Whose Right to a “Reasonable Level of Living”? Spouses with Differing Care Needs in Swedish Nursing Homes

CRISTINA JOY TORGÉ
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Cristina Joy Torgé, Jönköping University, Sweden

Abstract: In Sweden, eligibility to move to a nursing home is usually based on an individual needs assessment. In 2012, an amendment to the Social Services Act was enacted, giving persons with residential care the right to live with a spouse in the nursing home, even if the spouse is relatively healthy and does not need nursing care. In this article, two contrasting case studies of cohabiting couples are presented. These case studies are based on field observations and qualitative interviews with the couples and staff in two nursing homes in two Swedish municipalities. The article shows that local municipal guidelines, establishing who has the right to help and care, affect the ways that both the staff and the couple talk about the spouse’s rights and roles as a coresident in the nursing home. In the two cases, there were also different staff attitudes about the spouse’s need for support in the role as spousal caregiver.

Keywords: Residential Care, Couple, Cohabitation

Introduction

In countries where needs assessment is a basis for residential care, spouses may not have a choice but to stay in the community if they lack care needs of their own (Taylor 2008). Consequently, older couples who have lived together for a long time may be at risk of separation during one partner’s move to a nursing home. Scholars have pointed out the negative consequences of unwilling separations caused by nursing home transitions, including negative effects on mental health (Taylor 2008) and the financial consequences for the community-living spouse (Hancock and Wright 1999). The community-living spouse may experience feelings of “married widowhood,” or mental distress and loneliness as a result of physical separation from one’s partner (Ask et al. 2014; Braithwaite 2002; Førsund et al. 2015). As there are now more possibilities for couples to move together to residential care facilities, the number of couples that choose to do so is expected to rise (Kemp 2008; Kemp 2012).

In Sweden, a country where couple-only households dominate among people over sixty-five years of age (Abellan et al. 2017), an amendment to the Social Services Act from 2012 facilitated a shift toward spouse cohabitation in nursing homes. Essentially, residential care still requires needs assessment. However, the amendment makes it possible for a person entitled to residential care to continue cohabiting with his or her spouse as part of a “reasonable level of living” (Socialtjänstlagen 2001:453, 1c§ ch.4). This amendment to the Act, dubbed the “cohabitation guarantee” (parboendegaranti), contrasts with earlier legislation in which it was only possible for couples to cohabit in nursing homes if both had an extensive need for personal care (Swedish Parliament 2011). The aim of the cohabitation guarantee is to support older couples in maintaining closeness in their last years despite health differences. Nevertheless, such arrangements demand a new way of conceptualizing the spouse’s role and involvement in the nursing home, from one of visitor to coresident.

Although family and spousal involvement in nursing homes is well-researched in Scandinavian and international literature, the majority of these studies are based on only one person’s transition to residential care, whose family continues to live in the community (Davies and Nolan 2006; Førsund et al. 2016; Kellett 1998; Milligan and Wiles 2010; Sandberg et al.)
Accordingly, a critique of the caregiving literature is that family roles in nursing homes are often limited to that of “visitors,” although frequent and highly engaged ones (Baumbusch and Phinney 2014). The realms of family and formal care have also remained in separate spheres in the literature. On the one hand, research exploring nursing home residents’ social careers has focused on friendships with other residents or with members of the staff (Kemp et al. 2012; Roberts and Bowers 2015). On the other hand, studies on staff-family interaction echo previous research on the family being regarded as visitors and outsiders in the nursing home (Baumbusch and Phinney 2014). These studies show that staff-family interactions often begin with a feeling of “us and them,” and that staff often feel that family members’ involvement disrupts nursing home routines (Bauer 2006; Hertzberg and Ekman 2000). In contrast, coresident family roles, such as when couples cohabit in a nursing home, is not well-researched. Kemp and colleagues, one of the few to explore cohabiting couples in the context of residential care, attribute this to the fact that couples are still a minority in these settings (Kemp et al. 2016). Still, their research has not specifically studied couples that have different levels of care needs.

Nursing homes are ambiguous environments, combining elements of home with institutional routines, and as such may still retain elements of institutional living (Hauge and Kristin 2008; Nakrem et al. 2013). As a nursing home can be a home for a couple, more systematic research is needed on couples’ experiences of everyday family life in the nursing home, the intersection of formal and informal care when the spouse is a coresident, and staff relations and responsibilities to the cohabiting spouse.

