Intersectional perspectives on family involvement in nursing home care: Rethinking relatives' position as a betweenship

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AUTHOR CONTRIBUTION

J. Holmgren was involved in the study design, data collection and analysis, and manuscript preparation. A. Emami was involved in the study design, critical revision of the manuscript and linguistic revision. L. E. Eriksson was involved in the study design, critical revision of the manuscript and linguistic revision. H. Eriksson was involved in the study design, data analysis and critical revision of the manuscript.

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ABSTRACT

This study seeks to understand, in the context of intersectional theory, the roles of family members in nursing home care. The unique social locus at which each person sits is the result of the intersection of gender, status, ethnicity, class and is situational, shifting with the context of every encounter. A content analysis of 15 qualitative interviews with relatives of nursing home residents in Sweden was used to gain a perspective on the relationships between relatives and residents, relatives and the nursing home as an institution, and relatives and the nursing home staff. We sought to understand these relationships in terms of gendered notions of the family and the residents, which are handed down from generation to generation and thus condition who, and how, relatives should be involved in care, and the ways in which relationships change as care moves from home to nursing home. It requires knowledge and awareness that the nursing home culture is based on intersectional power structures in order for relatives to be involved in nursing home care in alternative and individual ways.

Keywords: intersectional perspective, power structure, nursing homes, relatives, involvement, elder care, nursing staff, institutional care.

INTRODUCTION

Situating relatives' involvement in nursing homes

In recent decades, multiple studies have suggested that relatives wish to continue being involved in their family members' daily care activities even after they move to nursing homes (Bowers 1988; Dellasega 1991; Kellett 1999; Keefe and Fancey 2000; Ryan and Scullion 2000; Gaugler 2005). Bauer and Nay (2003) pointed out that the involvement of relatives could be an attempt to reduce the feeling of role loss among the relatives, to ensure that the specific knowledge they possess as informal caregivers about the residents is respected, and to ensure that the care is based on their knowledge about the resident. Hertzberg, Ekman and Axelsson (2001) emphasized that relatives also wish to have closer communication and cooperation with the nursing staff in monitoring the quality of care and in order to seek more spontaneous information about the residents' progress and daily life. Russell and Foreman (2002) stressed that relatives also strive for involvement that includes more than practical assistance and for involvement during care planning sessions with the medical care team. A move to a nursing home is generally assumed to be a relief for relatives, yet the contrary is often true. Relatives find that they are sometimes stressed and burned out from interacting with nursing staff (Almberg et al. 2000). Hertzberg and Ekman (2000) suggested that involvement of relatives is criticized by some health care professionals. Relatives have also found that the nursing staff sometimes avoid talking to them when they visit nursing homes, and that the care plan for their family members is sometimes revised without their involvement (Majerovitz, Mollott, and Rudder 2009). Despite a wide variety of research regarding the experiences of relatives' involvement in nursing homes, little attention has been paid to the issue of power relations among the nursing staff and relatives based on how each of their social positions intersect in elder care (cf. Hertzberg, Ekman, and Axelsson 2001; Lill 2007; Harnett 2010).

The intersectional perspective as theoretical framework

Nash (2008) emphasized that the intersectional perspective makes it possible to focus on health disparity and inequality in care (Pauly, MacKinnon, and Varcoe 2009) based on the experience of marginalized subjects. With an intersectional perspective, one can assess the interconnections that are relevant to the exercise of power and the conservation of inequalities (Crenshaw 1989; Cuadraz and Uttal 1999; Bowleg 2008). In such an analysis, it is also important to identify the problems around the normative positions, in order to better understand oppression (Racine 2003; Rogers and Kelly 2011). Intersectional theory holds that one's position is situational and determined by a given context. Each person may and usually does have multiple positions, which impede or enable a person's possibilities in life based on what is attributed to the different subject positions in society (Shields 2008; Van Herk, Smith, and Andrew 2011).

