or CINAHL, based on a MeSH search, 28 articles proved to be relevant with regard to the overall aim of this thesis. Many of the articles dealt with relatives' involvement but in other contexts than nursing homes, for example, within intensive care units or neonatal care. A great deal of the articles also focused on relatives of persons with dementia, and the caring challenges linked to it.

Although some articles originated from Asia (Kong, 2008) and the Middle East (Natan, 2009), the majority of the studies were conducted in an American (Chen, Sabir, Zimmerman, Sutor, & Pillemer, 2007; Gaugler & Ewen, 2005; Gaugler, 2006), European (Davies & Nolan, 2006; Ryan & McKenna, 2014; van de Bovenkamp & Trappenburg, 2012) or Scandinavian context (Lohne et al., 2014; Weman & Fagerberg, 2006; Voutilainen, Backman, Isola, & Laukkala, 2006). From this point of view, the involvement of relatives in nursing homes thus seems to be more of a Western concern. Most of the articles were published in nursing journals such as the *Journal of Older People Nursing*, *Nursing Inquiry*, and the *Journal of Advanced Nursing*. However, other journals within the medical and social

science fields were also represented, although not to the same extent. The concept of involvement was not explicitly defined in the 28 articles, which may be a reflection of its varying interpretations. The definition of involvement seems thus to be taken for granted in previous research. In some of the articles, the involvement of relatives was just one important aspect out of several (McVeigh, Jablonski, & Penrod, 2009; Weman & Fagerberg, 2006; Zimmerman et al., 2013). In these articles, relatives were mentioned as being significant but were still considered casual and peripheral. From an ontological point of view, only two articles used a critical approach or constructionist stance (Bauer, 2007; Baumbusch & Phinney, 2014) and only one of the articles used an ethnographic approach (Bern-Klug & Forbes-Thompson, 2008).

In several of the articles, the general starting point was that relatives continue to visit, engage with and take care of their older family members after they have moved to nursing homes (Baumbusch & Phinney, 2014; Davies & Nolan, 2006; Gaugler, 2010; Milligan, 2006; Weman & Fagerberg, 2006; Westin, Ohrn, & Danielson, 2009). In Sweden, this may be related to the “aging in place” principle (Lagergren, 2002). Another shared starting point identified when reviewing the articles, was the awareness of an aging Western population and the challenges it brings to caring for older persons (O’Shea, Weathers, & McCarthy, 2014; Zimmerman et al., 2013). However, there seems to be a difference in how this may be resolved in Sweden compared to other countries, such as, for example, the USA. While the number of nursing homes has decreased in Sweden and parts of the care responsibility for older people is transferred to relatives as informal caregivers at home, a great deal of older persons are still assigned a place in special housings in other parts of the Western world (Davies & Nolan, 2006; Gaugler & Ewen, 2005; Kellett, 2007; Natan, 2009). Further aspects emphasised in the literature were the acknowledgement of relatives as being important in society and as partners in the staff-family collaboration in nursing homes. Relatives are portrayed as fulfilling an important role in maximising the quality of care and well-being of residents. This has been highlighted in England, Australia and the USA at a governmental and juridical level which seems to differ slightly from the Swedish context (Bauer, 2006).

In the 28 articles, the involvement of relatives in nursing homes corresponded to different areas of care, which were partly intertwined. It seems as though the inter-relational aspects related to involvement constitute the main focus of previous research. The different groups will be presented chronologically below, with regard to both the positive and more challenging dimension of relatives’ involvement, as it relates to:

- Relatives’ caregiving roles
- Characteristics of care provided by relatives
- Staff-family relationships
- Family councils

2.4.1 Relatives' caregiving roles

It is well known that relatives continue to engage in the care of their older family members even after they are admitted to a nursing home. Nevertheless, being a relative to someone living in a nursing home may be both confusing and challenging for relatives in terms of creating new caregiving roles for themselves. In the mid-2000s, Davies and Nolan (2006) conducted a study focusing on relatives' new self-perceived caring roles in some English nursing homes. The relatives described that they went through a transition to "make things better" for the benefit of the residents. In establishing new caregiving roles, the relatives tried to maintain continuity for their older family member, keeping an eye on the care provided and contributing to community by socialising with other residents and participating in nursing home activities. The authors found that it is important for nursing staff to encourage relatives to be involved, as long as it is not contrary to the resident's wishes, as this was proven to be beneficial for both residents and relatives. Kellett (2007) has shown how relatives adapt to their new caregiving roles by seizing possibilities. Through a hermeneutic phenomenological approach, it was established that relatives developed new ways of caring by negotiating and modifying their roles as caregivers in relation to nursing staff. Genuine partnerships should be acknowledged where both nursing staff and relatives are respected and treated equally. These dimensions should be developed to enhance the quality of care. In a review conducted by Kong (2008), it was again emphasised that relatives' caregiving responsibilities do not end because of institutionalisation. However, the characteristics of involvement change, which influences the health status of relatives. This occurred because they continued to be influenced by their older family members' cognitive impairment and problems related to institutionalisation.

The review further showed that the burden on relatives decreased, even if the level of depression was unchanged by an older family member being moved to a nursing home. Relatives deal with a variety of problems in nursing homes related to institutionalization, and Kong (2008) suggests that it is crucial for nursing staff to be aware of the new and challenging situations that relatives are facing in order to be able to support them effectively in their new caregiving roles. In an Israeli study conducted by Natan (2009), a comparison between nursing staff and relatives' perceptions of their caregiving roles showed two significant differences. Although nursing staff and relatives shared the opinion that relatives should be involved, there were nuances within the involvement. Nursing staff thought that relatives should assume more caregiving roles than they did, however, not in the physical care. The perception of nursing staff was that the residents may be injured by relatives because they did not have enough competence in caring. Rather, they thought that relatives should engage in socialisation and taking their older family members away for external activities outside the nursing home. Relatives, on the contrary, wanted to be involved in the physical care of the resident and to be regularly updated about this aspect.

Baumbusch and Phinney (2014) recently made some conclusions based on their study about the role of highly involved families in some Canadian nursing homes. They highlight that the roles of relatives tend to be made invisible in relation to the philosophy of care and

organisational support in nursing homes. This continues, despite the recognition that relatives usually play a significant role, given poor staffing levels. Further, Baumbusch and Phinney point out that it is problematic that the limited role of relatives as “visitors” has not been challenged, as the goal should be to make relatives involved based on their own preferences in partnership with nursing staff for the benefit of the residents. However, O’Shea, Weathers and McCarthy (2014) show, in their study in Ireland, that the relatives were overall satisfied with their caregiving roles after the admission of their older family members to nursing homes, even if it had meant role changes. This seemed to be related to the family-centered approach among nursing staff. Finally, in the same year, Ryan and McKenna (2014) found that there is still room for improvement concerning the caregiving roles of relatives. These findings imply that the organizational prerequisites in the form of time, reasonable staffing levels and a profound understanding for relatives’ situations among nursing staff need to be implemented. Ryan and McKenna conclude by noting that there are nursing interventions to enhance family-focused approaches, but they must be used to a much greater extent in nursing homes.

2.4.2 Characteristics of care provided by relatives

Some researchers have focused on the types of care that are provided by relatives in nursing homes. Gladstone, Dupuis and Wexler (2006) have described the changes in relatives’ involvement after moving an older family member to a nursing home. It was found that the characteristics of care varied. This was in relation to previous caring responsibilities at home but also linked to the new care needs of the residents. The majority of relatives did not perceive themselves as caregivers; they performed the care that they thought was expected of them as family members. This could be personal care and psychosocial care, but also care of a more practical nature. During the same period, Milligan (2006) also focused on the transition of moving from home to institution and what it meant to relatives. They concluded that relatives engaged in a wide range of caring activities. The relatives were involved in physical care tasks, social care tasks, monitoring of quality of care and emotional care work.

Bern-Klug and Forbes-Thompson (2008), in an ethnographic study, found that relatives felt responsible for the surveillance of the care of their older family members. Their task was also to communicate biographical information about the residents and maintain their social network on their behalf. In line with these results, Habjanic and Pajnkihar (2013) later also identified similar and new care responsibilities for relatives. The Slovenian relatives described their involvement in terms of making visits and being useful, delivering personal items to the residents, providing hands-on care, physical care and being engaged in the organisation of activities in the nursing homes. This study also showed that some relatives could consider financial compensations for their caregiving efforts, which seems to be a new dimension in this field of research.

2.4.3 Staff-family relations

Although the involvement of relatives has been debated in the literature, much of the previous research points to the benefits of developing good staff-family relations. Gaugler and Ewen (2005) have, in an American context, stressed the importance of building relationships between nursing staff and residents, as this may lead to positive perceptions of relatives by nursing staff. He also suggests that the quality of care and quality of life for all involved in the nursing home may be improved by doing this. In order to enhance staff-family relationships and partnerships, Gaugler and Ewen call for a greater number of nursing interventions compared to what is available today in nursing homes. In another study made one year later, Gaugler (2006) found how dimensions of family-staff relations affected residents. The conclusion in this study was that relatives played a key role in maximizing the well-being of residents, in partnership with the nursing staff. However, the different dimensions of the involvement of relatives had great importance because they had both negative and positive outcomes for the psychosocial status of the residents. Therefore, involvement must be sensitive to the residents' needs.

The same year, Weman and Fagerberg (2006) presented some factors that influenced Swedish registered nurses' work together with family members. The results showed that the registered nurses perceived relatives mostly as a resource with whom they wanted to cooperate with. However, there were some factors that prevented good staff-family relations. The registered nurses sometimes felt that they lacked information from the physician, they did not have enough resources from the organisation, and it was hard to get in contact with relatives who withdrew. From this point of view, Weman and Fagerberg emphasise how important it is to consider the working conditions of nursing staff as this element influences all individuals who are involved in nursing homes. In a Finnish study, Voutilainen and colleagues (2006) showed that the relatives' perceptions of quality of care were linked to social parameters such as age, educational background and number of visits among relatives. The relationship between the involvement of relatives and quality of care was also proven to be strong. When relatives were given proper information and support and were invited to be involved in decision-making, the quality of care was highly rated. This finding indicates that there is a need for clearer, more family-focused ward policies where the nursing staff are encouraged to involve relatives in such ways.

If the staff-family relationship is conflictual, Chen and co-authors (2007) found that this may have consequences for the mental health of relatives. When exploring the association between depression, burden and the quality of staff-family relationships in nursing homes in the USA, it was found that conflicts in the staff-family relation were significantly associated with relatives' depression and burden. Therefore, interventions are needed to improve staff-family relationships to reduce relatives' negative stress. Utley-Smith et al. (2009) are other researchers, also from the USA, who have come up with some suggestions on how to provide a more family-oriented approach in nursing homes. In their study it was shown that nursing staff described family-staff interactions as challenging, problematic and time-consuming. In order to include relatives, Utley-Smith and colleagues suggest that the nursing staff may

inform the relatives on the unit face-to-face, without residents having to ask for the information. The staff may also communicate in writing or by phone to provide both positive and negative information regarding the residents and they may be interested in how the relatives experience their caregiving situation in the nursing home. Relatives should in turn have realistic expectations and seek out constructive dialogues with nursing staff.