**Aim**

This article explores the Swedish cohabitation guarantee that entitles older persons needing residential care the right to cohabit with a spouse in a nursing home. Since there is little research exploring coresident spouses in residential care settings, there is a knowledge gap on the organizational and social factors that affect spouses when they are not merely visitors. Also, since the cohabitation guarantee came into place there has been no systematic research on how the practical implementation of the guarantee shapes couples’ lives in the nursing home. The aim of this article is to contribute to filling these gaps. By comparing two illustrative cases where municipalities have organized the cohabitation guarantee in different ways, this article shows how perspectives that permeate the way staff and couple talk about the spouse’s needs and roles can be understood in light of local guidelines establishing who has the right to help and care.

**The Cohabitation Guarantee**

Nursing homes in Sweden are a form of supported accommodation for older people needing twenty-four-hour assistance. Eligibility to move to a nursing home is established by a municipal care manager who judges if the older person’s needs can no longer be met in other ways through the system of home care. Accordingly, nursing home residents are often very old, frail, and have multiple health conditions (Sund Levander et al. 2016).

Although there is twenty-four-hour access to nursing staff, nursing homes in Sweden are not to be understood as institutions, but are considered by law as the older person’s legal home (Paulsson 2002). In this regard, they are akin to what is referred to in the US as assisted-living residences because they are guided by ordinary tenancy agreements and have the ambition to cater to both social and medical care (Nord 2011, 2013). For residents, the nursing home is often their last home in life (Sund Levander et al. 2016). However, because living in a nursing home requires individual needs assessment, Swedish government reports also concluded that older people were at risk of being unwillingly separated from their spouse or partner in the transition to residential care (Ministry of Health and Social Affairs 2011).

To address the problem of older couples’ unwilling separations, the Swedish government revised the Social Services Act in November 2012 with an amendment called the cohabitation guarantee.
guarantee (Swedish Parliament 2011). The guarantee allows couples that have lived together for an extended period of time to cohabit in the nursing home, regardless if only one of them needs residential care. The accompanying spouse does not need to undergo needs assessment and may have little or no care needs at the time of the move. The cohabitation guarantee applies to all older persons entitled to residential care, regardless if the person needs to move to a facility specifically for persons with dementia (National Board of Health and Welfare and National Board of Housing, Building, and Planning 2013).

Sweden, like other Scandinavian countries, is often described as a welfare state characterized by universalism and equality (Anttonen 2002; Edebalk 2000). However, municipalities, the smallest units of government, are also handed autonomy to shape the provision of social welfare (Davey et al. 2014; Trydegård and Thorslund 2001). As a framework law, the Social Services Act ensures the general right to assistance but leaves the details of implementation to municipalities that implement the law according to the conditions specific to them. In this regard, welfare researchers Trydegård and Thorslund (2001) suggest that it is easier to think of Sweden as consisting of many “welfare municipalities.” On the one hand, municipal autonomy encourages diversity and creativity in social services. There is also enough flexibility to allow municipalities to plan services according to the available resources. On the other hand, this means that although social policy has a universal character, there is a large variation in the scope, quality, and organization of old age care between municipalities (Trydegård and Thorslund 2001).

Regarding the cohabitation guarantee, municipalities are free to decide on specific guidelines on its implementation, such as tenant contracts (National Board of Health and Welfare and National Board of Housing, Building, and Planning 2013). Local conditions that may affect the implementation of the cohabitation guarantee include the number of available nursing home apartments and the availability of large apartments in local nursing homes.

**Materials and Methods**

Material for this article is taken from a larger study called “Everyday Life and Care among Couples in Care Homes,” a three-year research project involving field observations and interviews in five nursing homes in five municipalities in Sweden. This specific article builds on data collected at two of these sites, which are used here as contrasting cases. In this article, these two nursing homes are called Aspen Homes and Birch Homes, both located in comparable mid-sized Swedish municipalities. In both cases, the couple consists of one partner that has been assessed to need residential care in a nursing home and an accompanying spouse that had not undergone needs assessment, is relatively healthy, and has only a few care needs.

The project and its design have been approved by the Regional Research Ethics Committee in Linköping (No. 2015/425–31). After obtaining consent from the nursing home manager and the couple at each nursing home, the author conducted a sustained period of field observations (Hammersley and Atkinson 2007) and interwove these observations with semi-structured interviews with the couple and members of the nursing home staff. Informal conversations with the staff and couple also took place, which are recorded in field notes. At Aspen Homes, the author conducted six recorded interviews over a four-week observation period. These interviews were made with the couple, three nurse assistants in a focus group, a nurse, and the nursing home manager. At Birch Homes, the author conducted seven recorded interviews over a seven-week period. These interviews were with the couple (together as well apart), two nurse assistants, and the couple’s care administrator. The interviews were between forty-five minutes and two hours long and have been transcribed by the author. Interviews and field notes have been coded, compared, and used as a basis for memo-writing in the process of analysis.