Previous studies of relatives' involvement in nursing homes focused on communication and relational aspects rather than on how power structures interact and condition the involvement of relatives. We felt there was a need to examine the position of relatives from an intersectional perspective, to help bring to the surface and make visible the invisible power structures based on gender, age, ethnicity and class that usually condition relatives' involvement in health care institutions. The intersectional perspective provides a robust and useful framework for studying relatives who are involved in nursing homes in order to understand how their positions are conditioned based on the multiple subject positions they are assigned. The intersectional perspective will help challenge the usual assumptions of the involvement of relatives and result in rethinking relatives' involvement in the elder care

arena. “Rethinking” in this study means using the acquired knowledge gained to purposefully create new dimensions of family participation in nursing home care.

Just as there is a gender order between men and women, several other power structures exist in everyday practices and institutions (Hirdman, 2001). These power structures can be controlled by ethnicity and the perception of "the Other" based on the colonial racialized division of “we and them” (Rushdie, Said, Fanon, and Spivak, 1999), or of age to assign what is and is not socially acceptable for people to do at different stages of life (Krekula, Närvänen, and Näsman, 2005), or of class based on economic, cultural and social capital (Bourdieu, 1987). Bourdieu spoke of social, cultural, and symbolic capital. He posited that each person occupies a position in a social space of many dimensions defined by every kind of capital summoned by one’s social relations. This *habitus* is always a mix of multiple engagements, in multiple social fields, in the world. The aim of this study is to acquire a better understanding of the social positioning of the relatives of those in nursing care homes, and to use intersectional analysis as a lens through which to view the reasons for the involvement of these family members in the care of their loved ones, and the possibilities and limitations imposed on them by their social locus in varying contexts.

METHODS

Informants

As part of a larger ethnographic research project on how the involvement of relatives in nursing homes is conditioned from a gender perspective, 15 relatives were recruited purposefully (Patton, 2002) from three different nursing homes in an urban community in central Sweden. The goal of using a purposeful sampling strategy was to find people who wanted to and could speak comprehensively about their reasoning for and views about their

involvement in nursing homes. The intention was to gather as much qualitative information as possible relevant to the aim of the study. The inclusion criteria were that a potential informant should declare him/herself as a relative and be able to understand and speak Swedish. The exclusion criterion was that they should not suffer from a health condition that made them unable to participate in the interview. Relatives in this study were defined as persons who identified themselves that way and who were identified as relatives by their elderly family members. Some but not all who participated in this study had previously held informal care responsibilities alone or together with other relatives. The term "relative" was the common term used in the nursing homes when referring to family members or significant others who in various ways were involved in the lives and care giving for the residents. Relatives visited at different times and with different frequencies, and fulfilled various functions for the residents. Some helped practically, while others played more of a socially supportive role.

The informant selection procedure was carried out in two different ways. All heads of units and nurses in the nursing homes were informed that the first author wanted to contact relatives of residents in order to interview them about their involvement. The heads of units and the nurses made contact with nine of the relatives who had listed themselves as official next-of-kin with the nursing homes. The relatives who agreed to participate in the study were then contacted by the first author, and an interview meeting was booked. The remaining six informants were recruited directly by the first author on site in one of the nursing homes. This was done in connection with a meeting for relatives of those in the nursing home, held regularly. Relatives who attended the meeting were given verbal information by the first author and initiated contact after the meeting. All participants also received written information about the study in order to provide informed consent before the interviews were conducted. Five participants were recruited from nursing home number one, seven from

number two and three from the last one. Nine women (eight daughters, one daughter-in-law) and six men, (two sons, one spouse, one live-apart, one son-in-law and one legal guardian) aged 39-83 years were interviewed once over a two-month period. The relatives had Scandinavian, Central European, and African origins. Nine were employed and the rest were retired. All relatives belonged to social categories that could be considered middle class or working class in terms of socioeconomic positions in society, based on what they said in the interviews. Most had spouses, siblings or adult children with whom they shared elder care responsibilities.