Westin, Öhrn and Danielson (2009) have also shown in their Swedish study that the involvement of relatives and their impact on the well-being of residents was of great importance. Therefore, it is crucial to take into consideration the fact that some relatives of residents in the nursing homes studied felt excluded and ignored by the nursing staff. If they are expected to be able to contribute positively to the quality of care of residents, the relatives must perceive that they are made welcome to become involved and that they are valuable in the staff-family relationship. However, in relation to other health care contexts, such as oncology and mental health care, it seems as if the staff-family relationships are of good quality. Van De Bovenkamp and Trappenburg (2012) described in a comparative review that relatives in nursing homes are considered as fellow carers, almost at the expense of the residents' autonomy. In mental health care, relatives are perceived to be more like outsiders, which may be connected to a cultural discourse about the autonomy and confidentiality of patients. This culture has legitimised the exclusion of relatives in that particular context. The authors highlight that it is a delicate balancing act, giving the resident full attention to avoid paternalism, without excluding their relatives. Much of the research has focused on the quality of care and well-being of residents so far. However, Zimmerman and colleagues (2013) conducted an intervention in some nursing homes that proved that families also matter in relation to nursing staff. Even though relatives were considered as "visitors", the intervention led to less burn-out and the establishment of greater partnership between relatives and nursing staff. Relatives may thus play an important role in nursing homes, not only in relation to the residents, but also given the workforce shortages that prevail in nursing homes today.

So far in the review, the focus has mainly been on positive factors related to the staff-family relations and the benefits of making relatives feel involved. Still, there are studies that also point to the more problematic aspects in these staff-family relations.

In a study conducted by Bauer (2006), it was shown that although some nursing staff in some Australian nursing homes had developed a family-focused approach, relatives were constructed as demanding and challenging. For example, the nursing staff considered themselves to be the experts in caring and that relatives interfered with the daily routines in the nursing homes. Sometimes the relatives were also described as competitors who needed to be controlled. Identified unacceptable behaviours among some relatives were perceived to be a part of their ethnicity and judged to be outside of what was considered socially acceptable. Bauer notes that there is still a gap between policy and practice concerning the involvement of relatives. He suggests that the task-oriented approach in nursing homes must be replaced if relatives are really to be made involved. Otherwise, they will continue to be

perceived as if they interfere with the “proper” care. In another study, one year later, Bauer (2007) further immerses himself in the more challenging behaviours in the staff-family relationships as constructed by nursing staff. In summary, nursing staff had a difficult time with some relatives who they thought did not really care about their older family members. It was also identified that relatives had unrealistic and naïve expectations of the care provided and again, that they interfered in the care work. Relatives who made too many demands were described as difficult and impossible to satisfy. Based on these findings, it is essential to question the dominant position of nursing staff knowledge in order to develop more collaborative working practices with relatives, according to Bauer.

Majerovitz, Mollott and Rudder (2009) focused on the communication aspect in staff-family relations in an American study. They found barriers which counteracted good communication which impacted on the involvement of relatives. Understaffing, under-educated staff, conservative routines, high staff turnover, rotating staff and lack of time constituted some of these barriers. To improve communication with relatives, Majerovitz and colleagues stress that there is a need for institutional and organisational changes where nursing staff are recognised, appreciated for their good work and provided with relevant family policies and adequate team training. Also in an American context, McVeigh and colleagues (2009), in a review, have identified two key areas as being the most important for relatives’ satisfaction with nursing homes: direct care, and the family-staff interaction. The greatest dissatisfaction was found to be the lack of empathy shown by the nursing staff in the encounter with relatives and residents in direct care. Other problematic aspects concerned the staff-family interaction where relatives lacked adequate information which was linked to lack of communication in nursing homes. The review also showed that relatives were dissatisfied with the level of involvement they were allowed to have in the care work and their influence in decision-making regarding care plans for their older family members. To improve the satisfaction of relatives, McVeigh and colleagues suggest that nursing staff should be provided and supported with in-service education to be able to go beyond the existing task-oriented approach in nursing homes. Only then it is possible that relatives will be satisfied when being involved individually with empathic awareness and proper information.

Five years later, Lohne and colleagues (2014) interviewed relatives in Scandinavian nursing homes concerning their experiences of dignity and uneasiness. The findings demonstrated that relatives felt vulnerable and powerless in relation to the nursing staff. The relatives sometimes witnessed that the dignity of resident was overlooked, which gave them a sense of uneasiness. In this study, it was also found that the relatives experienced that they were not given relevant information about the residents’ care and that certain questions about their intimate care were not welcomed. These kinds of questions made the staff-family relations feel strained and resulted in conflicts and struggles for the relatives. This also led to experiences of paternalism, disappointment and uneasiness among relatives as they were dependent on the nursing homes and had no formal power to make any decisions.

2.4.4 Family councils

A minority of the literature focuses on family councils with the aim of maintaining and improving the involvement of relatives. These articles are both from an American context. Curry, Walker, Hogstel and Walker (2007) found that the family council fulfilled an important function in supporting, empowering and getting the relatives involved. The family council provided relatives with a democratic platform where their voices could be heard in their quest for quality care for their older family members. A prerequisite for a successful family council seemed to be the institutional support and the attitudes of the heads of units. In the other article, published by Persson (2008), it was concluded that well-functioning family councils benefited all involved in nursing homes. Family councils may reflect a philosophy of care where relatives are recognised as an integrated resource in nursing homes.

In conclusion, previous research covers several important aspects of relatives' involvement in nursing homes, both from the views of nursing staff and relatives. However, the research carried out seems to be based on fairly traditional assumptions, which creates room for alternative approaches to involvement which have importance for relatives.

3 RATIONALE

Swedish care for older persons has gone through significant changes over the past decades. This is partly due to a recession during the 1990s and the introduction of the Ädelreform. As a consequence, the care responsibility for older persons has shifted from the state to the families in line with the “aging in place” principle and due to a decreased number of nursing homes. Today, relatives as informal caregivers not only represent a complement to the provision of public care for older persons, but they also constitute a social-bearing function.

In 2009, there was a change of law in the Social Services Act. From that point on, it stated that the municipalities not only *should* but *must* support relatives with individualised and flexible interventions in order to facilitate their situations and everyday lives as informal caregivers. When the care needs of older persons become too complex to deal with at home, the older persons eventually need to move to special housings, such as nursing homes, as a form of municipal support intervention. Today it is only the frailest older persons who live in nursing homes in Sweden and it seems to be considered to be a great relief and signals the end of relatives’ informal caregiving responsibilities. However, it has been shown that previously involved relatives want to continue to engage in the care of older persons even after they have been admitted to nursing homes.

After reviewing the previous research, the involvement of relatives in nursing homes seems to be important in relation to certain specific areas: relatives’ caregiving roles, characteristics of care provided by relatives, staff-family relationships, and family councils. The involvement of relatives could be said to be described in terms of role transitions, care practices, interactions and democratic engagement in nursing homes. Much of the existing research points to the importance of relatives’ involvement for the sake of the quality of care as well for the well-being of the residents. It is also evident that both relatives and nursing staff benefit from positive staff-family relations. Nevertheless, despite decades of research in this field, the involvement of relatives in nursing homes has not been improved at a pace that should be expected. Sometimes, relatives are still described as demanding and challenging “visitors” whose expectations of involvement are perceived as unrealistic. Furthermore, relatives are not always seen as a resource but as competitors, despite the knowledge they possess and the relationships that they have with the residents. Nursing staff do not get the support and resources they need, which may partly be the answer to why the care in nursing homes is still described as instrumental and task-oriented.

Although previous research is relatively comprehensive, there seems to be a lack of alternative understandings and new perspectives on relatives’ involvement. Recent research seems to build on fairly traditional notions of family involvement and it seems as though the focus has been on helping relatives to adapt to the institutional order. Consequently, the assigned social positions and conditions of relatives as informal caregivers are rarely or never questioned. In order to bridge this gap in the knowledge, this thesis will focus on the conditions for relatives’ involvement from a social constructionist stance and from the views

of some critical perspectives. In doing so, there will be an opportunity to rethink the concept of involvement which might provide alternative conditions for relatives' involvement as part of a quality care development in Swedish nursing homes.

4 AIM

The overall aim of this thesis is to describe and analyse how the involvement of relatives is conditioned in nursing homes from different critical perspectives. The specific aims are:

- I. To describe, from a gender perspective, how nursing staff's routines and reasoning act to condition the involvement of relatives in nursing homes
- II. To describe the biopolitics of involvement discourses articulated by nursing staff concerning relatives in nursing home institutions
- III. To understand, in the context of intersectional theory, the roles of family members in nursing home care

5 THEORETICAL FRAMEWORK

In this section, the ontological and theoretical underpinnings of this thesis will be presented. The social constructionist stance makes it possible to question common assumptions, while the critical perspectives are the “lenses” through which data will be analysed and explained.

5.1 SOCIAL CONSTRUCTIONISM

The ontological starting point in this thesis rests on social constructionism. Hacking (2005) discloses that constructionist ontology aims at questioning current conditions. A social constructionist criticises current social structures in the effort to change an established order. My starting point is based on the key assumptions that:

- X does not have to be this way, and X is not determined by nature or the unavoidable.
- X is not satisfactory in the way that it works now.
- Things would be much better if X would change.

Hacking (2005) describes that all constructionists are critical, but how much they want to change society might vary. In this thesis, I suggest that X could be replaced by the conditions for relatives’ involvement in nursing homes. The purpose of this thesis is not to completely replace the existing conditions for the involvement of relatives, but to contribute with alternative ways of constructing it.

According to Burr (2003), social constructionism rests on some basic starting points. Firstly, as in the key assumptions described above, taken-for-granted truths should be questioned and critically examined. This is because the meaning of social phenomena and social categories are considered to be social constructions. The constructions are produced and maintained in the interactions between people, a concept which suggests that social reality is understood as social products. Consequently, there is no essence or objective existence that could be uncovered, because social reality is constantly being renegotiated. Burr illustrates this notion by questioning the division of men and women in society in relation to gendered notions. She argues that it would be equally possible to divide people by length, for example. Similarly, the constructionist constantly needs to question their own assumptions as they are always co-creators of reality. Secondly, an understanding of the world and its phenomena are related to the history and the culture they derive from. What is presented and accepted as knowledge and obvious right now, may be redefined and considered obsolete in the future. Lastly, social actions are closely linked to social constructions in the form of different knowledge about the world. Consequently, knowledge may lead to both including and excluding practices because they are connected to power. There are some knowledges that are more accepted than others, and these appear as truths and common sense. Knowledge thus governs how to behave and determines what it is possible to do or not to do in society.

In line with the constructionist stance, I have chosen three critical perspectives. They will be used in the analysis of how the involvement of relatives is conditioned in nursing homes. These are as follows:

5.1.1 Doing gender

In the first study (I), a gender display perspective is applied, inspired by the way West and Zimmerman (1987) present it. The perspective builds upon the notion that gender is something that persons do, rather than something persons have or are by nature. Gender is thus performatively constructed and reproduced in the interaction between people in a way that makes it appear as natural. Fenstermaker and West (2002) define gender as “*the activity of managing situated conduct in the light of normative conceptions of attitudes and activities appropriate of one’s sex category*” (p. 5). This means that people hold each other accountable for their actions in relation to what is socially expected of them as men and women. If a person does not perform in accordance with gendered notions about male and female behaviours, there is a risk that this person may be perceived as socially deviant.

West and Zimmerman (1987) also state that a division of labor is inevitably linked to the reproduction of gender in an existing gender order in society. The division of labor is an effective tool to keep track of what people should devote themselves to in society. The gender display perspective further assumes that the gender order is maintained through a construction of difference. Gender was constructed through dichotomies whose binaries are not equivalent. This may be expressed in social positions as formal-informal, man-woman, and paid-unpaid, and in nursing homes, as working-visiting. This contributes to the understanding of women and men having unequal living conditions and different highly-valued social positions in society, not least related to caring responsibilities. However, it is also important to highlight that there can be different conditions within groups of men and within groups of women, which requires a wider gender analysis where the focus is not only on the relationships between men and women.

