<http://www.diva-portal.org>

Postprint

This is the accepted version of a paper published in *Journal of Applied Gerontology*. This paper has been peer-reviewed but does not include the final publisher proof-corrections or journal pagination.

Citation for the original published paper (version of record):

Torgé, C J. (2020)

“Being in-Between”: Spouses that cohabit with and provide care for their partners in nursing homes

Journal of Applied Gerontology, 39(4): 377-384

<https://doi.org/10.1177/0733464818803007>

Access to the published version may require subscription.

N.B. When citing this work, cite the original published paper.

Permanent link to this version:

<http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-41673>

“Being in-Between”: Spouses That Cohabit With and Provide Care for Their Partners in Nursing Homes

Cristina Joy Torgé

Abstract

It is increasingly possible for couples with differing care needs to move to nursing homes together. To our knowledge, this is the first study about spousal caregiving in this context. This study explores spouse and staff experiences when relatively healthy spouses cohabit with and provide care to their partners in Swedish nursing homes. The overarching theme, “being in-between,” reflects the spouse’s overlapping role transition and the staff’s unfamiliarity with the spouse’s role. The spouses are both “insiders” and “outsiders” and are torn between maintaining and letting go of caregiving. Meanwhile, the staff express concern about the spouse’s need for respite yet being constantly present, and struggle to balance the staff’s and the spouse’s control of the caregiving situation. This article provides insight into the challenges experienced by spouses who accompany their partners to residential care and how to best support them in this unfamiliar role.

Keywords

nursing homes, co-resident, family, caregiving, spouse

Background

Caregiving is often regarded by spouses as a natural extension of partnership (Torgé, 2014). At the onset of a partner’s disability, spouses are most likely to be the first caregivers and often continue this role for an extended period of time. The spouses’ caregiving role also evolves parallel with the partner’s illness trajectory (Hellström, Håkansson, Eriksson, & Sandberg, 2017). In old age, one event that can signal a transition for both the ill partner and the spousal caregiver is the partner’s need for long-term residential care.

A family member’s move to residential care is sometimes understood as a *transition from or relinquishing of* family caregiving (Brown & Bond, 2016). However, as studies repeatedly demonstrate, family members continue their caring role after a relative’s move to residential care, even though they accept no longer having full responsibility for caring (Davies & Nolan, 2006; Gaugler & Kane, 2007; Graneheim, Johansson, & Lindgren, 2014; Koplow et al., 2015). Spouses often develop visiting routines and become highly engaged visitors in nursing homes (Baumbusch & Phinney, 2014; Førsund, Kiik, Skovdahl, & Ytrehus, 2016). Their caring role might evolve from providing daily care to being an advocate, providing socio-emotional support and maintaining the partner’s self-identity as well as their identity as a couple (Graneheim et al., 2014; Hennings & Froggatt, 2016; Sandberg, Lundh, & Nolan, 2001). This indicates that spouses remain involved in residential care, even when the intensity and type of help, as well as the motivation for caregiving, might change.

Previous research on spousal caregivers’ experiences of having a partner in a nursing home indicate that involuntary separation is central to their experience (Glasier & Arbeau, 2017). This is better understood when eligibility for residential care is considered. Typically, in countries

where individual needs assessment is a prerequisite to long-term care, couples with differing care needs become separated (Carroll, 2015; Glasier & Arbeau, 2017). Accordingly, previous studies had only been able to explore the caregiver involvement of families in their role as nursing home *visitors* (Baumbusch & Phinney, 2014). A scoping review of previous literature confirms that common findings were “feeling married, being married” and “alone but . . .” (Hennings & Froggatt, 2016). These refer to the couple’s living arrangements, physical distance, and feelings of loneliness. Physical separation also underpins the theme “together but apart,” that was identified in a longitudinal interview study of spousal caregivers providing care to partners in care facilities (Hemingway, MacCourt, Pierce, & Strudsholm, 2016). The authors pointed to the spouses’ difficulties of getting on with their own lives while maintaining involvement in care facilities, as well as feelings of alienation from a care situation managed by staff.