Data collection

Data were collected during autumn 2010 and spring 2011. The interviews were conducted in Swedish, and the relatives were encouraged to speak freely. All interviews were conducted by the first author using the following open ended question: How can you be involved in the care of your family member living in the nursing home? The same question was asked of each participating relative. Additional follow-up questions were asked, to encourage informants to further explain their reasoning. Aware that we as researchers are co-creators of the ethnographic research process, the first author attempted to focus on not making unnecessary assumptions about the research subject. Before each interview ended, the informants always had the option of correcting or changing what they had previously said. All participants but two were interviewed in the nursing homes in a single interview room. One relative was interviewed by phone in his home, and another participant asked to be interviewed in her mother's apartment at the nursing home. The interviews lasted 19-63 minutes (an average of 39 minutes) and were recorded digitally and transcribed verbatim. The phone interview was digitally recorded via the loudspeaker function of the phone and transcribed in the same way as the other interviews as a part of the analysis.

Data analysis

A qualitative thematic analysis was conducted (Braun and Clarke 2006), using the perspective of intersectional theory (Crenshaw 1989). The method of analysis was chosen on the basis of its distinct analytical steps. According to Braun and Clarke (2006), this method is a useful tool for analyzing a large amount of qualitative data. The thematic analysis allows flexibility and broad application regardless of theoretical and epistemological basis. It is also possible to make interpretations of the data in various degrees using this method. The method may also provide rich or detailed accounts from data. This means that one can choose to focus on the data as a whole, giving the reader a rich and holistic picture. One can also focus on some aspects of the data, to deepen the analysis and provide a more detailed and nuanced picture. The latter approach may be most appropriate in a theory-driven analysis, as theoretical notions control analysis at a more specific level, as in this paper. The first approach is more open and flexible, which makes it suitable for a data driven analysis. In order to become familiar with the data and obtain an overall sense of the material, the interview transcripts were read through several times from the perspective of intersectionality. The data were then read again while the interviews were simultaneously played back from the digital recorder. Codes covering the same themes focusing on power structures based on gender, age, ethnicity and class were grouped into comprehensive themes. This was accomplished through a dynamic process of checking the consistency between the codes and the themes they were grouped under, and between themes and the whole data set to make sure that there was a coherent relation between codes and themes. When discrepancies were discovered, the codes were restructured and refined to ensure that each theme was well presented through the codes and that the data were appropriately coded and organized into relevant themes. The analysis process resulted in the construction of three comprehensive themes that covered all the

interrelated codes that could indicate in various ways the different power structures that were identified in the data. Each theme was illustrated with representative quotations. Throughout the analysis process the communication and analysis language was Swedish. The results were then presented in English, with the selected data used as quotes being translated to English and reviewed by a professional linguistic editor. Independently, the co-authors reviewed each translated quote to ensure accuracy and validity of the translation.

Ethical considerations

The study was granted approval by the Regional Ethical Review Board (No 2010/658-31/5) and ethical standards were in alignment with the Declaration of Helsinki (World Medical Association 2002). All informants received both oral and written information about the purpose of the study before informed consent was solicited or granted. They were informed that their participation was voluntary, and that they could withdraw their participation at any time without restriction. In order to protect the informants' integrity, the names, ages, nationalities, professions and places mentioned in the interviews were encoded.

RESULTS

In describing the reasoning for and views of the involvement of relatives, in the care of their elderly family members who lived in nursing homes, the following three themes were constructed through the analysis: (i) squeezed between gendered generational family responsibilities and reversed care roles; (ii) being an alienated spokesperson - a complex position as “the Other” between family members and the institution; and (iii) obtaining hegemonic reciprocity between nursing staff and relatives.

Squeezed between gendered generational family responsibilities and reversed caring roles

It was mainly female relatives who were involved in the care of their elderly family members in the nursing homes. They saw it as their family responsibility and their specific gender role to ensure that their family members received the care they needed and were used to, especially just after moving into the nursing home and/or when temporary nursing staff replaced the regular nursing staff. There were some male relatives who visited regularly and were involved in care. Both male and female relatives believed that it made sense to stand up for their elderly family members and they suffered from guilt if they felt that they hadn't visited them often enough. Although the male relatives had guilt feelings about not being as fully engaged as they felt they might be with their aging family members, they did not allow themselves to be weighed down too much by this fact. Those male relatives who were employed said that they wanted and needed to devote time to their jobs and hobbies. The feeling of having found a balance between their involvement in the nursing home and the commitment to their professional lives strengthened when they knew that their elderly relatives were well cared for in the nursing home. In contrast, it was clearly apparent that the female relatives felt they were squeezed between several competing obligations based on their gender and their notions of generational caring responsibility.