5.1.2 Discourse analysis

The second study (II) is inspired by Allen and Hardin’s (2001) perspective on discourse analysis. Allen and Hardin highlight the methodological benefits of having a semiotic view of language when focusing on issues of injustice in society. They call for a postmodern stance in the understanding of qualitative interviews, where social, cultural and historical aspects are taken into consideration. A discourse is presented as an area of social conversation that is constructed through language. Social structures and institutions should be understood as discursive effects governed by discourses. The discourses are upheld through the marking of difference in language and through repetition. This means that meanings are constructed in the difference and in the displacement of syllables. In practice, this has consequences for what it is possible to say and do within a certain discourse. Individuals are preceded by language in the form of discourses, and language also constructs identities. It is not possible

to go beyond a discourse to find out how things “really are”. However, as an individual it is possible to change social positions and be ascribed various positions within discourses.

Allen and Hardin have been influenced by the French philosopher, Michel Foucault, in presenting their view of a postmodern discourse analysis. Foucault is one of the 1900s’ most original thinkers. He is probably most known for his unorthodox interest and research focuses on institutions, power, discipline, sexuality, “deviations” and madness. Foucault, more particularly, studied the historical emergence of institutions as well as the constructions and the boundaries of what is considered to be “abnormal” and “deviant” (Nilsson, 2008). Bearing concepts such as *discourse*, *power/knowledge* and *biopolitics* are other typical foucauldian concepts applied in this thesis. Foucault was not only a postmodern researcher and a writer but also a left-wing political activist. However, in alignment with his own questioning of normative and imposed social positions, he would probably oppose this type of categorisation. Foucault may be considered as a source of inspiration for queer scholars, feminists and postcolonial theorists in his critique of Western knowledge tradition. Characteristic for his thinking was his anti-universal approach and constant attention to history in the understanding of the present (Tengland, 2012).

Foucault (1956/2012) posits that access to reality runs through language in the form of discursive formations, also called discourses. A discourse can be said to be a set of linguistic statements which, in relation to each other, construct various option strategies that form rules for what it is possible to say, do and think in a certain context. A discourse is defined just as much by what it is not, as what it is. In this way, meaning and sense can be said to occur in the difference. This means that meanings are defined in relation to other meanings. In this way, discourses are demarcated from each other. In the analysis of discourses, it is significant to know that discourses constitute practices as well as institutions. In light of this view, professionals and academic disciplines may be understood as bearers and producers of discourses. Unlike the modern project’s belief in the subject’s free will and the ability to reflect on one’s own self, the subject is considered to be “dead” in a foucauldian sense. Subjects are thus governed and constituted by discourses. However, subjects still constitute language and discursive formations to a certain point, as they are able to choose between diverse options and strategies within discourses. This leads to the construction of dynamic subject positions, which fluctuate depending on context and discourses.

Discourses are connected to power as social relations and produce knowledge as both truths and subjects. According to Foucault (1975/2004), power/knowledge is inseparable and they presuppose each other. Foucault suggests that power exists everywhere and is reproduced and maintained through language, practices and institutions. Power is thus not exercised top-down but as a part of all social relations between people. The power has an intention and a goal but is not governed by subjects. It is consequently not interesting or fruitful to state who has the power or to state that institutions in themselves have any power. Institutions should rather be understood as discursive effects. Foucault argues that dominance is always power, but that power is not always dominance. Within the relational characteristics of power, there

is always room for resistance and renegotiation within discourses. Power, in this sense, could never be total because there is always a measure of instability, depending on context. The purpose of studying discourses is to reveal the effects of discourses, regardless of whether they are perceived as true or reasonable. By doing this, it is possible to identify the biopolitics of a discourse.

Biopolitics could be described as a “power over life”, governance over people’s lives that was launched during the 1700s (Foucault, 1976/2002; Foucault, 1975/2004). Its aim was ultimately to create a self-regulating, sound and healthy modern subject. Unlike previous societies, at this point, citizens are seen as a resource of the state that needs to be disciplined and governed to act rationally and “normally”. In order to do this, knowledge and truths were needed. Foucault suggests that it was at this stage that the medical and psychiatric sciences gained a crucial foothold in the construction of the modern subject. Through these scientific discourses, its practices and institutions, a public health policy was developed and the lives of the citizens were mapped demographically (Foucault, 1972/1988). The biopolitics thus came to be about birth, life and death, defined and demarcated by medical and psychiatric scientific truths.

Allen and Hardin (2001) present three methodological advantages based on the semiotic and postmodern view of language, which are: linking language to practice by identifying what differences are marked in the speech of subjects; asking social and historical questions and find out who else has marked differences in a similar way and identify what consequences this have had; and creating a public model of subjectivity which means understanding the subject’s accounts as a performance governed by discourses. A discourse analysis is not interested in understanding what is going on in the subject’s head because the content of a research interview is not considered to be a reflection of a social reality. On the contrary, using a discourse analysis makes it possible to understand the subjects’ social positions in identifying the underlying discourses their accounts derive from.

5.1.3 Intersectionality

The intersectional perspective is central in the third (III) study. Kimberlé Crenshaw (1989), professor of law, introduced the concept of intersectionality in the late 1980s. Her research has focused on race and ethnicity and she has made visible the notion that further marginalised social positions are present in society, and that these can not only be understood through an understanding of gender. Crenshaw’s launching of the concept of intersectionality is positioned as a black feminist criticism as much of the understanding of women’s living conditions had previously emanated from the norm of the white, heterosexual, middle class woman. Mattsson (2010) describes, in her book on intersectionality in social work, that the focus on gender has made the oppression of “other” women invisible throughout history. Social categories in addition to gender, such as ethnicity, class and age/generation, are also important aspects in the understanding of how power relations interact and reinforce each other. Each power structure has its own internal logic and operates in different ways, but always in intra-action with each other.

The dynamic development of intersectional theory has partly been punctuated by lively discussions among feminists and other critical researchers. Lykke (2005; 2009) describes intersectionality as a feminist theory but with influences from black feminist and postcolonial theory, with a long historical development. Lykke emphasises that with the help of intersectionality theory, power relations may be revealed as being both including and excluding with regards to discursively constructed categories such as gender, ethnicity, class, age/generation and sexuality. From a feminist point of view, it has been important that one category should not be seen as more dominant than the other; the point is that they intra-act. Although intersectionality theory was introduced quite recently in research contexts, intersectional discussions about women's conditions related to gender and ethnicity have been ongoing since the 1800s. In Sweden, it was de los Reyes and Mulinari (2005) who first introduced the concept of intersectionality. However, the feminist movement was already discussing the intersections of gender and class in the 1960s and 1970s.

To avoid reducing intersectionality theory to a fixed and essential analytical tool, Lykke insists that it is crucial to consider feminist theories as a dynamic and as discursive processes based on a postmodern stance. It is thus neither desirable to strive for one single way of conducting an intersectional analysis nor to consider social identity categories as something other than constructions (Lykke, 2005). Carbado, Crenshaw, Mays and Tomlinson (2013) claim, in their mapping of the movements of intersectional theory, that it should be understood from the view of what it does, rather from what it appears to be. They also note that international and interdisciplinary interests have resulted in a favorable development of intersectionality theory whose potential is yet to be discovered. With a post-traditional approach, intersectional theory may continue to serve as an analytical tool in illuminating interlocking power structures in the political quest to find strategies that counteract marginalisation.

As shown in this presentation, based on the constructionist stance, the critical perspectives represent different angles and levels that will be used in the methods of this thesis.

6 METHODS

An ethnographic method has been used in this thesis. The three papers included are qualitative in character. The red thread that connects the papers is the constructionist stance, held together by the ethnographic method. The first study (I) focuses on the involvement of relatives linked to the routines and reasonings among nursing staff from a gender display perspective. In the second study (II), the biopolitics of involvement discourses constructed by nursing staff are studied from a discourse analysis perspective. The last study (III) examines relatives' conditions for involvement from the relatives' own points of view as they relate to intersectionality.

Table I. Overview of the studies

Study	Aim	Sample and informants	Data collection	Data analysis
I.	To describe, from a gender perspective, how nursing staff's routines and reasoning act to condition the involvement of relatives in nursing homes	41 nursing staff	Focused ethnographic fieldwork; participant observations, formal and informal qualitative interviews and gathering of documents	Thematic analysis and gender display perspective
II.	To describe the biopolitics of involvement discourses articulated by nursing staff concerning relatives in nursing home institutions	27 nursing staff divided into six focus groups	Focus group interviews	Discourse analysis
III.	To understand, in the context of intersectional theory, the roles of family members in nursing home care	15 relatives	Individual qualitative interviews	Thematic analysis and intersectional perspective

6.1 FOCUSED ETHNOGRAPHY

More specifically, a focused ethnography method has been used in this thesis (Roper & Shapira, 2000). This orientation of ethnography has often been used in nursing contexts (Gerrish, Naisby, & Ismail, 2013; Higginbottom, Rivers, & Story, 2014; Higginbottom et al., 2015). There are some particular aspects characterising this orientation of ethnography, which

have been taken into account. Despite that the results of this focused ethnography may *help to improve* health care settings such as nursing homes, this thesis has also touched on a *distinct research problem*, namely, the conditions of relatives' involvement in a specific context, the nursing home culture. The data collection has also been conducted on a *small qualitative sample*, a small group of people consisting of nursing staff and relatives. The data collection period of four months, between September 2010 and January 2011, has been *isolated* and intensive (Roper & Shapira, 2000).

Ethnography is both a process and a product, a process that could be said to be far from linear. Anthropologists have largely engaged in this process to describe and analyse different cultures with their specific knowledge and practices. The focus in ethnography is thus both on what people know and what people do. In the ethnographic process, you learn about people by learning from them in situ. The ethnographic research questions are traditionally studied through fieldwork using a variety of data collection methods, such as participant observations, qualitative interviews and the analysis of documents. The field notes, taken during the fieldwork, have an important role as part of the documentation of the data collection. The field notes serve as memos and should provide a rich picture of the complexity of the culture studied (Roper & Shapira, 2000).

Hammersley and Atkinson (2007) have expressed the duality and great deal of sensitivity that is required when applying ethnography. They suggest that there is often a dual purpose in ethnographic study. It is partly about providing an accurate, detailed and nuanced picture of a social reality and a distinct culture, while it is also about uncovering and studying the central mechanisms and dynamics using ethnographic theoretical concepts and tools. This method comprises a dynamic movement between the emic (insider) and etic (outsider) perspectives. The multiple way of collecting data also characterises the ethnographic method and the researcher's reflexivity (Roper & Shapira, 2000). The analysis often includes ideology, power aspects and cultural order. This is why ethnography is challenging; to succeed in creating a consistent and theoretically impregnated narrative, while still allowing for an understanding of the detail and cultural variation of the culture studied. The balancing act in this thesis has involved analysing what happened in the nursing homes from different critical perspectives without distorting what was learned in the field. The critical perspectives helped questioning the taken-for-granted, but also helped to make visible the discursive effects at play in the nursing home culture (Hammersley & Atkinson, 2007).

6.2 THE NURSING HOME SETTINGS

To gain access to the nursing homes, a municipality was selected on the basis that it was medium-sized (140,000 inhabitants) and situated in central Sweden. Initially, the director of care for older persons in the municipality was contacted in order to make a presentation of the research project. Then the director invited all heads of units of each nursing home that was municipality-run to meet, to provide them with information about the research project. There were three of five heads of units who participated in the meeting. One head of unit had missed the invitation that was sent out by mail, and one head of unit declined to participate

due to ongoing organisational changes. The present heads of units gave their approval for their staff to participate in the research project, provided that the nursing staff gave their informed consent. In the nursing homes the contact was handled via three “facilitators”. These acted as liaisons and arranged the practical issues related to the research project. They made sure that I obtained the keys to unlock the nursing homes and necessary information about the nursing homes. They also helped to form the groups of nursing staff who were interviewed during the data collection based on the research project’s inclusion criteria (study II). They also supplied me with the documents I collected and analysed (study I).