In recent years, it is increasingly possible for couples with differing care needs to move together to residential care facilities, which prevents involuntary separation (Kemp, 2008, 2012). Yet, research about this and its implications is still lacking (Torgé, 2018). This article fills a gap in the research, by describing results from a unique project that explores the spouse and staff experiences when relatively healthy spouses cohabit with and provide care to their partners in nursing homes. To our knowledge, this is the first study analyzing spousal caregiving in this context.

Theoretical Framework

At the onset, two theoretical frameworks guided the study’s design. The first premise of this research is that the site where care occurs influences how care practices are shaped and experienced (Jeppsson Grassman & Whitaker, 2012). Nursing homes are facilities for formal care, shaping everyday life and the character of family caring within it. Daily routines often revolve around staff schedules, and even private spaces are semi-public (Harnett, 2010; Nord, 2011). In studying spouses’ experiences of cohabiting with and providing care for their partners in nursing homes, the spatial boundaries of formal and informal care further overlap. One way to understand this blurring of boundaries is Milligan’s (2009) concept of landscapes of care, which are “organizational spatialities that emerge from the intersection of formal and informal caregiving in both the domestic and institutional environments” (p. 9). This study aligns with this concept, by studying the interface of nursing care and spousal caregiving in a home with institutional characteristics.

The second theoretical approach deals with informal care through a lifecourse perspective. This perspective acknowledges caregiving as a continuous and reciprocal process intertwined in relationships. It has sensitized researchers to “trajectories of care” and similar concepts, where changes in the care receiver’s needs or sources of support also affect the caregiver in terms of caregiving responsibility, and feelings of burden or satisfaction (Roberto, McCann, & Blieszner, 2013). One useful concept in understanding spouse caregiving through transitions is Pearlin and Aneshensel’s (1994) caregiving career. By drawing on the notion of “career,” they emphasized the prolongation and interconnectedness of different phases of caregiving. In addition, they stressed that informal caregivers do not only identify themselves with a caregiving role but are holders of older self-identities over a longer period of time, such as being a husband or a wife (Pearlin & Aneshensel, 1994).

These theoretical approaches permeate the study design and influenced interview guides, where the character of the spouses’ new caregiving role and how it feels to live in the nursing home were discussed.

Method

Data Collection

This article is based on a qualitative study about family life and spousal care of couples with differing care needs in nursing homes, in a Swedish context. In Sweden, nursing homes provide both residential care and skilled nursing care, and eligibility is established through individual needs assessment. Previously, it was only possible for couples to live together in nursing homes if both had been evaluated to need skilled nursing care. To prevent involuntary separation of couples with differing needs, an amendment to the Swedish Social Services Act was passed in 2012, dubbed as the cohabitation guarantee (Social Services Act, 2001:453; 1§ ch.4). This policy made it possible for couples to apply as co-residents in nursing homes, even if only one of them has the need for nursing care and the other may be relatively healthy.

The author, a social gerontologist who had conducted similar research about older couples, was the sole investigator. Information about the number of co-resident applications in all Swedish municipalities was obtained through the National Board of Health and Welfare's statistics in 2016. Of these, five municipalities were selected for the study that had more than 10 couples that had been granted co-residence, and with reasonable geographic spread. The nursing homes where the couples resided were identified through phone calls. In consultation with the nursing home managers, one nursing home was then selected in each of the five municipalities. The overall criteria for this selection was that both partners could participate in interviews and were willing to participate in the study. Partners with dementia were not excluded, if the partner was able to communicate. However, nursing home managers sometimes indicated inappropriateness of couples to be included in the study, for example, when a partner was at the end of life, and this was respected.

Data collection, analysis, and further case selection were done in an iterative manner. Municipalities can organize the cohabitation guarantee in different ways, and nursing homes have different layouts. Thus, to include a range of different conditions in the study, theoretical sampling was applied (Corbin & Strauss, 2008). Nursing home managers acted as gatekeepers in the identification and selection of subsequent cases. For each subsequent case selection, the goal was to find variation in the couples' apartment sizes, the co-resident spouses' own care needs, gender of the spouse, the number of couples living in the same nursing home, and differences in local legislations. Table 1 shows a summary of the nursing home and participant characteristics, where nursing home names have been changed.