For example, Peggy, a 61-year-old Swedish woman with a younger brother, had arranged a place for her mother in the nursing home because the mother had trouble eating. Peggy explained that she visited her mother frequently to keep her company and to make sure that she ate and was doing well. She and her mother had always been close, so it was obvious to her that she would be involved in the care of her mother. She also said that she usually

cleaned her mother's apartment when she visited since she didn't think it was cleaned well enough by the cleaner in the nursing home. Peggy shared the following about her involvement:

> The situation has required a lot of us as relatives, but perhaps most of me. My brother has the propensity to trust in me because he is a bit sensitive… It's very much in woman's nature, whether you have an aptitude or interest in such things [laughs]. We are born to be caregivers, one can say; though I would say that we are brought up to it [laughs]. My mom and I have always been close to each other and there are things she would not ask my brother for or tell him. Both she and he are counting on me. If there is something with my mom and I'm out of town, my brother calls for me to solve the problems. And everything related to my mother's illness I must take care of, because he does not. I visit almost every day and he visits too, but not nearly as often as I do. This responsibility has been hard, but should be better now that mom has moved to the nursing home.

In the quote above, Peggy described her involvement in the care activities regarding her mother as something natural as well as something women are brought up to. With laughter, she stresses that both nature and culture tells her that this is something she wanted and that she believed she should be involved in as a woman, daughter and sister. Although it was difficult to take care of her mother, in arranging a nice place for her to live without much support from her brother and in a way squeezed between her mother's and brother's needs, she reasoned that it was her gender role and generational responsibility as a female relative to take care of her mother and ensure that everything went smoothly in the nursing home.

Other relatives also expressed the feeling that it was natural to care for aging parents, and some relatives wanted to pay back their relatives for a great childhood and good relationships with their elderly family members. Amy, a 59-year-old Swedish woman, described her relationship with her aging parents as a motive for caring:

> I always say that mom has helped us so much with our children, because I've always had a job that has been quite challenging and my parents have always been there for our children...I've never had to take maternity leave or time off for [a sick] child and things like that, mom and dad have always come…but now it's time for me to be there for her. She gave so much to us when we needed help...

While Amy felt a need for reciprocity between her and her parents, other relatives felt that they basically had no choice about whether they would take care of their family members or not. Expectations of being cared for thus seemed to come both from residents and from other family members. With respect to reciprocity, Amy is caught between gendered generational structures regarding care. These structures are transferred from generation to generation. Connecting herself with her mother and her children shows how knowledge of who will pursue and take responsibility for informal care and how they will do it is handed down from generation to generation. In these connections and in general, women embody a responsibility for the caregiving role that is paramount over other duties, including care for themselves.

Even though several relatives were content with the care their elders received, many expressed concerns about the quality of care provided to the resident when temporary or younger nursing staff served in the nursing homes. This caused the relatives to feel responsible and wanting to be involved. Some relatives were afraid of being perceived as

inspectors, but others saw it as both their right and duty to be in control of what happened between the nursing staff and the residents. Pamela, a 41-year-old Swedish woman with brothers, sisters, a husband, and children, spent nearly all her free time with her father, who had suffered a major stroke that left him paralyzed and unable to speak. She described her motive for being involved:

> One can say that I'm daddy's girl ... He taught me everything: welding, selling things, and pruning trees. All I can do today I have him to thank for. We have always been there for each other, and what we have promised each other, we have kept. I think that is the basis of the situation we find ourselves in today. I want to give back what he has given me.

Pamela considered it to be her gendered generational responsibility as a relative to make sure that her father had the will to continue living. Staying in the “promised land” she had created with her father was a way for her to reciprocate and pay him back for confirming her as a daughter while she was growing up, and was also proof of the close relationship they had. Pamela also said that she repeatedly discovered nursing staff "cheating" in the care of her father, which she felt diminished the quality of care. This was something she would not accept, and as a result she only allowed specific nursing staff to take care of her father. She knew she was not as well liked as her brother among the nursing staff, but this was acceptable to her in return for obtaining the level of care she wanted for her father.