The three nursing homes were built in the 1990s. On the municipal website, a distinction was made regarding the different types of special housings; service apartments, nursing homes and group homes. The nursing homes had a total of 106 (36 +36 +34) apartments and offered around-the-clock service and care to older persons with great care needs, who had become needs assessed and were offered accommodation. The nursing homes were similar to each other when it came to architecture and planning, both their interiors and exteriors. The apartments were divided into three different floors of apartments located on either side of corridors, which were often linked through a central kitchen and dining room. In close proximity there was also a dayroom, laundry room, store room, storage room, the office of the head of the unit, the nursing staff’s own spaces such as a coffee room, and a staff toilet.

In each nursing home there was an opportunity for the residents to go outdoors in the form of a terrace or balcony. The furniture was of various designs and older ornaments and artwork were common items of decoration. The kitchen was the hub and starting point for many of the activities that took place in the nursing homes. It was there that all meals were taken, but also a place for the residents to exercise and take part in musical entertainment. The radio and television were often on in the background. Each resident’s apartment was approximately thirty square meters in area, with a kitchenette, bedroom and a large bathroom. The wallpapers were light in colour. The beds belonged to the nursing homes to ensure effective ergonomics, but otherwise the residents decorated their own apartments with their own furniture. Linen, clothing, and supplies such as personal hygiene items were the responsibility of the residents and their relatives to arrange.

In the nursing homes there were set routines; a predictable and recurring work schedule for each shift. The nursing staff worked day, evening or night shifts. The night staff did not work dayshifts and vice versa. Each shift began with a hand-over-reporting among nursing staff that completed and commenced their shifts. In those reports, all information that had significance for the care of the residents was communicated. After the report, the work was distributed among the nursing staff, which could be about the showers schedule for the residents, social activities during the day and visits to the hairdresser and for foot care. In general, each member of the nursing staff was responsible for the same residents each time they worked, in order to provide continuity and safety for the residents. The majority of the residents were attended in rounds by a doctor, who visited the nursing homes regularly. At these rounds, which were conducted in the nursing homes, the registered nurses also

participated. In addition to registered nurses, enrolled nurses and nursing assistants provided the residents with care. In the nursing homes, there was also a head of unit and administrative staff. A dentist, physiotherapist, occupational therapist and a property manager were also linked to the nursing home, although they were not situated there permanently.

6.3 PARTICIPANTS AND RECRUITMENT PROCEDURES

During arranged meetings at each nursing home, the nursing staff were informed about the research project. I described the various components of the research project with the help of a PowerPoint presentation. I also outlined what my physical presence in the nursing homes would mean for the nursing staff. They had the opportunity to ask questions about the research project during the meetings.

Although I moved between the nursing homes during the data collection period, I basically visited the nursing home that I have called number 1 first, then the second and finally the third. When arriving in the nursing homes, on the first day of fieldwork, all nursing staff received both written and oral information about the research project. The information was a short version of the overall information provided during the previous meetings. Subsequently, those who wanted to participate provided their informed consent in writing. The inclusion criterion regarding the nursing staff was that they should be permanent employed, assuming that anyone with steady employment had full insight into the nursing home structure as opposed to someone who deputised or was a summer employee. There was a total of 42 nursing staff of which one declined to participate. Although the residents were not subject to the research project, they also needed to provide their informed consent because they dwelt in the environment that was being studied. When a resident did not want to participate in the research project, their wishes were taken into account by not intruding in his or her apartment in the participant observations of the nursing staff. Information about the research project was posted on the information boards and in the elevators, while the research project was being conducted. The demographics of the nursing staff included in the study are described in Table II.

Table II. Demography of the included nursing staff

	Regular staff	Women	Men	Ethnicity	Age range	Job title	Employment level	Work experience (years)
Nursing home 1	9	8	1	European	37-64	1 head of unit 1 registered nurse 5 enrolled nurses 2 nursing assistants	75-100%	9-17
Nursing home 2	25	24	1	European Hispanic Asian	25-63	1 head of unit 1 registered nurse 17 enrolled nurses 6 nursing assistants	37-100 %	5-17
Nursing home 3	7	6	1	European Hispanic Asian	42-60	1 head of unit 1 registered nurse 4 enrolled nurses 1 nursing assistant	50-100%	3-8
Total	41	38	3	European Hispanic Asian	25-64	3 heads of units 3 registered nurses 26 enrolled nurses 9 nursing assistants	37-100%	3-17

6.4 DATA COLLECTION AND DATA ANALYSIS

In the following section, the data collection and data analysis are described separately for each study (I-III). All data were collected based on the focused ethnographic method and each study is related to a specific part of the ethnographic fieldwork. A timeline of the fieldwork is presented as follows:

Table III. Timeline of the focused ethnographic fieldwork 2010-2011

Field notes from:					
participant observations,					
formal/informal	—————→				
qualitative interviews,					
gathering of documents					
(study I)					
Individual qualitative interviews					
with relatives (study III)					—————→
Focus group interviews with nursing staff					→
(study II)					
	2010				2011
	Sep	Oct	Nov	Dec	Jan

I will share some overall starting points related to the data collection and analyses in this thesis. Firstly, even though the data were collected from three different nursing homes (sites), the data have been analysed as a coherent whole, but still with consideration for each aim. Secondly, the interest in analysing and explaining the conditions for relatives' involvement was built upon what both nursing staff and relatives have said and done in the nursing homes. Thirdly, the analyses started simultaneously with the data collection. This means that I started to reflect upon what people told and showed me in situ, which also allowed me to continuously put forth new questions to deepen my understanding. Roper and Shapira (2000) describe this process as linking emic (insider) meanings with the researcher's etic (outsider) analyses of those meanings. Linked to the above table, I moved between these positions (insider/outsider), back and forth through the fieldwork, as part of a dynamic movement. My intellectual distance as both an outsider and researcher partly enabled me to analyse what the informants did and also allowed me to explain the meanings they ascribed to their actions through the lens of the critical perspectives. The analysis was thus conducted in dynamic

movement in consideration for the focused ethnographic method, the discourse and thematic analyses of the data gathered during the field work, and the critical perspectives.

The process of analysis undulated back and forth, but on an overall level it contained the following parts: a first-indicative tentative analysis was made in the field (etic) of what was said and observed in the field (emic). Thereafter, systematic discourse and thematic analyses of the field notes, interviews and documents, were conducted (etic) (Allen & Hardin, 2001; Baxter, 1991; Braun & Clarke, 2006) outside the field. Being integrated with the above-mentioned process, the critical perspectives were used as “lenses” through which the talk and actions of nursing staff and relatives (emic) were tentatively analysed in the field (etic). They were also a part of the further processing during the more systematic analyses (etic) made outside the field. Finally, in the writing of this thesis I completed a condensed re-representation of the different studies (I-III), which has been put into an overall context which then became the product of the ethnographic process.

6.4.1 Study I

This study took its point of departure from the notion that gender is something that is constructed and done by the nursing staff (West & Zimmerman, 1987). In order to describe how this was articulated among nursing staff, this part of the fieldwork consisted of participant observations, formal and informal interviews, and the analysis of documents.

The data collection included 41 nursing staff who had given their informed consent to participate. The collection of data involved the nursing staff extensively in this part of the fieldwork, as I visited the nursing homes frequently and intensely during this period. Each time my work team had received a report within the working shift, I adjusted to the division of labor that was planned for the day. I mostly followed one specific nursing staff member during the day in order to get a clear understanding of the daily routines. However, this individual varied from shift to shift. Sometimes it was difficult to know how involved I should be in the daily routines. At times the nursing staff asked me to help in the care of the residents; it could be about feeding, bed-making and transfers. I tried, wherever possible, to be flexible and responsive because this was an opportunity for me to learn as much as possible from them their routines and reasonings.

What I observed, I jotted down in my computer as field notes and in memos in situ. In each nursing home, I had my own temporary working area where I sat down and worked on my computer. The nursing staff soon got used to this and accepted that I took notes during the shifts. The field notes consisted of both descriptions and my own reflections. From what I observed, I tried to get a dense story linked to the purpose of the study by asking the nursing staff to tell me more and to expand on their reasoning. These informal interviews could, for example, take place in the kitchen, hallway and during coffee breaks. Where possible, these were digitally recorded and transcribed. Formal and more structured interviews with the heads of units and some registered nurses were also conducted. During these interviews, I used an interview guide as support. The focused questions touched upon relatives,

involvement and routines in the nursing homes and encouraged the nursing staff to reason about these areas. To supplement the fieldwork I collected some welcome brochures intended for residents and their families when they moved into the nursing homes. An overview of the data collection is accounted for as follows.

Table IV. Overview of the data collection for study I

	Participant observations (number)	Participant observations (hours)	Informal interviews (number)	Formal interviews (number)	Documents (number)
Nursing home 1	14	87	6	2	1
Nursing home 2	9	47	7	2	1
Nursing home 3	7	46	5	1	1
Total	30	180	18	5	3

During the fieldwork, the nursing staff told me about different gender aspects of their work and also spoke in relation to the relatives they met (emic). Generally, these discussions focused on what they perceived were biological sex differences between men and women, which also ascribed gendered meanings in relation to the relatives. For example, one of the informants told me that it was a bit “strange” and “odd” that a male relative wanted to be involved in the intimate care work of his mother. However, that a daughter-in-law or a wife did engage in the intimate care of a male resident was described as “natural” and was usually also welcomed among nursing staff. When I heard of these reasonings, I had my “doing gender” glasses on (etic) (West & Zimmerman, 1987) in order to make a premature analysis on how gender was constructed and reproduced and how this contributed to the gender order in the nursing homes. This reasoning, based on male and female differences linked to a gendered division of labor, occurred quite often. Nevertheless, there was also another reasoning (emic) based on differences, but this time it concerned the relatives in relation to the nursing staff. If the starting point was that women were accepted as informal caregivers in the intimate care work to a larger extent than male relatives, the overall and surprising division of labor dealt with the nursing staff’s and relatives’ shifting caring responsibilities. In the table below, an example of this reasoning is shown in an analysis of an interview transcript (etic).

Table V. Example of the analytical process from meaning units to theme

Meaning unit	Condensed meaning unit	Code	Theme
We are experts in caring and they are not. But then, they think that they know their mom or dad that we care for and I can understand that. But that was when they were healthy, not now...	The staff are formal caregivers and the relatives are informal caregivers	Formal and informal caregiving	Division of formal and informal caregiving – a matter of contributing without competing
Relatives can cheer up the older persons' everyday life through socialising because we have to focus on the daily caring activities and we do not have the same time as relatives	Relatives contribute with a social dimension that the staff say they do not have time to engage in	Relatives can help with the informal caregiving	

In line with Baxter's (1991) analytical steps, I first read through the field notes, the interview transcripts and the documents to obtain an overall picture of the data. Then I marked sections of the text as condensed meaning units. More specifically, it meant that I was looking for passages of text that demonstrated how the nursing staff did gender through their speech and actions based on their gendered assumptions, in relation to the relatives (etic). Further, the condensed meaning units were turned into codes that represented the core of the analysed gender meanings, in this case the division of formal and informal work of nursing staff and relatives. Finally, these codes were formed into new abstracted entities in three different themes presented in consideration of gender display theory. This analysis not only describes traditional gendered patterns between men and women in the nursing homes but also provides broader meanings of the division of labor connected to additional dynamic binaries besides gender.