Ethnographic methods, involving observations and interviews, were used in data collection. Nonparticipant observations at each site, with repeated visits over a 4-week period, were interweaved with semi-structured dyadic interviews with the couple (11), semi-structured interviews with the co-resident spouse (6) and unstructured staff interviews (15). Dyadic interviews were the preferred interview method, but on days when a partner was feeling weak, only the spouse could be interviewed. The interviewed staff consisted of those that worked closest to the couples, as identified by the couples and the nursing home managers. The 32 recorded interviews were transcribed by the author. In addition, field notes and informal interviews were made during the field observations. Written consent to participate in the study was obtained from the nursing home managers and the couples. The study design was approved by the Regional Ethical Review Board in Linköping (reference number 2015/425-31).

Data Analysis

Interview data were coded using the data management software NVivo and analyzed using thematic analysis (Braun & Clarke, 2006). Thematizing meanings is a shared characteristic of

TABLE 1. SUMMARY OF NURSING HOME- AND PARTICIPANT CHARACTERISTICS

Nursing home	Characteristics of interviewed couple	Room characteristics	Is the accompanying spouse entitled to full residential- and nursing care in the facility?	Interviewed staff in contact with the couple
"Aspen Homes"	(M, 102 years old) passed needs assessment (F, 92 years old) accompanying spouse with some hours of home care for IADL needs Married for 68 years	55m ² two-room apartment	No, but the spouse is entitled to home care for IADLs, provided by nursing home staff).	1 nursing home manager 1 nurse 3 nurse assistants (including contact person) in a group interview
"Birch Homes"	(F, 78 years old) with dementia diagnosis, passed needs assessment (M, 83 years old) accompanying spouse with no care needs Married for 59 years	Two one-room apartments of 33m ² each, on different floors (one in a residential care facility and one in a dementia unit)	Yes	1 case manager 1 nurse assistant in Birch Homes' residential care facility (contact person) 1 nurse assistant in the dementia unit
"Chestnut Road"	(F, 90 years old) passed needs assessment (M, 85 years old) accompanying spouse with no care needs Married for 59 years	68m ² two-room apartment	No	1 nursing home manager for Chestnut Road's residential care facility 1 nurse 1 nurse assistant (contact person)
	(F, 87 years old) with dementia diagnosis, passed needs assessment (M, 89 years old) accompanying spouse with no care needs Had been living together for 60 years, married for 50 years	44m ² one-room apartment in a dementia unit	No	1 nursing home manager for Chestnut Road's dementia unit 1 nurse assistant (contact person)
"Daffodil Gardens"	(M, 90 years old) with needs assessment (F, 88 years old) accompanying spouse with some hours of home care for IADLs Married for 68 years	60m ² one-room apartment	No, but the spouse is entitled to home care for IADLs, provided by nursing home staff.	1 nursing home manager 1 nurse 1 nurse assistant (contact person)
"Elm Homes"	(M, 97 years old) with dementia diagnosis, passed needs assessment (W, 98 years old) accompanying spouse with support needs for activities of daily living (ADLs) Married for 63 years	Two adjacent one-room apartments of 30m ² each, in a dementia unit	Yes	1 nurse assistant (contact person) 1 nursing home manager (unrecorded)

qualitative methods but has also been developed as a distinct methodology (Vaismoradi, Turunen, & Bondas, 2013). The inductive approach to thematic analysis has many similarities with Grounded Theory and builds on data familiarization, coding, and generation of themes from codes (Braun & Clarke, 2006; Corbin & Strauss, 2008). The hermeneutic relationship between emerging themes, sets of data, and the whole data corpus, is also a feature shared with Grounded Theory's "constant comparison" (Corbin & Strauss, 2008). In thematic analysis, themes are "reviewed," which means that themes and subthemes are compared with the coded extracts and the whole data set, to test for viability. In contrast to Grounded Theory, however, thematic analysis does not have an expressed ambition to generate theory (Braun & Clarke, 2006), perhaps making it comparable with postmodernist traditions in Grounded Theory. Thematic analysis is also distinct from similar methods of thematizing such as qualitative content analysis, as its focus is on presenting meaningful patterns that cross-cut the data, rather than categorizing the text's manifest and latent content (Vaismoradi et al., 2013).