Coding and constant comparison are tools for analysis that originate from Grounded Theory research, but are also used as general analysis methods in the social sciences (Taylor and Bogdan 1984). The aim of coding and constant comparison is to systematically produce inductively
derived generalizations about the phenomenon under study (Stebbins 2001). Grounded Theory methodology was initially developed as a response to the dominance of quantitative social research and to establish rigor in qualitative analysis and theorizing (Glaser and Strauss 1967). Codes, the basic operation of analysis in Grounded Theory, are not formed with a given theory in mind but developed through close reading and re-reading of the text. As codes emerge and develop, they are compared with other codes and sets of data (Charmaz 2006; Kelle 2007). This process, called constant comparison, is aimed at making analytical comparisons between similar incidents in the data (Charmaz 2006; Corbin and Strauss 2008). Subsequently, codes are linked together to form categories that give explanatory power (Charmaz 2006). It is worth noting that scholars developing Grounded Theory disagree about the level of abstraction required. Grounded Theory has been criticized for having positivistic undertones of using a rigid set of methods to discover overarching theories “hidden” in the data (Charmaz 2006; Clarke 2005). In this regard, this article aligns itself with constructivist Grounded Theory in which the methodology is seen as “a family of methods” (Bryant and Charmaz 2007, 11) and a “set of principles and practices, not as prescriptions or packages” (Charmaz 2006, 9). Besides coding and constant comparison, the analysis in this article draws from case study methodology in which each case is understood as “a bounded system” involving specific social, organizational, and physical contexts (Stake 1995). In this way, the perspectives expressed by staff and spouses in these cases could be seen as resulting from the specific contexts to which they belong.

The author carried out all of the interviews and observations. Transcriptions and analyses were made by the author using NVivo 11. Established ways of ensuring validity in naturalistic qualitative research were followed. Lincoln and Guba’s (1985) criteria of trustworthiness were met by following certain procedures in the research process to increase credibility, transferability, and dependability of the research (see also Creswell 1998). Prolonged engagement in the field and persistent observation over several weeks was performed in order to increase analysis credibility (Lincoln and Guba 1985). Peer debriefings, in which working hypotheses are presented to other researchers during the analysis process, were also carried out (Lincoln and Guba 1985; Schwandt, Lincoln, and Guba 2007). To know more about the transferability of the results in similar cases, thick descriptions of each case is used. Further, a strength of the analysis is that it builds on data captured from all the types of informants in the two cases, allowing for data triangulation (Creswell 1998; Lincoln and Guba 1985; Schwandt et al. 2007).

Two Case Studies

Aspen Homes

The couple in Aspen Homes has been married for almost seventy years. After the husband suffered repeated falls at home, the couple decided that it was time for him to apply for residential care. A relative informed them of the possibility to cohabit in the nursing home, which was for them a natural decision.

In Aspen Homes, most apartments are designed for single living, although there are so-called double apartments on each floor designed for couples. The couple lives together in one of these double apartments, a suite with a floor area of fifty-five square meters. The apartment has a bedroom, a separate living room, a bathroom that includes a washing machine, and a small pantry.

The municipality in which Aspen Homes is located applies a straightforward interpretation of the cohabitation guarantee which is based on the rights of the needs-assessed client. All social welfare, according to the Social Services Act, should ensure the person’s “reasonable level of living” (Socialtjänstlagen 2001:453, 1§ ch.4). The amendment, or cohabitation guarantee, extends the definition of this to include cohabitation with one’s spouse or partner, stipulating that “for the individual who has been given a social welfare decision in the form of supported
accommodation, it should be considered as part of his or her reasonable level of living to continue cohabiting with a spouse or partner. This is under the condition that the couple has lived together for an extended period of time or, if the individual already lives in supported accommodation, they have previously lived for an extended period of time” (Socialtjänstlagen 2001:453, 1c § ch.4).

The wording of the amendment suggests that the right to cohabit with one’s spouse or partner in the nursing home belongs to the person who has the right to residential care. In the Aspen Homes municipality, therefore, it is the needs-assessed client who is the signatory to the apartment contract, while the spouse can accompany as a coresident. As the needs-assessed partner, the husband in Aspen Homes is entitled to all of the services offered, including cleaning, laundry, showering, and an hour of “free time” with the staff every two weeks, in which he usually goes for assisted walks. He is also entitled to the medical services in the residence through the on-site nursing staff. The coresident spouse, although sharing in the physical space of the nursing home, stands outside this system of service and care. She is included in the nursing home meals (she pays for this separately), but in all other respects she is expected to manage by herself. She must also, in contrast to the other residents, go to all healthcare-related visits in the primary health care clinic outside the nursing home. This is because the nursing staff does not have access to her medical records and is thus unable to make medical assessments for spouse coresidents. On the whole, the expectation on the coresident spouse is that she should be regarded, as the nursing home manager describes, “as any other spouse in the community.”