6.4.2 Study II

The starting point for this study was the focus on the biopolitics of an "involvement discourse" (Allen & Hardin, 2001). To identify the discursive effects of the "involvement discourse", I conducted focus group interviews with the nursing staff as part of the ethnographic fieldwork. Focus group interviews are relevant when finding out how a group collectively constructs different meanings regarding a topic (Roper & Shapira, 2000). The facilitators in the nursing homes helped me to form the groups of four to five persons in each group. All group participants should have been permanent employees and I also asked the facilitators to account for gender representation and other social categories such as ethnicity

and age. It was also desirable that the nursing staff who participated had a variety of numbers of years of work experience, as the objective was to obtain as multifaceted focus groups as possible. This selection process resulted in that I conducted six different focus group interviews over a period of one month. The nursing homes were represented by two groups from each setting. Each interview took about one hour and was conducted in the nursing homes, adjacent to the nursing staff's regular shifts. The demographics of the informants are presented in Table VI.

Table VI. Demographics of informants in study II

Participants	Age range (years)	Work experience (years)	Employment level (%)	Origin
27	36-63	2-18	37-100	European Asian

Additionally, the distribution of job titles is presented below.

Table VII. Distribution of job titles in the focus groups, study II

	Registered nurse	Enrolled nurse	Nursing assistant
Focus groups 1	0	3	2
Focus group 2	0	2	2
Focus group 3	0	4	0
Focus group 4	0	3	1
Focus group 5	1	3	1
Focus group 6	1	4	0

The interviews began with an opening question where I asked the nursing staff to describe how an ordinary day might look in the nursing home. Based on this question, I asked focused follow-up questions on the basis of an interview guide. The participants spoke to a varying degree and seemed to occupy different statuses within the group. As well as me, the last co-author participated during the focus group interviews. My task was to listen, to ask new questions and follow-up questions. The co-author was more active in the end of the interviews and asked some overall questions in relation to what I might have missed. Before the interview ended, the participants had the opportunity to withdraw, change or correct what they had said during the interviews.

The analysis was conducted by means of asking the following questions based on the methodological implications outlined by Allen and Hardin (2001):

- What differences do the nursing staff mark and construct through their language linked to the practice of involvement for relatives in the nursing homes? What “involvement discourse” is identifiable?
- What other groups or institutions in society have historically marked and constructed differences in a similar way and what are the consequences?

- What possible subject positions are available for relatives, based on the “involvement discourse”?

First, I did a naïve reading of the focus group interview transcripts. When I intuitively understood the overall content, I put the first question to the data. Units that were about involvement, explicitly, served as sources of data, when identifying key statements that were recurring during the interviews. These were discussed among the co-authors. The key statements constituted the upholding structure of the “involvement discourse”. In a second stage, the second question was put to the data, but this time in consideration of the gathered key statements and how they could be understood as supportive to an “involvement discourse”. The “involvement discourse” was then applied to a broader societal context, where similar discourses of involvement were identified, historically. In a third stage, I returned to the transcripts, now focusing on the key statements that provided different subjects’ positions. By distancing these key statements from the informants, an alternative reading was conducted, creating public models. The different stages of analysis were discussed throughout the process among the co-authors.

6.4.3 Study III

In this study, fifteen relatives were qualitatively interviewed to analyse their dynamic intersecting social positions conditioned by various social categories (Crenshaw, 1989). They were recruited purposefully from the nursing homes and were expected to speak Swedish. Additionally, they had to be healthy enough to participate in an interview. Six relatives were recruited by me at a meeting for relatives in one of the nursing homes. The rest were recruited with the help of the facilitators and by the heads of the units. The qualitative individual interviews took place during a period of two months during the fieldwork, either in the nursing homes or in a place that suited the relatives. Also, in this study, an interview guide served as a support. Before the interviews were conducted, each informant provided their informed consent in writing. The initial question posed to the relatives was; how can you be involved in the care of your family member living in the nursing home? The relatives always had the opportunity to revise what they had shared, at the end of the interviews.

Braun and Clarke (2006) argue for their thematic analysis when dealing with large text materials where one is looking for a specific focus and depth, as in the last study of this thesis. The focus was linked to the intersectional perspective, where power structures were made visible, as highlighted by Crenshaw (1989). In order to become familiar with the data and obtain an overall sense of the material, I read through the interview transcripts several times. The data were then read again while the interviews were simultaneously played back from the digital recorder. When reading, passages of text were marked where the informants linked their social positions to gender, ethnicity, age/generation and class. For example, could the discussion might be about female relatives who talked about their caring responsibility as a “natural” female characteristic. It could also include male relatives’ stories about their influence and possibility for involvement thanks to their social statuses. The marginalised positions of immigrant relatives were also a focus in the analysis. The emphasis in this study

was thus on the interacting power relations related to gender, ethnicity, age/generation and class and how they interacted. For example, to be a woman with a specific ethnic background may provide certain subjective positions that are both privileged and unprivileged, depending on context. Codes covering these areas were grouped into comprehensive themes. Each theme was illustrated with representative quotations, and represented how the involvement of relatives was conditioned by different social categories.

7 ETHICAL CONSIDERATIONS

Because the research project involved human beings, the relevant ethical guidelines as proclaimed in the Declaration of Helsinki (World Health Association, 2008) have been followed. Additionally, the research project has been approved by the Regional Ethical Review board in Stockholm, with reference number 2010/658/-31/5. The director of care for older persons, as well as the heads of each unit had given their permission to conduct the research project in the nursing homes for which they were responsible. The ultimate goal has been to protect the informants (nursing staff and relatives) who were included in the research project. The informants have received both written and verbal information and they had the opportunity to decide whether or not they wanted to participate in the research project. If they decided to participate, the informants provided informed consent in writing. The nursing staff and the relatives have had the right to end their participation in the research project at any time, without giving reasons for doing so. Although the research project itself did not concern the residents, informed consent was sought from them as well, as the participant observations of the nursing staff sometimes took place in the apartments of the residents. In the event that some residents did not give their informed consent, these wishes were respected by not entering their specific apartments.

In the cases the interviews with the informants that were recorded, the digital files achieved were stored safely in a password-protected computer, intended only for use during the research project. Similarly, all data materials such as transcribed interviews and field notes were kept in binders in locked cabinets in the university responsible for the study. In all studies (I-III), details of informants such as their names, ethnicity, age and place of work or residence were decoded in order to protect the identity of the informants. For example, the names of informants were consequently replaced with similar names. Anna could become Maria, and Mohammed might be changed to Ahmed. One specific ethnicity was replaced by another. For example, if someone stated that s/he came from Finland, it might be changed to Norway. Demographically, the ethnic backgrounds of the informants were linked to continents, instead of exact countries. The ages of the informants are fictitious, but are still near the actual ages because age, as other social categories, is thought to be important in the life conditions of individuals.

In ethnography, there are some major ethical aspects that need to be highlighted (Roper & Shapira, 2000). Firstly, the researcher conducting field work is considered to be a co-creator in the interaction with the informants. To be reflexive thus includes an awareness of the dynamic interaction between the researcher, the field and the persons studied. This has led to reflections of how I may have influenced the data collection and analyses, based on my previous understanding and knowledge about health care settings, nursing staff and relatives. My experiences as a registered nurse have probably coloured the data collection and data analysis, because the nursing home culture is similar to that of health care in some sense. However, my lack of experience in older persons' care, both as a professional and as a relative, I would like to consider as a resource. The nursing home culture has been a

completely new world for me to discover and the ambition has been to be curious, humble, non-judgmental and flexible during the field work. In ethnography it is crucial to search for differences to obtain a holistic picture from many kinds of perspectives (Roper & Shapira, 2000). This I have tried to do, by not assuming things and taking things for granted, but to continually put forth new questions and to encourage the informants to share their knowledge. Because the research project is about involvement, it has caused me to reflect on how I have made myself involved in the everyday matters that actually only concern the nursing staff, residents and their relatives. The nursing staff involved me in their daily work in a generous manner and sometimes I have been surprised by their outspokenness. This, I am thankful for, as it is not obvious that I should have been involved as a stranger to them. The confidence I have been given implies an ethical responsibility to provide a nuanced and faithful picture of their workplace. The number of informants included in this thesis is high and without in any way questioning the autonomy of the nursing staff, I have wondered if it would have been possible for them to not participate in the research project. The nursing home culture is in some sense characterised by a collective stance which may make it difficult to oppose what a superior, researcher or a colleague may decide.

Secondly, in considering both an emic (inside) and an etic (outside) perspective (Roper & Shapira, 2000), I have moved between these positions. As an insider, I have sometimes felt lost, lonely and naïve in the effort to grasp the cultural meaning. Initially, in each nursing home, much time was spent in getting to know the informants to obtain their trust to be able to learn things about their culture, values and rules of behavior. At the same time as being an outsider, I have needed to consider the research project when collecting and analysing data with a scientific distance in relation to the field. From the etic perspective, I have tried to distance myself to be able to describe the nursing home culture from an ethnographic point of view. Thirdly, it has also been important to provide the nursing staff with correct and relevant information about the intention of the research project and my role as a researcher.

8 FINDINGS

In this section, the most important key findings reported in the papers (I-III) will be presented under three different subheadings.

8.1 BEING PERCEIVED AS A “VISITOR” IN THE NURSING STAFF’S WORKING ARENA

The relatives were primarily considered as “visitors” in the nursing homes. This conditioned both the characteristics and level of their involvement. The social position as “visitor” was constructed through an overall division of labor that was partly based on gender role assumptions. This division held the relatives accountable for their specific caring activities in the nursing homes.

The nursing staff seemed to construct differences between themselves as nursing experts and relatives as informal carers and “visitors”. The nursing staff sometimes attributed themselves with having greater power than the relatives who were awarded with the social position of “visitors”. The basic principle suggested through routines and reasoning seemed to be that relatives were welcome. However, they were also expected to contribute as long as they did not compete with the nursing staff. The conditions of relatives’ involvement could be said to be based on a dichotomised reasoning and legitimised by social categories such as gender.

The manoeuvring space of relatives seemed to be limited, linked to the notion that they performed unpaid care in their leisure time. The code of conduct for relatives, which was in some sense prescriptive, assumed that relatives would mainly be in the public sphere and help the nursing staff with practical and social issues. The intimate care was considered to be the responsibility of the nursing staff. This was in respect for both the residents and the nursing staff. Being a man and wanting to be involved in the more intimate care was regarded as being a bit strange and inappropriate. In contrast, being a female relative and assisting residents with toileting and washing was considered to be in alignment with the code of conduct. In this way, the social positions seemed to be dynamic related to gender. This may be linked to the notion that the presence of women in nursing homes was perceived as “natural” and unproblematic based on gendered assumptions.

The nursing staff seemed to construct “we and them” based on family characteristics such as relationships, social status and ethnicity among the relatives. The relatives who were considered to be demanding and had difficulty with social interactions were sometimes assigned less manoeuvring space compared to the majority. Relatives with ethnic backgrounds “other” than Swedish were now and then expected to adapt to Swedish conventions in order to blend into the nursing home activities. It seemed as though these cultural demarcations were part of an important process of the setting of boundaries because it circled and reinforced the professional identity of the nursing staff.