Results

The emerging overarching theme was "being in-between" (Figure 1). This theme expresses the caregiving spouses' overlapping roles and unfamiliarity with the role of co-resident. Being in-between captures how the spouses defined themselves, but also how the staff described their relationship with the spouses. The theme also captures the dilemmas of spouse and staff in their unfamiliar roles. On one hand, the spouses fall in-between "insider" and "outsider" roles, and they are torn between maintaining and letting go of caregiving. On the other hand, there is no clear consensus either among the staff regarding the ideal extent of the spouses' caregiving. They are concerned with providing respite for the spouse, but also see value in the couple's patterns of caregiving. Because the staff have primary responsibility for the cared-for partner, they also feel in-between taking control over the caregiving situation and letting the spouse influence the caregiving situation.

FIGURE 1. SUB-THEMES OF THE OVERARCHING RESULT / THEME "BEING IN-BETWEEN."

Spouses' Experiences of Being In-Between

Being an "insider"—Being an "outsider."

Common to all the spouses interviewed is that they have been married to their partner for six or seven decades before their partner's need for residential care. At the time of their partner's application to residential care, some spouses also applied for nursing care but were assessed to be too healthy. Other spouses initially chose to live apart and visited the nursing home practically every day before deciding to apply as a co-resident.

The decision to move to nursing home to be with one's partner during their last years of life was not an easy decision to make. Several factors contributed to uncertainty, such as the small size of the apartments in which they would live, terminated tenancy at the event of the partners' death, and the question of how much of their privacy and activities would be sacrificed. In three municipalities in the study, local guidelines further established that co-resident spouses were not entitled to the health care at the facility, and the spouses knew this beforehand. "I brooded about these things many times before moving here," one spouse disclosed. Nevertheless, like the other spouses interviewed, she maintained that the decision to move was self-chosen and to some extent even inevitable for older couples that have been married for many decades. In the words of another spouse, "I moved here to be with him, to the bitter end."

Although firm in their decision, the spouses knew that their relatively good health could mean difficulties in adapting to life in the nursing home. Most of the interviewed couples had already been residing in the facilities for about a year, but the spouses still felt that they did not belong. Although they participated in the group activities and accepted their new place of residence, they also described themselves in ambivalent terms, such as "a popular oddity," "neither fish nor fowl," and "an appendix." This suggests that despite being co-residents, they also felt like "outsiders," not being care recipients. Many spouses described that at the beginning of their stay, they neither felt adapted to their new surroundings nor felt that the staff knew how to interact with them. As one recalled,

I felt like a strange bird. I was clueless. I knew why I was here—for my husband's sake. [The staff] knew I was here for his sake too. That's obvious. But they must have thought that I didn't quite belong. I had this feeling, that they thought that I didn't contribute to anything.

Sometimes, the spouses' belongingness in the nursing home was questioned by others, as when acquaintances reacted with disbelief when they heard where they lived. This feeling of non-belongingness had even led one of the spouses to wonder if he was staying in the facility legally: "In the beginning, I thought I was living here at the mercy of the staff!"

Only two interviewees, who were in municipalities that granted co-resident spouses their own tenant contracts and service entitlements, expressed that they stayed in the nursing home "legitimately." However, their "outsider" status was apparent in another way. Both had moved in with their partners with dementia. One of them lived in his own residential care apartment, a floor above the dementia unit. The other lived together with her husband in the dementia unit, in adjoining apartments. Both spouses underlined the asymmetry between themselves and the other residents. They also mostly talked to their partner or the staff, as the spouse in the dementia unit admitted:

[Residents here] are not able to hold a conversation. They're living in their own minds, is that right? I could probably talk to some of them, but they're in their little groups. And one, she can't talk but she screams. I mostly talk to the people who work here.

Maintaining caregiving—Letting go of caregiving.

In the spouses' interviews, the pivotal reason for applying for residential care for their partner was the burgeoning amount of caregiving that they had to bear at home. Before their move, the spouses were the lone caregivers for many years, with some reporting only a few hours of municipal home care services for cleaning or meals on wheels. The spouses described the demanding nature of their caregiving role, which for some involved help with bathing and hygiene. Those with partners having dementia also described the emotionally and mentally taxing work of "keeping an eye day and night," especially if their partner was wandering. Recalling these experiences, they found that the move to the nursing home was a relief from the burden of round-the-clock caregiving. One spouse, who shared an apartment with his wife with dementia, expressed his relief saying, "here at least I know that there are people who look after her. It's a relief, because before we moved here, I felt I was close to hitting the wall."