In the couple’s everyday life, this arrangement leads to what was regarded by the couple as a rigid and bureaucratic division of tasks in their shared apartment. For example, the healthier spouse is responsible for washing her own clothes while her husband’s clothes are washed by the staff. The couple has managed to resolve this awkward situation through the spouse volunteering to wash both their clothes. At times, however, the unequal entitlements create uncertainty. For example, when the couple had just moved into the apartment, the staff were unsure if the whole apartment should be cleaned or if both beds should be bedded, as only the husband was entitled to room cleaning. This uncertainty was resolved at the municipal level by granting the spouse a separate decision for home care services specifically for cleaning, which is in turn performed by the nursing home staff.

Figure 1: Living Arrangements and Eligibility for Assistance in the Case of the Couple at Aspen Homes

Source: Torgé 2017
**Birch Homes**

The couple in Birch Homes have been married for sixty years. The wife has been diagnosed with dementia. The couple first tried to manage living at home and later tried short-term residential care/respite care so that the husband could get time off from caring. Not long afterwards, however, the wife was assessed to need long-term residential care at a nursing home. The husband moved in with her there after six months as he found living at home alone and travelling to his wife every day lonely and physically taxing.

The first difference between the two cases is that the couple in Birch Homes does not live in a double apartment but in two separate apartments of thirty square meters each. The primary reason for this is that Birch Homes does not have any double apartments. All apartments are designed for single living. As is typical in most Swedish nursing homes, these apartments are bed-sitting rooms with a toilet and a pantry and would be too small for couples. Another and more significant reason for having separate apartments is that the wife lives in a part of the nursing home specifically designed for people with dementia. The husband’s apartment is located on a different floor for residents without dementia. Cohabitation in separate apartments, or even on separate floors, is a possibility even with the cohabitation guarantee since not all municipalities have large nursing home apartments and shared apartments cannot be guaranteed. Thus, in the guiding document provided by the Social Welfare Board, cohabitation has been defined as living in the same or separate apartments in the same building (Swedish National Board of Health and Welfare and Swedish National Board of Housing, Building, and Planning 2013).

The second main difference between the two cases is how the municipalities have chosen to implement decisions on cohabitation. Rather than taking a straightforward interpretation of the cohabitation guarantee, the municipal social services at the Birch Homes municipality takes a two-step approach. First, they give a decision for assistance to the needs-assessed client in accordance to his or her right to live in a nursing home together with a spouse. Additionally, they give a separate decision to the accompanying spouse, entitling him or her to service and care in the nursing home without having to undergo needs assessment. This arrangement is possible because of a section of the Social Services Act that accords autonomy to municipalities to give assistance beyond a mere reasonable level of living, if good reasons exist for this decision. This paragraph stipulates that, “The board of social welfare may give entitlements to assistance beyond what is described in 1§ of the Social Services Act, if there are reasons for this” (Socialtjänstlagen 2001:453, 2 § ch.4).

What this two-step approach means in practice is that the spouse in Birch Homes is included in the nursing home’s system and is eligible to all services and care offered there. The spouse is also a signatory to his own apartment contract. Like the spouse in Aspen Homes, he pays for food in the nursing home. However, because he too is granted assistance in the form of supported accommodation, he must also pay a care fee like the other residents, regardless of his own health status. The municipality’s care administrator, in her interview, has dubbed this arrangement an “all-inclusive approach.” On the other hand, it is a more expensive option for couples, who in effect must pay an extra care fee regardless of how much help is needed. On the other hand, as expressed by the care administrator, the separate entitlements and equal payments mean that the spouse is “treated by the care and nursing staff as any other resident in the nursing home.” Like all of the other residents, the spouse is entitled to cleaning, laundry services, and one hour’s “free time” two times a month, which he utilizes for help with grocery shopping. The staff also helps him with buying medicine from the pharmacy, and he is entitled to help from the nurses at Birch Homes if healthcare needs should arise, eliminating the need to seek healthcare outside of the nursing home.

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2 In Sweden, depending on an individual’s pension, individuals may get a state subsidy for nursing home fees.
Two Perspectives on the Spouses’ Needs and Roles

As evident through descriptions of the case studies, the different ways of implementing the cohabitation guarantee do not only represent two possibilities of putting the new law into practice but deal more importantly with two ways of establishing who has the right to help and care in the nursing home. In this section, we delve deeper into this through the analysis of interview data. The interviews suggest that the municipalities’ ways of organizing the cohabitation guarantee have significance for how the spouses’ role and relationship with the staff are understood by the different actors involved. The analysis reveals two different underlying perspectives in the two cases: a “legitimate need” perspective and an “own right” perspective. These perspectives do not only reflect ways of establishing entitlements to assistance, but they also trickle down to spouse-staff relationships. These underlying perspectives can be observed at the level of nursing home leadership, echo through the statements of the staff at the personnel level, and re-emerge in the couple interviews, revealing how these actors make meaning out of the role of spouse coresident. The perspectives are illustrated in some key citations from the two cases.