8.2 REPLICATING THE FAMILY – BIOPOLITICS IN FAMILY-ORIENTED DISCOURSES

The biopolitics in the “involvement discourse” could be linked to a discourse resting on a “new” versus “old” family rhetoric. Through the language, the nursing staff placed themselves in the families. The family rhetoric became about upholding assumptions and legitimised the “involvement discourse” in the nursing homes and provided different subjective positions for both nursing staff and relatives.

The first assumption upholding the “involvement discourse” showed how the nursing staff, as members of a “new” family, replicated the “old” family of the resident, ascribing themselves the crucial role as formal caregivers. The coalition between them and the residents seemed to be legitimised by them being professional caregivers. To be “part of a family” involved a 100% responsibility for the residents. It seemed as though the nursing staff took a step into the families and were involved on several levels. In the subject positions as “new” family members, they engaged wholeheartedly in all parts of the residents’ lives. This included not only direct physical care, but also engagement in the residents’ family relations. The “involvement discourse” seemed to be based on both personal experiences and a common perception among nursing staff.

The second assumption that contributed to upholding the “involvement discourse” was about how the nursing staff mainly listen to the residents, even though the contribution of relatives and staff-family collaboration may have resulted in quality care and well-being of the residents. This seemed to be based on a top-down family configuration (staff-residents-relatives). This positioned the nursing staff in the center of the families which became crucial for the involvement of relatives. This gave them the right of interpretation and the opportunity to decide if relatives were listened to or not. In order to uphold this assumption, a distanced professional approach was valued among nursing staff. To “keep the relatives short”, was a more common practice than negotiating to involve relatives.

The third assumption that maintained the “involvement discourse” was based on a division of labor and a formal and informal care mandate. This conditioned what caring activities relatives could be involved in. In practice, this meant that relatives were supposed to hand over the care responsibility in due course. Relatives who found this particularly difficult eventually had to let go in order to fit into the “new” family order. With this, the involvement of relatives was kept within certain boundaries that the relatives needed to address. As “visitors” the relatives should engage in socialising with the residents, while the nursing staff took the responsibility of the intimate care, a domain that particularly seemed to belong to them with a formal mandate to care.

8.3 INTERSECTIONAL PERSPECTIVES ON FAMILY INVOLVEMENT IN NURSING HOME CARE: RETHINKING RELATIVES' POSITION AS A BETWEENSHIP

The relatives were in a social position that may be described as a *betweenship*. This betweenship meant that the relatives found themselves squeezed in-between the expectations of their older family members, the nursing homes and the nursing staff. The betweenship was conditioned by interacting gender, ethnicity, age/generation and class categories related to their involvement.

Both gender and generation had an inevitable impact on how the relatives described their involvement. While male relatives could accept that they would hand over the caring responsibility to “someone else”, the women felt that they did not have the same manoeuvring space to do that. Although the women were aware that they were likely brought up to take care of and be caring, it was not easy to break this pattern. They themselves believed that it was “natural” that they should be responsible for their older family members. They also saw it as their generational responsibility to care for their older relatives. What they had received in the form of warmth and security during their upbringing they wanted to give back to their own parents, a belief that seemed to be handed down from generation to generation, mainly between women.

The relatives now and then perceived that they needed to serve as spokespersons and mediators in the nursing homes for the benefit of the residents. The betweenship between nursing staff and residents became clear when relatives had to step in as interpreters to enable the nursing staff to understand the residents who did not speak Swedish. Even the residents had expectations that the relatives would bring food and interpret to make them feel comfortable. This task seemed to be attributed mostly to daughters and daughters-in-law. These female relatives were also expected to help the residents with more intimate care, both linked to them as women and linked to their ethnicity. Relatives described how they sometimes felt helpless and alienated when they were met with suspicion among the nursing staff. They were afraid that possible opinions concerning the care work would indirectly affect the residents. For relatives, it was about being able to negotiate and be flexible, in order to not be attributed with a position as “the Other”. This seemed to be further complicated if they did have limited social capital.

Some relatives highlighted an alternative image. This picture was based on relatives' accounts about a flexible and influential social position. They described a manoeuvring space where they had the opportunity to influence and make different choices concerning their older family members. They also had the possibility and energy to socialise with other residents and spend some time with them in the public areas. What made this possible was explained as a form of social capital that gave these relatives a hegemonic position in the nursing homes. Access to social networks and mutual recognition between relatives and nursing staff gave them privileges. That some of these relatives were highly educated with

stable economic backgrounds and were perceived as nice, strengthened their positions further. This was sometimes at the expense of the relatives who did not have the same social capital.

9 DISCUSSION

In the following section the findings will be discussed in relation to previous research and linked to the critical perspectives. Thereafter, the methodological strengths and weaknesses will be accounted for.

9.1 CONDITIONS FOR RELATIVES' INVOLVEMENT IN NURSING HOMES

How can the conditions for relatives' involvement be understood? The specific contribution of this thesis includes some main findings that have stemmed from each paper (I-III), responding to this question. The discussion will be based on these main findings:

- The involvement of relatives is conditioned by the notion that relatives are considered as “visitors”. This notion conditions both the characteristics and level of caring activities that relatives may be involved in in nursing homes (I).
- In the talk about involvement in nursing homes, family-focused metaphors are used as natural assumptions in the upholding of the biopolitics of the “involvement discourse”. The “involvement discourse” conditions the involvement of relatives because it partly legitimises the replacement and exclusion of relatives in the care of the residents (II).
- Relatives' involvement is conditioned by being positioned in a betweenship. Being a relative means taking on caring responsibilities, sometimes squeezed in-between the expectations of older family members, the nursing homes and the nursing staff (III).

Overall, the findings show that the conditions for relatives' involvement may be understood as quite traditional and predictable in nursing homes. This is despite the high quality of care provided by the nursing staff and also in view of the scarce personnel and organisational resources available today in Swedish care for older persons. Firstly, relatives seem to be considered as “visitors” in the nursing homes. This appears to have greater impact on the involvement of relatives than previously highlighted. It has been described as “natural” that relatives have been called “visitors”, which may be a part of the institutional structure and a result of the traditional division of labor in nursing homes. However, this thesis shows that the meaning of the concept “visitor”, when it comes to the involvement of relatives, is linked both to power and knowledge about care. From the light of the doing gender perspective it has thus been possible to provide a broader understanding of the concept of gender. Gender not only conditions the involvement of male and female relatives in isolation from each other, but also within these groups, in relation to a division of labor and constructed binaries (West & Zimmerman, 1987). The temporality of different subjective positions seems to be more dynamic and visible in some contexts than others. As a “visitor”, there are routines and reasonings you have to consider and take into account that sometimes also set boundaries for the involvement of relatives in the care of the residents. By linking language to practice and identifying subject's positions (Allen & Hardin, 2001), the findings also reveal that relatives

have to adjust to the biopolitics of an “involvement discourse” that is linked to the notion of relatives as “visitors” with limited involvement. The “involvement discourse” is built up on assumptions about the “nature” of family and is articulated in terms of family metaphors in the nursing homes. The discursive practice is about supporting relatives to gradually hand over the care responsibility to the nursing staff. This forwarding, legitimised by the biopolitics of the “involvement discourse”, is usually not questioned, as it is considered to be a relief for relatives to hand over the care responsibility. This may be related to historical biopolitics, building on notions that it is the main responsibility of the Swedish “caring state” to take care of the older population, an explanation that is possible to draw from when asking historical questions in the deconstruction of involvement discourses. This is also an example of the power of everyday discourses in relation to the consequences of medical discourses. Lastly, being a relative sometimes means finding oneself in a betweenship, squeezed between the expectations of older family members, the nursing homes and the nursing staff. As expressed by relatives, this is regardless of whether they wish to be involved or not in the care of their older family members. Based on intersectionality theory (Crenshaw, 1989), this betweenship, as a social position, implies both advantages and disadvantages for relatives in the nursing homes depending on intersectional social categories. Gender, ethnicity, age/generation and class have thus been made visible as important conditional social categories for the involvement of relatives. It seems as though the relatives more or less pass into an institutional pattern where they, in time, become aware of what and how they can be involved in nursing homes.

9.1.1 Being perceived as a “visitor” – a pervasive watershed

The conditions for relatives’ involvement in nursing homes today, may be understood in the light of the development of Swedish older persons’ care a few decades previously. Trydegård (2000) describes how the care responsibility of the older population has historically shifted from the family to the state, and then from the state back to the family. This development is a consequence of the introduction of the Ädelreform in the beginning of the 1990s but also a result of poor state finances. Nowadays, the “aging in place” principle is more the rule than the exception, and the relatives as informal caregivers represent a crucial social bearing support function in the enabling of the care of older persons living at home (Lagergren, 2002). When the care needs of the frailest older persons become too complex, they eventually move to special housings such as nursing homes. At this stage, previous research illustrates that relatives have been highly involved in the care of their older family members for quite some time (Socialstyrelsen, 2012, 2014a).

Moreover, research shows that relatives wish to continue to be involved in the care of their older family members, even after the admission to nursing homes (Baumbusch & Phinney, 2014; Milligan, 2006). However, this thesis shows that the staff in the nursing homes assume that the relatives will hand over the care responsibility to them as caring institutions. Many relatives in Sweden perceive that the public care sector should have the main responsibility for the older population, but still they want to be involved and have difficulties expressing

what kind of support they need (Socialstyrelsen, 2014a). Here, it is possible to see a discrepancy in the view of caring responsibilities and involvement of relatives and nursing homes. In nursing homes, it is considered to be a relief for relatives when the nursing staff take over the care responsibility from relatives. However, relatives want to continue to be involved on their own terms with the support of the nursing staff (I). This is expressed when the nursing staff mean that it is their job as paid caregivers to provide professional care. The relatives as “visitors” are expected and encouraged to sit down, relax and have coffee (I), something that may be difficult and challenging when one is accustomed to taking on the full care responsibility for someone close.

The results of this thesis show that relatives are both considered as “visitors” (I) and sometimes positioned in a betweenship (III). This is in line with previous research that has focused on the transition and complexities involved for relatives to find new caregiving roles in the nursing home context (Davies & Nolan, 2006; Kellett, 2007; Kong, 2008). Baumbusch and Phinney (2014) have specifically stated that it is problematic that the concept of “visitor” has not been analysed from a critical point of view before. However, while earlier studies have focused on how to support relatives in the institutionalisation process per se, this thesis wants to question if it would be possible to change the focus, starting from the views of relatives and the residents instead. To be considered as “visitors” has consequences for the characteristics and level of caring activities that relatives may be involved in because it builds on notions about formal-informal care, paid-unpaid caregivers, men-women, working-visiting and expert caregivers-novice caregivers. Doing these differences, constructs a division of labor where the relatives’ knowledge about care regarding the residents is considered to be outdated and quite irrelevant. This finding is in contrast with previous research that emphasises that the biographical information (Habjanic & Pajnikihar, 2013) provided by relatives and the involvement of relatives are beneficial, both to residents, (Gaugler, 2006) and relatives (Davies & Nolan, 2006) and sometimes also to nursing staff (Zimmerman et al., 2013).

It appears that although the nursing staff welcome the involvement of relatives on a general level (I, II, III), they should be involved in a certain manner without having to compete with the nursing staff (I). This finding is in line with the results of a study conducted by Bauer (2006), where relatives were sometimes perceived as competitors and not as a resource. Further, research by Natan (2008) also supports this notion, that there is a difference between which caring activities relatives are engaged in, in relation to what the nursing staff is expecting of them. The overall view of the nursing staff was that relatives should be involved to a greater extent in the caring but with a focus on socialising and external activities. However, in contrast, the relatives wanted to be more involved in the physical care and also to be provided with continuous updates about it.