Although the role as primary caregiver had ended, the new role as co-resident was not as simple as letting go of help-giving patterns that have formed through decades of marriage or relinquishing caregiving to the staff. On the contrary, the spouses stated that their main motive for co-residence was to maintain proximity to their partner while also continuing caregiving in some way. Those who tried a period of "living apart" felt that the role as visitor was unsatisfying, even if they visited every day. Some expressed that if they were not willing to "provide help for everyday things," then there would not have been a point in living together. As a husband explained,

As you can see, it's small acts of help that she wants to have. She's on a wheelchair all day. I can help her. Of course, I could leave it to others. But we never need to press the room alarm if I can provide her help with these small things. I can do a lot of small chores that benefit her. I do them gladly.

At the end of the day, spouses described being available as a caregiver was part and parcel of life together, which they had chosen when they decided to be a co-resident.

Nevertheless, desiring relief from caregiving and desiring closeness through caregiving can create conflicting feelings. Finding a balance was especially hard for spouses who experienced caregiver stress at home. This was vividly illustrated by a spouse who described fighting her deep-rooted tendency to provide help for her husband, even if she did not feel comfortable in "being passive." Before the move, she was the lone caregiver for her husband and provided help for lifting and hygiene. In the nursing home, she found it difficult to "hold back," even though she knew that she should:

No, I don't want to be more involved [in his care]. I know I shouldn't. Because I'm aware that—(sobs) Oh, this is difficult! . . . I know what the result would be if I helped him. I know that my energy would run out. So, I can't. I need to be strict with myself. I need to be! And it's like an instinct for me to help him when he needs help. But I have to hold back, and hold back, and keep on holding back. It's not that easy . . . My own desire to help, it's deep within me. It's my nature (sighs). But I can adapt. I try to avoid helping. I am totally passive.

All the spouses gave expression for role overlap, where one was no longer the primary caregiver but still felt caregiver responsibility. Several spouses maintained that although they were no longer primary caregivers, their partners relied on them more than the staff, and they thereby filled an irreplaceable role in the care of their partner. One spouse demonstrated this, saying, "if there is something that she really wants to tell the staff, she comes to me with it first." In some cases, however, the strong feeling of responsibility also made it difficult for spouses to trust the ability of the staff to give adequate care. For example, one spouse was constantly worried when she was not in the apartment, anxious that the staff might not be keeping an eye on her husband while she was away. Proximity to one's partner may be why these patterns for caregiving are

held on to, even when the context is now different. There also seemed to be a reluctance by spouses to let go of old patterns of caregiving, as this was too intertwined with life together.

The Staff's Experiences of Being In-Between

Acknowledging caregiving—Providing respite.

Although a couple's home, a nursing home is inevitably a facility for skilled nursing care. The interviewed staff acknowledged that they were now responsible for the partner's care but were aware of the spouses' wishes to be involved. Shared responsibility was unfamiliar to most of the staff, who mostly had experiences of visiting family members.

One staff experience of being in-between had to do with acknowledging the value of spousal caregiving while also providing respite for the spouse. On the one hand, the staff spoke about positive aspects of the spouses' caregiving. Many believed that co-residence increased the partner's feeling of security. Some also felt that they were able to give more personalized care, for example "because there is another person there to speak for the partner and can tell us about the partner's situation." The staff all believed that the wish to continue caring for one's partner should be respected, if this was the couple's and the partner's own preference. However, there was also no consensus on the appropriate extent of caregiving by the co-resident spouse, or what to do when the spouse risks helping "too much."