According to the relatives, inexperience and youthfulness of the nursing staffs was a cause for concern and affected their need to be directly involved. Relatives had more difficulties relaxing and trusting that their elderly family members received good care when the nursing staff was composed of recent graduates, and thus inexperienced. Eve, 59, summarized the

complex position for relatives as experienced by her in relation to the nursing home as an institution: “If things don’t work properly in the nursing home, we don’t have any time to relax since we have to be involved all the time in the care of our elderly family members.”

Being an alienated spokesperson - a complex position as “the Other” between family members and institution

In the interviews with relatives, almost every one of them cited sometimes feeling challenged or ignored by the nursing staff based on what could be interpreted as broken expectations between the institutions and the relatives. The relatives suggested that they sometimes felt alienated and powerless when visiting their elderly family members because the nursing homes, as part of the institutional culture, exercised power by setting limits that could determine inclusion or exclusion of relatives in the actual care performance. Zenani, for example, a 40-year-old daughter-in-law from Africa, was eager to share her views of being a relative to her mother-in-law since she considered herself to be an ethnic minority in the nursing home. Zenani struggled a long time seeking to have her mother-in-law cared for by a nursing staff who spoke her native language, since she did not understand Swedish.

> I've talked to many...I think it's a shame that I have been told…I have been told that we are in Sweden now, we live in Sweden now...I find it very offensive that you say so, for the person who will work will be both Swedish and Arabic-speaking and can help everyone [at the nursing home]. Now the world is mixed, all lives everywhere, there are Swedish people who live in other countries, there are other people [from abroad] who live here. It was not that smart to say so, now we're in Sweden. How does that help my mother-in law, Abebe who does not speak Swedish?

Although Zenani wanted to be involved in the nursing home, she didn't view her involvement as voluntary but as a necessity as long as the nursing home was not taking her mother-in-law's needs seriously and not providing care on her terms. She said that she not only acted as a language interpreter, so the nursing staff could understand her mother-in-law, but also as a spokesperson when misunderstandings arose between Abebe and the nursing staff. Zenani also said that as immigrants and relatives, she and her family were expected to adapt to Swedish conditions and that the institution misinterpreted her based on gendered and racialized notions. This left her with a sense of frustration when she could not control the situation, which made her feel alienated and powerless. This can be interpreted as Zenani being squeezed between the needs of her mother-in-law and the nursing home's view of her and her husband as "the Other", who due to their immigrant status were separated from the dominant mainstream of which the staff considered itself representative. She suggested that this affected both the quality of care of her mother-in-law and also her own freedom of choice about how involved she wanted to be in the nursing home care.

Relatives further described how they found themselves as spokespersons for their family members with the nursing staff. The latter followed nursing home routines, which made relatives appear to be demanding and troublesome, and thus people who could be kept away and excluded. Both James, an 82-year-old husband, and Paul, a 64-year-old son-in-law, described how they had told the nursing staff that their family members needed more exercise and rehabilitation and they felt powerless and alienated when their requests were not approved and/or implemented by the institutions. Those occasions when relatives felt they had an opportunity to present their views were at formal council meetings for relatives, while such opportunities were rarely afforded them during the actual caregiving performed by the nursing

staff. Although most relatives said they knew that they could formally approach the heads of the units with more specific questions about the residents' care, some said that they found it difficult to understand the proper communication channels in the nursing homes between the nursing staff, the administration and themselves. When relatives had an opportunity to talk to the nursing staff, they sometimes felt they had to make tradeoffs about how they expressed themselves. They shared the feeling that they couldn't be fully open because that would risk being seen as difficult and demanding, which could negatively influence the involvement they were allowed. Others said that it was all about negotiating with nursing homes and playing the role of spokesperson, which involved both give and take, when discussing the care of their family members. This approach, however, reproduced the division and power relations between the relatives—them—and the institutions—we—since the relatives were limited in what it was possible to express in the nursing homes. Some relatives described how, out of fear of penalizing consequences for their elderly family members, they sought to carefully and strategically choose the appropriate timing for pursuing a dialogue with the nursing staff. They tried to not be perceived as intrusive, critical, or offensive. Mary, a 44-year-old Swedish woman and a part-time cleaner and single mother with two teenagers, shared her concerns about how she could express her views regarding the care of her mother:

> I think my mother should be allowed to have her alarms available around the clock, but the staff finds it hard that she calls all the time so they shut it off at night. I also wish that mom would get a shower a little more often but it's too hard. I'm afraid that if I say something, the staff will think that I interfere and that I'm demanding. Then they may be punitive to my mother so that it will take even longer before the staff responds to her ringing or that they would grab her even harder than they already do.

Several family members were afraid that expressing their views would result in retaliation against their elderly relatives. Mary, in the quote above, had fought for a long time for her mother to get the quality care that she was entitled to in the form of emergency aid and more showers every week. The staff chose to instead to listen to her mother, who did not want to take a shower despite her poor hygiene. Mary said she was not treated seriously and what she was trying to convey was turned against her. Mary had no social capital that could provide her with self-confidence and did not have a wide social network with which she could share the care of her mother. She said that she was not accustomed to speaking up for herself since she had not learned it at home or at school as a young woman. She was always encouraged to think in terms of collectivity and solidarity in her profession as a part-time cleaner. Although she had known her mother all her life and had been responsible for the informal care of her mother at home for a long time, she said that she felt alienated and marginalized in the institution as she tried to be her mother's spokesperson.

Another relative, Aileen, a 51-year-old Swedish daughter, said that she was generally satisfied with the nursing home. However, there was one issue that worried her, which she shared during her interview:

> My mother has stomach problems and needs to go to the bathroom frequently, even at night. Now, the night staff has indicated that they find it hard to handle this, so it takes a long time before they help her according to my mom. My mother is used to looking after herself and being independent, but now when she lives in the nursing home, she is dependent on others. I'm so sad, I don't know if she gets the help she needs... [starts crying]. My sister thinks that the staff doesn't always listen to mom, but I do not know if

mom could be the one who has misunderstood the situation. I have talked to the nurse so now we'll see what happens.

Aileen's story in the quote above is another example of relatives' alienated positions between their family members and the nursing homes. In Aileen's case, this was expressed as sense that while trying to maintain her mother's dignity and ensure her right to adequate care, she risked being perceived as challenging and unreasonable, which in turn might risk her mother's well-being. Relatives tried to ensure that their elderly family members received adequate care, yet doing so meant walking a social tightrope. They felt a need to be gracious and flexible with the staff to avoid having their views result in a negative impact on their relatives. Being perceived as "the Other" due to institutional norms that question the relatives' knowledge of the residents' care needs sometimes gave relatives a feeling of powerlessness and alienation. This was in contrast to their desire and intention of being involved in performing care for their elderly family members.

Obtaining hegemonic reciprocity between nursing staff and relatives

Some relatives had a particularly privileged position in the nursing homes, something that could be viewed as hegemonic reciprocity. This occurred when certain relatives had the possibility of expressing their views and engaging in a reciprocal dialog—a dialog of equals. Such a dialogue between the nursing staff and these relatives was characterized by reciprocity, which gave the favored relatives the power to be involved in the care work. This was sometimes exercised at the expense of other relatives, who found it difficult to gain recognition and support from the nursing staff. Although the position was desirable, it was far from consistently available, and it was linked to intersectional power structures. Depending on the economic, cultural and social capital relatives had, it was possible for them to create a

more or less pleasant life for their elderly family members in the nursing homes. For example, Jill, a 62-year-old, well-educated manager in a company with a great social network whose mother had lived in the nursing home for some years, reasoned as follows:

> The staff may not know the residents in the same way as the relatives do after a lifelong relationship. Nevertheless, the understanding of the residents and their relatives is built on, now and then, in everyday communication with each other.