While relatives are expected to behave as “visitors” (I) and informal caregivers, they themselves and their older family members, in addition to the nursing staff and nursing homes, seem to have certain expectations of them (III). This has not been highlighted much in

earlier nursing research, but Grundy and Henretta (2006) and Vreugdenhil (2014), within the field of sociology, suggest that this may be understood as an act of solidarity between generations. The care responsibility of middle-aged women can be seen as being “sandwiched” between the caring needs of aging parents and their grown-up children. This thesis shows that women in particular, as informal caregivers, see it as their main responsibility to take care of aging parents. It can be related to gendered generational notions where the care is a proof of “payback” between generations, but also as part of a “natural” gendered role of being a woman. The caring responsibility seems to be handed down from generation to generation, particularly by women. This picture is supported by previous research that points out that both men and women are highly involved in the care of older family members, but with an emphasis on caring middle-aged women (Ulmanen, 2013). The involvement of relatives is thus not only conditioned by a difference policy where relatives are considered as “visitors” (I), but also by gendered generational competing musts, with a focus on women’s care responsibilities (III).

9.1.2 Replicating the family – looking in from the outside

In the talk about involvement in the nursing homes, family rhetorics about “new” versus “old” families seemed to play a crucial role in the replication of the residents’ families (II). The relation to the residents and the responsibility of the care provided by the nursing staff seemed to rest on family-oriented discourses. This finding is supported by Berdes and Eckert (2007), who have described that nurse’s aides use family metaphors in their work. The link to the family caring is partly a measure of the high quality care provided as a golden standard but also as a resource for how to deliver this extraordinary care. The residents in this thesis were described as being a part of a “new” existing family, which gave the nursing staff a specific mandate to care and replicate the relatives of the residents because they thought they had the formal competence to care. In this way they ascribed themselves self a central role, even though the relatives continued to be involved as the “old” family members. This finding is in line with previous research that shows that relatives try to find new caregiving roles by being socially active with their older family members, creating continuity (Davies & Nolan, 2006), keeping an eye on the care (Bern-Klug & Forbes-Thompson, 2008) and seizing possibilities (Kellett, 2007).

However, connected to the biopolitics of the existing “involvement discourse” in nursing homes (II), the risk may be that relatives would find themselves situated on the outside, looking in on the caring relations as described previously (Baumbusch & Phinney, 2014). Aligned with this concern, McVeigh et al. (2009) have identified that the greatest dissatisfaction among relatives has to do with a lack of information and communication in nursing homes and that relatives experienced that they were excluded from decision-making processes regarding the residents. McVeigh and colleagues suggest that if relatives are to be satisfied, there is a need for a replacement of the existing task-oriented approach in nursing homes. In order to reach this point, where relatives are involved individually with empathic awareness, the nursing staff need to be equipped with the relevant tools, partly in the form of

training. Further, as a consequence of the family rhetorics, the nursing staff seemed to see it as their task as “new” family members to protect the residents from their relatives in case there were disagreements (II). This finding is in line with what Bauer (2006) has stated, that despite a family-focused approach, relatives are still perceived as non-experts and that they interfere in the “real care”. He suggests that this situation will continue, as long as the task-oriented approach dominates in nursing homes and as long as there is a gap between policy and practice regarding the involvement of relatives. In a later study, Bauer (2007) also stresses the relevance of rethinking what is considered as “valid” knowledge about care and that the sometimes dominant position of nursing staff should be questioned. This approach may be linked to this thesis’ constructionist stance. Is it unavoidable and determined by nature that formal knowledge of care should be regarded as more valuable and more authentic in relation to informal knowledge of care?

Nevertheless, it has been described that the involvement of relatives in the nursing home context has been relatively favorable (Gaugler, 2006). Gaugler describes that the social positions of relatives in mental health care through the years has been quite exclusively related to a discourse about the patients’ integrity and autonomy, whereas the involvement of relatives in nursing homes has almost been at the expense of the residents’ autonomy (van de Bovenkamp & Trappenburg, 2012). Therefore, Gaugler (2006) suggests that it is crucial to be responsive to the needs of the residents because the involvement of relatives may lead to both positive and negative outcomes. Still, even though relatives do not have the formal right to make any decisions in nursing homes (The National Board of Health and Welfare, personal communication, Nov 2014), they usually play a crucial role in the lives of the residents (Gaugler & Ewen, 2005) and have an impact on their well-being (Gaugler, 2006).

In the biopolitics of the “involvement discourse”, there were also dynamics and opportunities for unreflected negotiation between nursing staff and relatives. This thesis shows that some relatives had opportunities to obtain more privileged social positions in relation to the nursing staff than others in the nursing homes (III). In previous research, the staff-family relationship has been thoroughly investigated. Although that research differs somewhat from the results of this thesis, the importance of cooperation and partnership between nursing staff and relatives has been carefully emphasised (Utley-Smith et al., 2009; Voutilainen et al., 2006). In relation to what was previously known about relatives feeling excluded and not visible by nursing staff (Westin et al., 2009), the findings of this thesis suggest that this may have to do with interacting power relations (I, II, III).

Although the impact of ethnicity has been pointed out as one possible explanation to “socially deviant behavior” among relatives (Bauer, 2006), it seems that intersecting gender, ethnicity, class and age/generation categories condition the involvement of relatives to a greater extent than has been highlighted before (III). Even gender and social capital seemed to play a specific role for the relatives when creating solid positions for themselves in the nursing homes. This gave them the space to set boundaries but also to be generous in relation to the nursing staff (III). O’Shea, Weathers and McCarthy (2014) have highlighted in their study

that relatives are satisfied overall with the nursing home care, although their caring roles become transformed. This thesis may explain why some relatives are more satisfied than others and is linked to intersecting power orders. However, Weman and Fagerberg (2006) point to the importance of taking organisational aspects and nursing staff's working conditions into account, as barriers to good staff-family relations. They describe that even though the nursing staff wanted to collaborate with relatives, they experienced a lack of information from the physician colleagues, a lack of organisational support and the withdrawal of relatives.

9.1.3 Relatives' position as a betweenship – a squeezed social position

This thesis shows that the involvement of relatives seemed to be conditioned by several competing musts. This might be understood as relatives being situated in a betweenship, squeezed by the expectations from older family members, the nursing homes and the nursing staff (III). In previous studies it has been described that relatives engage in all kinds of caring activities of their older family members in nursing homes. They are involved in the physical care, function as a psychosocial and emotional support, and monitor the care provided by nursing staff (Milligan, 2006). However, Gladstone, Dupuis and Wexler (2006) emphasise that the characteristics of care provided by relatives change as a result of the move to nursing homes. The relatives instead performed the care that they thought was expected of them in the nursing homes.

In this thesis the relatives sometimes found it difficult to cooperate with the nursing staff which made them feel powerless and alienated (III) and they perceived that they were expected to behave in certain ways linked to the notion of them as "visitors" (I). Chen and colleagues (2007) suggest that a conflictual staff-family relationship may lead to bad health, depression and burden among relatives. This thesis also shows that the nursing staff found dealing with relatives to be one of the most challenging tasks even though they thought they should be involved and played an important role (I, III). This does not seem to be specific to the included nursing homes, as it has been expressed before that relatives are now and then perceived as being demanding and difficult with naïve and unrealistic expectations. However, the option does not seem to be available that relatives should not be involved in the care, because then the nursing staff in previous research suggest that relatives do not seem to care enough about the residents (Bauer, 2007).

The different spectrum of characteristics of relatives based on gender and ethnicity (I) seem to have special importance for the betweenship position (III). Although the relatives were included as a natural part of the residents' lives in the welcome brochures and the nursing staff had an overall family-friendly approach (I), relatives sometimes experienced the opposite when trying to care for an older family member (III). For example, although most of the relatives were described as friendly and helpful, some relatives fell outside of this description. To be a man, wanting to be involved in the intimate care of a mother, was perceived by nursing staff as "odd" and a bit "strange", while it was considered to be "natural" for a female relative to do the same. This finding is partly in line with previous

research that has illuminated that relatives are not supposed to be involved in physical and intimate care (Natan, 2008). This thesis, however, shows that it seems to be more acceptable that women are involved in this type of care than men (I, III).

In relation to the nursing homes as institutions, the betweenship was articulated as leading to frustration and powerlessness among relatives (III). In this thesis, relatives were torn between the needs of the residents and the institutional notions. Lone and colleagues (2014) have described something similar, that relatives may feel vulnerable and powerless when they experience that the quality of care lacks. Relatives sometimes found themselves in a struggle for the benefit of their older family members, when being dependent on the nursing institutions. Experiences of disappointment, uneasiness and paternalism also appeared in these situations. In this thesis, it could be about different care needs of the residents that the relatives had identified that they wanted to point out (I, III). They were aware that they could raise the questions in the family council meetings or talk to the heads of units (III), however, from experience, the relatives knew that they could be perceived as demanding and challenging which made them hesitate and postpone voicing their opinions. Person (2008b) and Curry et al. (2007) suggest that a successful family council is based on institutional support and a caring philosophy where relatives are the focus. The family councils should provide the relatives with a forum where they can share their views about the quality of care in nursing homes. Instead, in this thesis, a division of “we and them” (I, II, III) was constructed in the nursing homes, which reinforced the position of betweenship among relatives. The question is; would it be possible to actively rethink the involvement of relatives, possibly not based on these constructed differences?

9.2 ALTERNATIVE ASPECTS OF RELATIVES' INVOLVEMENT

In summary, based on the findings in this thesis, the conditions for relatives' involvement seem to be intertwined and dynamic, but at the same time conservative and limiting in practice, and linked to power structures. This is although researchers have called for better organisational preconditions for nursing staff and clearer family-focused organisational policies (Voutilainen et al., 2006). Thus, there still seems to be a need for relevant training (McVeigh et al., 2009), fair staffing levels, and a nuanced understanding of relatives' and nursing staff's situations in order to provide quality care in nursing homes (Ryan & McKenna, 2014). A relevant question is; would it be possible to flip the picture presented in this thesis? To reconnect to the questions raised in the discussion, the answer would be yes. It is reasonably not given by nature or unavoidable that relatives should be considered as “visitors”, or that formal knowledge of caring is the sole “true” answer for quality care or that constructions of differences should appear as natural conditioning the involvement of relatives. In relation to previous research, it might be said that these systems are about role transitions, care practices, interactions and democratic engagement in nursing homes. This thesis suggests that the conditions for relatives' involvement also might involve learning, responsibility and emotions. From this alternative point of view it is perhaps the nursing staff

who should be considered as the pedagogical, professional and caring “visitors” in the nursing homes, for the benefit of the residents and their relatives.

9.3 METHODOLOGICAL CONSIDERATIONS

In order to reflect upon quality issues in this research project, the concepts of credibility, dependability and transferability will be discussed at an overall level (Patton, 2002).

Regarding the study’s *credibility*, it has been important to account for my own subjectivity that may have colored the analysis process (Bryman, 2012). It is likely that my previous experiences as a nurse, woman, relative and my participation in the public older persons’ care debate may have influenced the research project. To cope with this possibility, I have been open and honest about it because it is crucial to be aware of it to be able to manage its consequences. Regarding the recruitment procedure, it may have influenced the findings if the informants not had been hand-picked by me, the facilitators and the heads of units, and instead were randomly included. The risk is that the informants were chosen related to their willingness to speak about their involvement in the nursing homes. There is also a risk that the informants felt that it was difficult to decline to participate in the research project, when asked by a superior colleague. However, in qualitative research it is an accepted and well-known method to include people purposefully (Patton, 2002). The informants were also well informed about their right to end their participation in the research project whenever they wanted to. Collecting data over a period of some months may strengthen the credibility of the research project. This is because the experience of collecting data may have improved the quality of the data. Initially, it was challenging to observe and conduct interviews, but as time went by I felt more relaxed.