Some thought that it was up to the couples themselves to decide the extent of spousal caregiving. For example, a nursing home manager who stressed that the apartment was the couple's home believed that couples "should be allowed to live a normal life together," which included a share of spousal care and minimal interference from staff. Similarly, a nurse emphasized that they had to respect that couples wanted to do things "their way" and did not call nurse assistants for certain errands. However, a fine balance also appeared on how much the staff should encourage the spouse to refrain from too much partner care. Some stated that although co-residence was positive because it allowed couples to be with each other daily, the spouse's constant presence meant that respite, which may have been the reason for the move, became next to impossible. This was especially so when couples shared small apartments. Some staff informants expressed that spouses risked "living in their partner's illness" or merely "continuing the caregiving pattern from before." Another nursing home manager saw a risk that couples move in together, only to find that they "suddenly become too near; too near each other's diaper changes and all that," and she emphasized that the spouses' personal integrity may be lost.

Even as they acknowledged the challenging situation of the spouse, the staff thought that they could do little about this situation, partly because of the nursing home layout and because they did not want to interfere with the couple's relationship. Some nurse assistants expressed that they wanted to show more appreciation for the spouse's involvement, but they also found it problematic when the partners constantly called after their spouses while they were providing care. A nursing home manager also observed this, saying that the nursing home might not be providing enough distance from caregiving, requiring that respite be sought elsewhere:

[Her partner] was longing for her to move here. A very strong longing. But it was also so that she couldn't cope with the caregiving at home, because he needs so much help. She provided so much help for him. And their daughter expressed worry that things would be the same here. And in a way, it is. It's possible that she can't keep up in the long run. I've had talks with her about this, and that maybe she should spend some days away from here, at her daughter's place.

Only the staff in one nursing home were an exception, as they did not feel torn in-between acknowledging care and providing respite. As the couple there had rooms in different floors of the building, the staff felt that they could be sensitive to the spouse's needs. A nurse assistant explained, "that's how it is in dementia care. A lot of it is supporting relatives." The spouse visited his wife's apartment several times a day but also retired to his room at certain hours.

Staff control—Spouse control.

In general, the staff thought of spousal caregiving as a complement to their work. Formal and informal caregiving existed side by side and many of the interviewed staff exemplified how spousal caregiving could be a "resource," saving them time and effort. Mainly, the staff was responsible for help with medicine, hygiene, and feeding. Other daily activities such as shopping, cleaning, fetching meals, and taking walks were often done by spouses and thus "saved work." Sometimes, activities that spouses were responsible for were formalized through a written document called the care plan. An example of this would be if the couple preferred a specific routine, such as eating their breakfasts in their apartment rather than in the common dining area.

Nevertheless, the staff also gave examples where they thought the spouse's involvement might be problematic, or when the spouse may be exercising too much control. These situations accentuated the double nature of the nursing home apartment as both a home and a workspace. Ideally, as many staff informants stated, working in nursing homes should be no different from working in home care, where the staff work in individuals' homes. In practice, however, nursing homes are workplaces characterized by staff shifts and work regulations. There were times when the staff felt that the spouse's domestic control challenged their work routines. Friction could arise, such as when spouses moved furniture to make the apartment more "homelike" and "less like a hospital." In one case, the re-arrangement of the bed made it difficult for the staff to operate the ceiling hoist in an ergonomic way. The nurse assistants pushed away furniture but had no time to ask the spouse's permission. Later, one of the nursing assistants was shocked at the angry reaction of the spouse. The nurse assistant admitted that she felt a bit uncomfortable with the spouse after that, and said, "I felt like my every move might be watched."

Being in-between allowing spouse control and exercising staff control was also experienced when spouses had strong preferences, and the staff were unsure if this was also the cared-for partner's wishes. The staff reported that spouses sometimes had opinions on whether their partner should or should not shower on the scheduled day, stay awake despite the staff's advice to nap, or go out to social activities in the nursing home despite not feeling so well. "It results in a kind of interference by the spouse," one nursing home manager described. In these cases, the staff try to ask the partner his or her intention. However, it may be hard to know what the partner may have wanted, leading to a dilemma. As a nurse assistant recounted,

They can have different preferences. It's not always easy. Usually when there's an activity or something. The spouse makes the decision because she really wants to participate, but the partner doesn't want to go. One can suggest, "You can stay if you want to," but it can end up with him saying "No, I'll come along anyway." It's hard. Maybe because they don't like being apart.

Discussion

This article investigated how co-resident spouses experienced their caregiving role in the nursing home, and how the nursing home staff viewed caregiving by the co-resident spouses. By studying a situation where caregivers live together with the care receiver in the same long-term care facility, this article extends what is known from previous literature on spousal caregiving in residential care.