Aspen Homes: The “Legitimate Need” Perspective

Needs assessment is a function of welfare distribution that “results in decisions about priorities of needs and priorities of actions to meet those needs” (Witkin and Altschuld 1995). Interviews with the different levels of staff at Aspen Homes reveal that they understand their duty as helping those that are eligible for help. In the words of the nursing home manager, they are “implementers” of the decision for assistance that has been established through individual needs assessment. The staff informants believe, referring to the needs assessment process, that only individuals that have the greatest need should receive the help offered in nursing homes. Conversely, they also hold that people who can still manage by themselves—such as coresident spouses—should not receive more help than they actually need.

This principle can pose a dilemma for the staff when a coresident spouse has acute or chronic health conditions that can be self-managed. To avoid potential tension between the spouse’s possible need for assistance and the staff’s scope of responsibility, the staff at Aspen Homes express that they must be firm in their demarcation of obligation. That is, it must be made
clear that their duty lies in helping the needs-assessed partner alone, even though they may feel a dilemma when not being able to assist the coresident spouse. In explaining their line of action, the interviewed members of staff first demarcate their scope of responsibility. In the same line of reasoning, they tend to emphasize the character of the spouse’s needs as non-legitimate. In the words of the nursing home manager: “The principle is that accompanying spouses that have not had a needs assessment are healthy enough to manage by themselves. Otherwise, they would have had decisions for assistance. So, we shouldn’t either offer such services. We shouldn’t make [spouses] worse than they are or create needs they haven’t had before…I believe many think it would be neat if the staff helped them and accompanied them to errands. But that’s not what we’re here to do. It doesn’t have anything to do with tight resources actually, but about doing the right thing.”

The “legitimate need” perspective is evident in that the nursing home manager makes a judgement about the validity of the coresident spouse’s wish for help—in this case, her request for “free time” given to other residents, for help with going out for errands. The manager interprets this as something that the spouse would think “would be neat,” but not a legitimate cause for the staff to help her, as spouses that are not needs assessed “should manage by themselves.” The needs-assessment process is here instrumental for framing residents’ needs as prioritized and legitimate needs, entitling them to the right to assistance. The coresident spouse’s needs are, in the “legitimate need” perspective, neither prioritized nor legitimate, but it can also lead to staff dilemmas when spouses are not very healthy themselves.

The spouse in Aspen Homes was hospitalized within a year of the couple moving in to the nursing home. At the time of the interview, she was visiting the primary health care clinic for an infection. Situations like these present a dilemma for the staff. It is not possible for the nurses at Aspen Homes to help the spouse beyond simple advice, mainly because they do not have access to the spouse’s medical records. In her interview, one of the nurses explained that it would actually be easy for her to help the coresident spouse with things such as changing bandages. However, she underlines that medical errands are something that the spouse “should fix herself.” Echoing the view expressed by the nursing home manager, the nurse’s interview suggests that being clear in one’s scope of responsibility, or demarcating one’s obligation, is necessary in order to “hold a professional distance.” She then adds that the spouse’s requests for help may not be a matter of necessity but rather a tendency of human beings to take advantage of, or even exploit, available help. Accordingly, the “legitimate need” perspective is also evident here since the nurse resolves the potential tension between her formal obligation and the spouse’s needs by undermining the legitimacy of those needs:

I can say [to the spouse], “get [medical] help there and there.” But she should fix that herself…I don’t make the call myself. It’s not my duty to call and ask the primary health clinic if she can come there…It’s because you must set a limit. If I start [making calls], she might begin to think that I can help her a little bit more, a little bit more, and a little bit more until I pass the limit for what I can do for her…If I cross the line, she might think that I can offer her more help too. Because that’s how human beings work. I choose to hold a professional distance there. (Nurse, Aspen Homes)

The “legitimate need” perspective can be linked to the ethical principle of justice (Beauchamp and Childress 2001). Both the nursing home manager and the nurse at Aspen Homes also argue in line with the justice principle, believing those who do not have help needs established through a needs-assessment process should not take resources from those who do need help. The principle of justice might also be the motive for the municipal guideline concerning apartment contracts in the cohabitation guarantee. In the Aspen Homes municipality, coresident spouses have three months to move out of the nursing home in the event of the needs-assessed partner’s death. The nursing home manager believes that this is to avoid a situation in which healthy spouses remain in apartments meant for those with “real” needs. The cohabitation guarantee, she
maintains, “does not say anything about what to do when the needs-assessed partner goes away, but only says that the couple has the right to cohabit—when both are alive, that is.”