It was obvious to Jill that she knew her mother better than the nursing staff did and knew how she wanted to be cared for. This starting point separated her from other family members who said that they were expected to partially hand over the care to the nursing staff and largely rely on their judgment. Jill was pleased with the process of moving her family member into the nursing home and felt that she had control the whole time. She had made contact herself with the assistance officer at the municipality and stated that her mother needed to move to special housing. Two weeks later, the mother moved to the nursing home. This could be an example of how Jill's social capital in the form of a strong network and significant contacts gave her an important and hegemonic position in organizing to meet her mother's care needs. She further believed that while relatives had a great responsibility to get involved, it wasn't the responsibility of relatives to take on the role of being the caregivers. She suggested, however, that the relatives should support and facilitate to minimize the risk that the nursing staff would feel squeezed between relatives' wishes and the scarce resources they had available. Jill had the ability to control her relationship with the nursing staff based on her cultural capital, and she thought their good relationship depended on her leadership experience as a well-educated manager in a medium-sized private company, which meant being both responsive and clear in relation to the staff. This, in turn, meant that she was trying

to relieve the staff by not requiring “too much” in relation to what the nursing staff conveyed they had personnel and time resources for. She also stated that the relationship between the nursing staff and relatives was reciprocal and based on confidence in each other.

Even Matt, a successful and well-known 50-year-old Swedish entrepreneur, thought it was a relief that his elder care responsibility could be shared with the nursing staff. He could then relax a bit and did not have to think about how his mother was doing all the time. He knew that she received all she needed. Matt had previously had a tough time, since he had sole responsibility for his mother when she lived at home; while he had a brother, they had issues in their relationship and did not have any contact with each other. He shared his views:

> Most staff are experienced and relatives have to give them a free hand and have confidence. It is the staff’s responsibility to ensure the residents have a good quality of life, and we must be fair and facilitating for them. Being a caregiver is more than a profession and the relatives should be able to lean on experienced and stable staff.

Matt expressed his support for the nursing staff and said that he trusted them because they were professionals and provided his mother with the best care. He also said that he used to take all the residents and nursing staff on a trip to his home in the countryside where they could go fishing, have coffee, and enjoy the waterfront. It was possible for him to do this thanks to the economic capital he had in the form of a successful business. His economic wealth gave him a certain freedom so he could devote time to both his mother and the other residents. Additionally, his social capital and his gender gave him a hegemonic position in the nursing home as he was a famous local figure, was considered to be a “nice guy,” and was liked by the staff.

DISCUSSION

Becoming the relative - visible and invisible betweenship in nursing home care

The results show that in relation to social intersecting categorizations, the functions of actively-involved relatives may be understood and explained as a *betweenship.* The betweenship in this study means relatives are squeezed between different obligations, interests and competing power structures among the immediate family, the nursing home as an institution and the nursing staff. Betweenship as a theoretical concept has previously been used mainly in postcolonial research studying people's experiences of not belonging in a Western normative society and having their identities questioned (Rushdie et al. 1999). It is obvious that there are consequences in a study such as this, where the intersectional perspective served as an interpretative framework through which the stories of relatives are understood. The interpretation given is both partial and situated from this study's specific circumstances. This means that using other frameworks might generate different results. However, this study does not make any claim that the results are generally applicable. Whether or not they are, the results can and should still contribute to a rethinking of the involvement of relatives in nursing homes. The portrait in this study of relatives' reasoning for and views of their "squeezed" involvement as a betweenship demonstrates an important new link to power structures. This result is partly in line with previous research on middle-aged relatives squeezed between caring responsibilities for adult children and aging parents, a group of relatives who have come to be called the "sandwich generation" (Spillman and Pezzin 2000; Grundy and Henretta 2006; Chassin et al. 2009). In these research studies, issues of solidarity across generations, work, and ethnicity as a condition of relatives' position have had a significant impact, although an intersectional perspective was not explicitly cited.

The betweenship as a synthesis of the results comprises three different displays of power structures related to what it means to become an involved relative in nursing homes. These relational and dynamic power structures are inevitably linked to gendered generational, ethnic and class intersections and emerge differently, depending on the situation. It is therefore important to emphasize that these relational and social power structures have different origins, operate in different ways and are not additive and coherent in terms of quantifying their importance for the specific situation or its individual importance.