As common in ethnography-based research, this study is based on a small sample studied in depth. The study's strength, despite its small sample size, is the variation of the five cases through theoretical sampling. Including a range of conditions in which couples could live reduces the risk that the resulting themes would be effects of similar living conditions. It is not possible to foresee all possible living conditions for couples with differing care needs in nursing homes. Nevertheless, the sample allowed the emergence of stable themes across the board, while also accounting for variation in contrasting cases.

In keeping with the concept landscapes of care (Milligan, 2009; Milligan & Wiles, 2010), this article affirms the emplaced nature of care and how material and affective aspects shape care practices. The healthy spouse's constant presence in the nursing home blurred taken-for-granted boundaries between the domestic and the institutional, and spaces linked with formal and informal care. Accordingly, there were no longer clear-cut roles on which to rely on. The spouse was neither a visitor nor a care recipient, and the staff had to deal with a person that was a nursing home resident but not a patient.

This role ambiguity linked to physical space may help explain why informants described their experiences as "being in-between." Their dilemmas reveal how new role identities form in the ambiguous spatial context between "a home" and "not home," between "the staff's sphere" and "the domestic sphere." For the spouses, this ambiguous space creates questions about belongingness and caregiving responsibility. For the staff, dilemmas concern the proper extent of spousal caregiving, and how to acknowledge it without letting it take over.

This study confirms that family caregiving continues in nursing home transitions. The results describe a caregiving career where husbands and wives' old and new caregiving roles overlap (Pearlin & Aneshensel, 1994). The notion of caregiving career has only been previously applied to spouses living in the community. This study may add another dimension to understanding the caregiving career as a continuum in the marital relationship, in time and space, with other challenges for adapting caregiver identity. Because nursing home staff normally do not have a formal responsibility for accompanying spouses, this study shows that spouses were often left to navigate their new roles on their own. However, it is when the staff managed to both acknowledge the new caregiver identity and respond to the spouse's needs, that the situation was experienced as a balance.

Spouse involvement was sometimes perceived negatively by the staff as attempts to interfere, even though spouses' motives were to maintain closeness. A recommendation that can be drawn from the results is that there needs to be a clearer dialogue at the onset of the nursing home transition about the significance of caregiving for the couple and the staff's expectations. The staff could investigate the spouses' views on the extent of caregiving, to support them in the best way and to plan the organization of care in the couple's apartment. In this study, not all nursing homes had formal planning with the spouses when they moved in, and only some had spouse responsibilities formalized into a care plan. Yet, doing so might prevent feelings of "being in-between" for both the spouse and staff, and reduce uncertainty. Earlier studies emphasize that understanding the dynamics of the couple relationship gives insight into why spouses choose to continue caregiving despite difficulties, or even when formal help is available (Torgé, 2014). A mutual agreement on specific spouse tasks could be one way to help spouses define areas of responsibility, where a feeling of meaningful involvement can be maintained.

As it becomes more likely for couples to reach old age together and live in different types of supported housing, further research on this area is necessary. Important implications of nursing home co-residence demand future investigation, for example, on effects on the spouse's health, and how spouses project their futures when the partner passes away. Ultimately, studies in this area may also require other ways of conceptualizing individual care and family involvement in

nursing homes. It opens up the study of the interface of care practices as seamless landscapes, rather than distinct spheres of formal and informal caring. In this new landscape of care, supporting the spousal caregiver should perhaps not be seen as outside the scope of the staff's work but rather part of it, just as the spouses' informal care contributes to the care provided by staff.

Declaration of Conflicting Interests

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

Funding

The author disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by FORTE, the Swedish Research Council for Health, Working Life and Welfare [grant number 2015-00131].