The analysis of the data is also an issue that needs to be discussed. The ambition has been to honestly reproduce what the informants have communicated. It is nevertheless understandable if they are not able to follow or recognise their views of the nursing home culture. This may be considered as the reverse side, when analysing data from different critical perspectives. In this sense, the critical perspectives become the dominating “lenses” through which the nursing home culture, in relation to involvement, was analysed. The strength of this method is that the critical stance provides new ways of understanding the social reality of nursing homes, but it may also be a weakness, in that other important aspects may have been left out. The co-authors have, independently of each other, reviewed the analyses in relation to the critical perspectives and then discussed them mutually. Additionally, the informants have had the opportunity to withdraw or revise their information in connection with each interview. The credibility of the research may have been enhanced, due to the diverse data collection approaches that the ethnographic method offers, all focusing on the conditions for relatives’ involvement.

The *dependability* of the research project has to do with both the researcher and the hardware used during the data collection (Bryman, 2012). Even though I had conducted qualitative interviews before, in using a digital recorder there was tension caused by the worry that

everything would work smoothly during the interviews. I always made sure that there was enough space on the digital recorder to store each interview and I brought with me spare batteries to avoid being out of power. I did not want to lose any data. Sometimes I found it difficult to place the digital recorder in front of the informants as I noticed that this hampered them when communicating their accounts. Some of the informants spoke after I had stopped the recording, and I tried to write down this valuable information afterwards. On occasions, it was hard to hear the informants speak because of noises in the environment and was also related to the fact that several nursing staff talked at the same time. Therefore, I tried to focus on one informant at a time during the qualitative informal interviews. Further, even though it may have hampered the group somewhat as we were two researchers conducting the focus group interviews, the quality of the interviews may have been enhanced by this collaborative effort. To be able to pick up on all of the important questions and issues raised during a focus group interview, it is valuable to have two facilitators. I practiced making participating observations in a convenient and responsive manner, and my skills improved over time. Perhaps the quality of the data might have been better if the data collection had been divided into separate periods. Then it would have been possible to digest the data and focus on one aim at a time. It would also have helped to develop further questions based on what I had been told, which could have been asked in forthcoming data collection periods. On the other hand, the concentrated and focused data collection contributed with a comprehensive understanding of the nursing home field and the period that I had to interfere in the nursing homes was limited. This may have been beneficial to the residents and their relatives, as the nursing staff's primarily task was to provide the best of care without me interrupting.

It is ultimately up to the reader to decide about the *transferability* of the research project (Bryman, 2012). If the findings presented in this thesis are generalisable in a qualitative sense, this is determined by the accuracy and transparency of the research process. The ambition has been to present the research process as thoroughly as possible. The findings or parts of this research may be applicable in similar institutions, similar to the nursing home culture. The transferability is also dependent on whether the findings are considered to contribute with something scientifically and practically valuable and new.

Finally, the weaknesses and strengths of the research at an overall level must be discussed regarding the choices of ethnographic method, critical perspectives, analysis methods and my subjectivity as a researcher in relation to these aspects. The strengths of this research may be connected to the benefits of adopting a well-known method such as ethnography when focusing on complex social phenomena in situ (Hammersley & Atkinson, 2007; Roper & Shapira, 2000). Through the collection of various types of data (field notes, interviews and the gathering of documents) in three different sites, it has been possible to respond to the objective of this thesis and gain a deep understanding of the practices and reasonings in the nursing home field. The multiple data collection methods have also provided several angles in response to the research question about involvement. Nevertheless, a longer data collection period, as in traditional ethnographies, and inclusion of more nursing homes may have enriched the quality of the data (Hammersley & Atkinson, 2007). The critical perspectives

have made it possible to gain new insights and alternative “stories” about the conditions for relatives’ involvement, all in line with the social constructionist stance in this thesis (Hacking, 2005). However, given the aspect of limited time, and number and choices of critical perspectives and their complexities, assuming these perspectives have allowed for possible further depth of analyses in future research. The choice to conduct two different thematic analyses has required different knowledge covering almost the same data analysis issues, but it has also shown that data can be analysed in several ways without clinging to any actual ontological domicile. However, the discourse analysis has contributed by providing a postmodern stance and an analysis in relation to its ontology. I, as a researcher, have probably influenced the research process based on my own subjectivity (Roper & Shapira, 2000). Therefore, it has been valuable to be able to discuss the choices made, the analyses, and the content of the final thesis with other research fellows and the co-authors of the included papers.

10 CONCLUSIONS AND IMPLICATIONS

10.1 CONCLUSIONS

- Relatives' characteristics and level of involvement are conditioned based on how they are considered as "visitors". This marginalised or sometimes privileged social position is reproduced through the routines and reasoning among nursing staff, inevitably linked to a traditional division of labor. The division of labor is based on gender assumptions of what is regarded as masculine and feminine tasks, also involving care work. In this case involvement may be linked to pedagogical issues, where learning about language and constructions of difference are crucially linked to the status of "visitors".
- The "involvement discourse" is upheld and legitimised by a "new" versus "old" family rhetoric. The new family members (nursing staff) replicates the old family (the relatives), and is attributed with a powerful social position as formal caregivers. The "involvement discourse" rests on obvious and natural assumptions which also uphold the biopolitics of the "involvement discourse". Involvement is related to a professional awareness, which may influence and lead to re-evaluation of the existing family rhetoric.
- The relatives' social positions may be described as a betweenship where they are squeezed in-between the expectations of their older family members, the staff and the nursing homes as institutions. Relatives are provided with different social positions that are linked to gender, ethnicity, age/generation and class. These social positions sometimes make them feel alienated and powerless, which contributes to a sense of otherness. The betweenship is related to caring interventions as involvement evoke emotions among relatives.

10.2 IMPLICATIONS

Unlike previous research, this thesis suggests that involvement comprises learning, responsibility and emotions which include pedagogical, professional and caring considerations. In the very beginning of this thesis, Andershed (1998) describes the involvement of relatives as being a part of something, to have the knowledge, to be included and to be engaged. Indeed, these dimensions are probably what we regard as significant for involvement. However, there seems to be further aspects of involvement also presented in this thesis, which need to be taken into account. Based on the findings, it would be possible for policymakers in Swedish older persons' care to initiate a process of change. To refer back to the last point, as presented by Hacking (2005), criticism itself is not a goal. The review and the criticism of operations, such as nursing homes may also provide opportunities to learn and

rethink. This may lead to positive changes in terms of better working conditions, improved care and involved relatives.

- The process of learning should be based on genuine interest in all the women who care for older people, a difficult and important task in society. By answering Socratic questions it is possible to re-evaluate notions regarding conditions for relatives' involvement and find new alternative ways of thinking about providing care for the older person. For example, it would be possible to make an overview of the physical environment and learn about the impact of the language used in nursing homes, in order to rethink artefacts and discourses that reinforce constructions of differences. The successful pedagogical work of such change management in Swedish preschools and schools, may serve as good examples of how this can be implemented, conducted and maintained.
- Another possibility would be to discuss the professional role in nursing homes linked to responsibility and limits and reflect upon how far the "steps into families" should be. It is also possible to learn from other professionals working closely with families. For example, be inspired by the professional codes of bodyguards in terms of discretion, deference and minimal impact on the persons involved.
- It may also be valuable to provide support in the form of care where the relatives' emotions are taken seriously, and where relatives are listened to and prioritised. It is probably more about listening, than about informing, even though initiating and facilitating the connection with the contact persons in the nursing homes, family councils and the municipal centers for relatives are important as well.

Finally, my hope is that this thesis may contribute with alternative ways of understanding the conditions for relatives' involvement in light of the critical perspectives. This may lead to some new insights and opportunities which may be of importance in the development of the quality of care in Swedish nursing homes.

11 FUTURE RESEARCH

Based on the findings, there is a need for future research which may involve:

- Implementation of pedagogical, professional and caring approaches in nursing homes.
- How residents reason about the involvement of relatives, considering ethical aspects such as integrity and autonomy.
- How relatives with various ethnic backgrounds perceive their involvement in nursing homes.
- Descriptions of the visiting patterns among relatives from an intersectional perspective.

12 SVENSK SAMMANFATTNING/ SUMMARY IN SWEDISH

Det övergripande syftet med denna avhandling var att beskriva och analysera hur anhörigas delaktighet villkoras vid äldreboenden utifrån olika kritiska perspektiv. Genom avhandlingen anlades genusperspektiv, diskursanalys och intersektionell teori, baserade på en social konstruktionistisk ontologi. Avhandlingen består av tre kvalitativa artiklar och data grundar sig på fokuserat etnografiskt fältarbete vid tre kommunala äldreboenden i form av formella/informella intervjuer, deltagande observationer samt insamling av dokument.

Utifrån genusperspektiv studerades och analyserades tematiskt vårdpersonalens rutiner och resonemang i relation till hur det villkorade anhörigas delaktighet i vårdarbetet (I).

Vårdpersonalen intervjuades även i fokusgrupper. Detta i syfte att beskriva och diskursivt analysera den biopolitiska innebörden i delaktighetsdiskursen, som de kollektivt konstruerade i sitt tal om anhörigas delaktighet (II). I den sista studien (III), analyserades tematiskt intervjuer med anhöriga i ljuset av intersektionell teori, om sin delaktighet vid äldreboendena.

Resultatet visade att villkoren för anhörigas delaktighet var dynamiska och i omförhandling, men också konservativa och oflexibla. Detta försåg anhöriga både med privilegierade och oprivilegierade sociala positioner på äldreboendena, vilket hade betydelse för deras delaktighet. Anhöriga betraktades som "besökare", vilket villkorade hur och på vad sätt de kunde vara delaktiga i vårdarbetet av de boende. Den sociala positionen som "besökare" var kopplad till genusfierade föreställningar kopplade till arbetsdelning, både inom grupperna av manliga och kvinnliga anhöriga men också mellan vårdpersonalen och anhöriga (I).

Anhörigas delaktighet villkorades av en biopolitisk innebörd i den delaktighetsdiskurs som rådde vid äldreboendena. Denna byggde på familjorienterade retoriker och metaforer som upprätthöll och legitimerade föreställningar om anhöriga. Anhöriga betraktades som familjemedlemmar tillhörande den "gamla" familjen i relation till den "nya" familj som vårdpersonalen representerade (II). Anhöriga beskrev att de befann sig i något som skulle kunna betraktas som ett mellanförskap, klämda mellan olika sociala måsten från de äldre familjemedlemmarna, äldreboendena som institutioner samt vårdpersonalen. Deras delaktighet villkorades av de samverkande intersektionella maktordningar som de tillskrevs och kategoriserade sig själv med i form av genus, etnicitet, ålder/generation och klass (III).

Genom att vända på den rådande bilden av anhörigas delaktighet, skulle det vara möjligt att se på vårdpersonalen som pedagogiska, professionella och vårdande "besökare" på äldreboendena till förmån för de boende och deras anhöriga. Detta skulle kunna realiseras genom ett konstruktivt förändringsarbete med betoning på vårdpersonalens lärande, deras ansvar och anhörigas känslor. Detta med fokus på alternativa föreställningar om delaktighet där anhöriga inkluderas i utvecklandet av vårdkvaliteten vid svenska äldreboenden.

Nyckelord: anhöriga, delaktighet, deltagande observationer, diskursanalys, fokuserad etnografi, fokusgruppsintervjuer, genusperspektiv, intersektionalitet, kvalitativa intervjuer, socialkonstruktionism, tematisk analys, vårdpersonal, äldreboende.

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