Interviews with the nurse assistants who worked with the couple on an everyday basis in their apartment revealed that these members of staff may be less rigid when it comes to the “legitimate need” perspective. Conversations with the couple and the nurse assistants revealed that the nurse assistants sometimes help with arranging transport and simpler errands such as buying newspapers. The nurse assistants also usually deliver the couple’s evening meal to the apartment without expecting the spouse to fetch her own meal. As this is beyond their formal scope of responsibility, they place these gestures on the informal plane of caring, which are based on informal bonds of reciprocity rather than duty. “We are humans too,” as one nurse assistant expressed. Other members of staff, including the nurse quoted earlier, also expressed the importance of reciprocity and kindness, even if one is not able to give care to the spouse. The interviewed nurse stressed that, for lack of formal duty toward the spouse, the staff’s responsibility to her may be one of “being a fellow human being.” Within the strictly structured routines of the nursing home, where each instance of help corresponds to specific time and staff resources, there is a window for informal help and support by the staff, at least to a certain limit. If the staff responsibility toward the coresident spouse lies in reciprocity and kindness, a relevant question is how the spouse sees her own role in the nursing home. In the interviews with the couple, they emphasize that she continues to do a lot of care work for her husband despite the possibility of calling staff. Indeed, the spouse’s impression is that she is doing more care work now than when they lived at home because her husband is frailer than he once was. She asserts, “I am an asset to the staff. I must admit that.” However, she is constantly worried that something might happen to her husband when she is away and tries to limit her time away from the apartment.

Although she regularly participates in the activities and social life of Aspen Homes like other residents, the spouse is also fully aware that she is not living there on equal terms. Not being a signatory to the apartment contract but having already sold their previous home, she is uncertain about what will happen to her if her husband dies. On the one hand, the couple expresses sadness about the spouse’s situation as an outsider—or in the husband’s own analogy, “like something that the cat had dragged in.” He says, “I get everything and she gets nothing.” On the other hand, they seem to have internalized the “legitimate need” perspective as the reason behind their situation.

Birch Homes: The “Own Right” Perspective

The Birch Homes municipality implements a two-step approach in implementing the cohabitation guarantee. A partner that has passed the needs-assessment process is first given a decision for assistance, establishing his or her right to residential care in a nursing home and cohabitation with his or her spouse. Additionally, in accordance with the Social Services Act, the municipality gives the accompanying spouse a separate decision for assistance, entitling him or her to all service and care in the nursing home as a tenant. A consequence of this is that the coresident spouse at Birch Homes is a resident on his or her own terms. The spouse’s entitlement to care is not dependent on the extent of his or her needs. Rather, whatever needs for care he
might have are made legitimate through his own right to assistance and by paying rent and care fees like other residents.

In this respect, the municipality’s arrangement may just another way of legally establishing who has the right to help and care. However, it is also apparent from the interviews at Birch Homes that the spouse’s own right to assistance has a greater implication than mere eligibility on paper. In contrast to the “legitimate need” perspective where greatest need was an overarching criterion, the staff at Birch Homes tended to talk about the spouse’s needs as legitimate on their own terms. By these needs, they often referred to the spouse’s social needs in the nursing home and his needs as a family caregiver to his wife with dementia.

When asked why the municipal social services had chosen to give coresident spouses their own decision for assistance, the couple’s care administrator explained that it was to give coresident spouses, “above anything else,” a sense of coherence. Thus, the focus is not only on the right of the needs-assessed client to cohabit with a spouse, but also how the well-being of the spouse can be guaranteed in such a situation. The care administrator explained, “A few months after the change in the Social Services Act came [the cohabitation guarantee], the first couples to get a decision had a very sorry situation. So we [at the municipal social services] sat down and thought, ‘something ought to be done,’ and the boss at the municipal social services gave her support for it. It’s to create a sense of coherence for the accompanying spouse above anything else. We have a salutogenic model in our municipality.”

In this interview, the care administrator supported the coresident spouse’s right to assistance from the need for a sense of coherence from the salutogenic model (Antonovsky 1996). The salutogenic model focuses on factors supporting well-being in individuals rather than on factors that cause disease. In the “legitimate need” perspective, nursing homes are primarily understood as places for medical care for the most frail. The care administrator understands the nursing home as a supportive environment in which couples can continue to live a normal life despite one spouse’s extensive help needs. This is also clearly seen in another part of her interview where the care administrator refers to the spirit of the law and the spouse’s own right to have daily contact with his wife with dementia. While she refers to the principle of justice, she applies this to the right of needs-assessed persons to cohabit with their spouses regardless of diagnosis. Accordingly, in the “own right” perspective, both the husband’s and the wife’s own right to cohabit, and their own specific needs are recognized:

[The spouse at Birch Homes] has some heart-related problems. But he manages well on his own and when you see him, he’s an energetic man and all that. But [before he moved in], it drained his energy to travel here every day to see her. And I thought, “well he also has the right to be able to live near her and have that daily contact when they both still can.” So, I do think of this as a question of justice...The Bill [for the cohabitation guarantee] says that we should consider the person who is needs-assessed and that the law is for all, even those who have a dementia diagnosis. It also says that municipalities are free to organize cohabitation this as they wish. That’s what one is entitled to actually: to live together. (Care Administrator, Birch Homes)

How does this perspective shape the everyday interactions between the staff and the accompanying spouse? The arrangement at the Birch Homes municipality dictates that the coresident spouse is the signatory to his own apartment contract and pays a care fee. In consequence, care and service for the spouse are included in the Birch Home staff’s scope of responsibility. Help with apartment cleaning and laundry are incorporated into weekly staff routines.

One of the nurse assistants was not even aware that the spouse did not go through the needs-assessment process. This nurse assistant assumed that this was the case and was rather surprised when informed to the contrary. When she asked the nursing home manager for an explanation, the nursing home manager explained that because the spouse has his own decision for assistance,
“It shouldn’t make any real difference to our work or to the nursing home budget whether the spouse is needs assessed.” In other words, the staff regard the spouse as the same as any other resident in the nursing home.

Because the spouse is included in the staff’s formal plane of caring, the interviewed members of staff did not express any tension or conflict between the spouse’s possible need for care, the nature or extent of the need for care, and their formal duties. The spouse at Birch Homes has heart problems that are self-managed through medication. He also takes seasonal medication for asthma. The staff agree that he is, on the whole, able to take care of himself. Nevertheless, when help is needed with practical or medical care, the staff does not hesitate if this is included in their work.

The nurse assistant that works most closely with the spouse confirmed that he is an independent person with very few care needs compared to those of the other residents. She described him as someone who “does things himself a lot,” although she also asks him what he would like to have help with. Like the care manager, the nurse assistant sees the spouse’s right to care as including both medical and social aspects. In line with the “own right” perspective, she also underlines the spouse’s specific needs for support as a family caregiver for his wife. Accordingly, she sees it as part of her responsibility as a member of the staff to support him in the caregiver role. She explained:

He’s quite an independent person and does things himself a lot actually. But when I met him at the start we wrote a care plan together, to see what he would like to have help with. He wanted help with getting his medicines from the drugstore, with cleaning and laundry. That’s about it…I try to be supportive and encourage him. If he needs to talk about his situation, I try to be observant about that. If he wants to talk about his wife’s illness. I mean, as if he were a caregiver. Because that’s how it is in dementia care. A lot of it is supporting relatives. It’s tough for relatives, they get affected. (Nurse assistant, Birch Homes)

In interviews with the couple, the healthier spouse admitted that he is far more mobile and independent than the other residents. Every morning, he goes down to his wife’s apartment and wakes her up, keeps her company, and sometimes takes her out for walks. Having been the primary caregiver for many years when they lived at home, he feels that his involvement in his wife’s care in Birch Homes is “quite balanced now…I don’t feel forced to do these things. I know she has care anyway.”

Nevertheless, the “own right” perspective also seems to shape how the spouse speaks about himself and his role in the nursing home. He mentions his wife’s own right to residential care but he also describes the cohabitation guarantee as “making it possible for me to live with her,” giving him clear advantages. He also views his situation in a pragmatic way, referring to his advanced age and that it was just “a matter of time” until he might also actually need the array of nursing care offered at Birch Homes. He remarked:

I don’t have any such thoughts [that it is not appropriate for me to live here]. Because of my age. I realize that it’s just a matter of time until I get a stroke or something. I will eventually need the help in, who knows, it could change within a day! It would have been a stressful situation, to be alone with no possibility to get help. That was one of my thoughts [about choosing to move here]. That it will come. That it is just a matter of time, even if I am relatively healthy right now. But of course, that is in combination with the fact that [my wife] lives here. And the law changed making it possible for me to live with her here after 60 years of being married. We have a fortunate situation. We can communicate and do things together, and still have that sense of security…Even if I haven’t utilized the services here so much, I am likely to do that one day. Within a day
or within a year (laughs). So that’s why I moved with her, for the clear advantages.  
(Spouse, Birch Homes)

Discussion

The question posed in the title of this article is “Whose right to a ‘reasonable level of living’?” This is not just a rhetorical question, but merits a discussion based on the results of the analysis. In the Swedish Social Services Act, the concept of a “reasonable level of living” is a central pillar and a cornerstone for all welfare entitlements. According to the Act, social welfare should ensure that the client’s reasonable level of living is guaranteed on a minimum level. Similar concepts such as “dignified life” are used particularly in eldercare and are written into the national goals for old-age care (Social Welfare Committee 2009). However, what counts as a reasonable level of living is not defined in the law, thus allowing social workers the possibility to interpret the concept in their own ways based on clients’ individual circumstances (see Pajalic 2013).