References

- Baumbusch, J., & Phinney, A. (2014). Invisible hands: The role of highly involved family members in long-term residential care. *Journal of Family Nursing*, 20(1): 73-97.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2): 77-101.
- Brown, L.J., & Bond, M.J. (2016) Transition from the spouse dementia caregiver role: A change for the better? *Dementia*, 15(4): 756-773.
- Carroll, R. (2015). Family law, involuntarily separated couples and their property. *Law Context: A Socio-Legal Journal*, 33:87-114.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks: Sage.
- Davies, S., & Nolan, M. (2006). "Making it better": Self-perceived roles of family caregivers of older people living in care homes: A qualitative study. *International Journal of Nursing Studies*, 43(3): 281-291.
- Førsund, L.H., Kiik, R., & Skovdahl, K. (2016). Constructing togetherness throughout the phases of dementia: A qualitative study exploring how spouses maintain relationships with partners with dementia who live in institutional care. *Journal of Clinical Nursing*, 25(19-20): 3010-3025.
- Gaugler, J., & Kane, R. (2007) Families and assisted living. *The Gerontologist*, 47(Suppl 1): 83-99.
- Glasier, W.C., & Arbeau, K.J. (2017). Caregiving spouses and the experience of involuntary separation. *The Gerontologist*, doi: 10.1093/geront/gnx163.
- Graneheim, U.H., Johansson, A., & Lindgren, B-M. (2013). Family caregivers' experience of relinquishing care of a person with dementia to a nursing home: Insights from a metaethnographic study. *Scandinavian Journal of Caring Sciences*. 28: 215-224.

- Harnett, T. (2010). Seeking exemptions from nursing home routines: Residents' everyday influence attempts and institutional order. *Journal of Aging Studies*, 24(4): 292-301.
- Hellström, I., Håkansson, C., Eriksson, H., & Sandberg, J. (2017). Development of older men's caregiving roles for wives with dementia. *Scandinavian Journal of Caring Sciences*, 31(4): 957-964.
- Hemingway, D., MacCourt, P., Pierce, J., & Strudsholm, T. (2016). Together but apart: Caring for a spouse with dementia resident in a care facility. *Dementia*, 15(4): 872-890.
- Hennings, J., & Froggatt, K. (2016). The experience of family caregivers of people with advanced dementia living in nursing homes, with a specific focus on spouses: A narrative literature review. *Dementia*. doi: 10.1177/1471301216671418.
- Jeppsson Grassman, E., & Whitaker, A. (2012). *Åldrande och omsorgens gestaltningar. Mot nya perspektiv [Ageing and forms of caring. Towards new perspectives]*. Lund: Studentlitteratur.
- Kemp, C.L. (2008). Negotiating transitions in later life: Married couples in assisted living. *Journal of Applied Gerontology*, 27(3): 231-251.
- Kemp, C.L. (2012). Married couples in assisted living. Adult children's experiences of providing support. *Journal of Family Issues*, 33(5): 639-661.
- Koplow, S.M., Gallo, A.M., Knafl, K.A., Vincent, C., Paun, O., & Gruss V. (2015). Family caregivers define and manage the nursing home placement process. *Journal of Family Nursing*, 21(3): 469-493.
- Milligan, C. (2009). *There's no place like home. Place and care in an ageing society*. Surrey: Ashgate.
- Milligan, C., & Wiles, J. (2010). Landscapes of care. *Progress in Human Geography*, 34(6): 736-754.
- Nord, C. (2011). Individual care and personal space and assisted living in Sweden. *Health and Place*, 17(1): 50-56.
- Pearlin, L.I., & Aneshensel, C.S. (1994). Caregiving: The unexpected career. *Social Justice Research*, 7(4): 373-390.
- Roberto, K.A., McCann, B.R., & Blieszner, R. (2011). Trajectories of care: Spouses coping with changes related to mild cognitive impairment. *Dementia*, 12(1): 45-62.
- Sandberg, J., Lundh, U., & Nolan, M.R. (2001). Placing a spouse in a care home: The importance of keeping. *Journal of Clinical Nursing*, 10(3): 406-416.
- Social Services Act 2001:453.
- Torgé, C.J. (2014) Freedom and imperative: Mutual care between older couples with physical disabilities. *Journal of Family Nursing*. 20(2): 204-225.
- Torgé, C.J. (2018). Whose Right to a "Reasonable Level of Living"? Spouses with Differing Care Needs in Swedish Nursing Homes. *The Journal of Aging and Social Change*. 8(1): 45-60.
- Vaismoradi, M., Turunen, H. & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting qualitative descriptive study. *Nursing and Health Sciences*, 15(3): 398-405.