First, we stress that becoming a relative means establishing oneself in a betweenship of a traditional gender power structure and a division of labor conditioning what male and female relatives "naturally" should be involved in, as well as how to perform care activities. The meaning of "payback time" and reciprocity as a generational caring responsibility becomes crucial for relatives in terms of "reversed" non-self-selected involvement between relatives and their elderly family members. We further suggest that becoming a relative also assigns a betweenship for relatives in relation to the nursing homes as norm-producing institutions. Through subtle and relatively invisible power structures, the institution encourages relatives to understand what is socially acceptable in the nursing home culture. From the construction of the homogeneous group of relatives, "the Other" was created which separated them from the norm.

While in agreement with what Ryan and Scullion (2000) and Gaugler (2005) state about relatives' wishes to be involved in care activities, this study also uncovers some of the invisible complexity of what it means to become a relative. Through the intersectional perspective, we have been able to shed light on the fact that power structures are important

and are present in the encounters that take place between the nursing staff and relatives in nursing homes. Relatives' maneuvering space and opportunities for involvement are thus intertwined and conditioned by various subjects' positions. We further stress, in agreement with Whitaker (2009) and Bauer and Nay (2003), that the motives of relatives for being involved are connected to a will to protect the residents' integrity and to provide the nursing staff with the residents' living stories. However, alluding to gendered generational power structures, one may also understand why the majority of those who care for their elderly relatives are women, and that their involvement is not always natural and self-selected. Being a woman means understanding that women are naturally caring, something that is handed down from mother and father to daughter over generations. We agree with Eriksson, Sandberg and Hellström (2012) that it is important for nursing staff to give relatives alternative options to be involved, decoupled from gendered generational notions. In line with Almberg et al. (2000) and Lundh, Sandberg, and Nolan (2000), the results of this study show that it is challenging for relatives to be involved in elderly residents' care in nursing home institutions. Nor does moving elderly family members to nursing homes always fulfill relatives' expectations of release and relief. Our results demonstrate that institutional power structures and notions of "the Other" effectively construct "difference", which maintains the relatives in the betweenship. Finally, the reasoning for and views of becoming a caregiving relative seem to be dependent on what position the relatives have achieved in the nursing homes, and on cracking the code in which some subjects' positions are more highly valued than others. In a study in school environments, Ambjörnsson (2004) draws conclusions similar to those of this study, finding that the positions of different subjects gives some people advantages at the expense of others. Skeggs (2000) also emphasizes that one is socialized into the class structure in the same way that we are brought up in gender structures. With a normative gaze (cf. Nilsson 2008), relatives are further examined without careful reflection

and informally included in or excluded from the community in the nursing home culture (Holmgren et al. 2012).

Through the lens of overlapping intersections, this study's specific contribution has been to make the invisible circulating power structures visible in reviewing the involvement of relatives in nursing homes by rethinking their position and understanding it as a betweenship. This study provides an understanding beyond the mainstream "blaming" of either the negligence of nursing staffs or the perceived unwillingness of relatives to be involved in the collaborative care of the elderly people in nursing homes (Hertzberg and Ekman 2000; Ryan and Scullion 2000; Majerovitz, Mollott, and Rudder 2009). This study shows that the challenge of relatives' involvement in nursing home care is related to broader power structures. Rethinking the position of relatives as a betweenship from an intersectional perspective helps draw attention to broader power structures by bringing to the fore what traditionally is left in the background when focusing on such problems in nursing research. The knowledge from this study can contribute to initiating a deeper and more comprehensive discussion about the involvement of relatives in nursing home care in going forward. This includes a holistic and socially constructed view of how the health care system should be established and developed to be better aided by the support and contributions of relatives. Although further research is needed in this area, the results from this study serve as call for nursing staff and policymakers to challenge the taken-for-granted norms and practices regarding the involvement of relatives in elder care. Valuable resources are going under- or unutilized. It is good nursing policy and good social policy to identify and make use of more flexible and diverse ways of incorporating family in the lives and care of those living in nursing homes.

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