In putting the cohabitation guarantee into practice, there is also interpretative prerogative by municipalities, which deals with what could be regarded a reasonable level of living—and for whom. If the wording in the cohabitation guarantee alone is the basis of the interpretation, then social services in the municipality are only obliged to guarantee the needs-assessed client’s reasonable level of living. Although the amendment frames cohabitation with a spouse as part of this, it still takes the individual client as a starting point. Accordingly, the coresident spouse is a non-client, yet in the government memorandum preceding the amendment, there is an argument made in favor of the cohabitation guarantee, which is to provide a sense of security for the couple in their last years of life together (Ministry of Health and Social Affairs 2011). Taking the couple rather than the individual as the starting point, the interpretation of the reasonable level of living could be open enough to include the coresident spouse’s perspective as well.

The analysis of the two case studies reveals that the interpretation one chooses and the different ways of implementing the cohabitation guarantee leads to different everyday relations between staff and spouse and different ways of understanding the coresident spouse’s needs and roles. From the spouse’s perspective, it could also mean the difference between seeing one’s situation as empowering or as something marked with uncertainty and lack of choice. One question that emerges from this analysis is: Is a narrow interpretation that only focuses on the individual client good enough? Conversely, to what extent can a welfare entitlement aimed at supporting a client’s reasonable level of living inadvertently limit the spouse’s own possibility for a reasonable level of living in turn?

In life course research, the concept of linked lives is an important principle underlining family interconnectedness over time (George 2013). It is often used to explain how older people experience intimate relationships in later life (Blieszner 2006) and how older couples often see themselves as a unit (Torgé 2013, 2015). Providing individual welfare entitlements when a situation concerns couples who had lived and continue to live linked lives over many years is a dilemma in interpreting and implementing the cohabitation guarantee.

One important implication of the results in practice deals with the support given to coresident spouses in their role as caregivers. Spouses are often the primary caregivers when older couples live at home, and they may need to construct a new caregiver identity when their partners move to a nursing home (Milligan and Wiles 2010). These two case studies suggest that the perspectives adopted by the staff also lead to visibility or invisibility of the spouse’s needs as caregiver, through either the demarcation or inclusion of these needs in their scope of formal responsibility.

A possible angle in this discussion is to what extent the “own right” perspective is a result of the marketization of welfare, i.e. the coresident spouse paying his own fees and being regarded as a paying customer. Marketization, however, seems to play only a small role in the two cases. Nursing homes in Sweden are regulated by public administration and are publicly subsidized
Public and private operators exist side-by-side, but municipalities have a responsibility to finance and supervise the services contracted out to private operators (Petersen and Hjelmar 2014). Citizens are free to choose between public and private operators; however, it is the municipal social services that decide who can move to a nursing home. Thus, it would not have mattered for the results if the couple at Birch Homes were at another nursing home run by another operator in the same municipality. Rather, the differences seem to lie in the fact that the municipal social services have chosen the two-step approach granting spouses their own right to live as a nursing home resident.

A more plausible explanation for why the two municipalities differ is the local conditions concerning availability of nursing home apartments. In the Birch Homes municipality, there is a surplus of nursing home apartments, while at Aspen Homes there is a long queue for residential care. The lack of nursing home apartments may be the primary reason why municipal social services in the Aspen Homes municipality must take a “legitimate need” perspective directed at the most needy. Meanwhile, in the Birch Homes municipality, the surplus of apartments means that local social services can be generous enough to employ an “own right” perspective, offering own contracts for accompanying spouses and taking the couple’s shared perspective as a guide in interpreting the cohabitation guarantee.

**Conclusion**

This article illustrates and analyzes two case studies in detail. The comparison shows that different ways of implementing the cohabitation guarantee is more than a matter of organization. They also lead to different perspectives on the staff’s sphere of responsibility and how coresident spouses’ roles and needs are understood by the actors involved. Although differences in organization are inevitable, comparisons of how municipalities implement couples’ possibilities to cohabit is important. Since the cohabitation guarantee came into effect in Sweden, allowing couples with different care needs to live together in nursing homes, there has been no systematic research on how couples’ lives are affected by the guarantee. This study has attempted to fill this gap in the literature.

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REFERENCES


ABOUT THE AUTHOR

Cristina Joy Torgé, PhD: Senior Lecturer, Institute of Gerontology, School of Health and Welfare, Jönköping University, Jönköping, Småland, Sweden
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