

ORIGINAL ARTICLE

Becoming an inadvertent home care user: The transition for cohabitating partners

Tove Harnett  | Håkan Jönson School of Social Work, Lund University,
Lund, Sweden**Correspondence**Håkan Jönson, School of Social Work,
Lund University, Box 23, 22100, Lund,
Sweden.Email: hakan.jonson@soch.lu.se**Funding information**Forskningsrådet om Hälsa, Arbetsliv och
Välfärd, Grant/Award Number:
Dnr2021-0815(2021-0815;2021-00506)**Abstract**

The aim of the study is to gain knowledge about the transition to living with formal home care for cohabitating partners. Data consist of 14 interviews with partners aged 64–85, most with extensive experience of home care. Grounded in a life course perspective, the study identified the key factors in the process of becoming an ‘inadvertent care user’, and two modes for that transition: (1) adaptations and negotiations that involve adjustments shaped by institutional regulations; (2) new roles and positions, where partners acted as guardians or mediators, but also developed new friendships. The introduction of home care often brought partners a sense of relief. While many adjustments were seen as necessary compromises, the unpredictable nature of staff visits necessitated unwelcome adaptations. The study provides new knowledge about how cohabitating partners’ lives are affected by home care and the strategies they employ in the presence of care workers.

KEYWORDS

cohabitating partners, eldercare, family carers, home care, transitions

INTRODUCTION

What has definitely changed is the mornings, with all the different times. I used to use my exercise bike in my nightie, but now I just think ‘Oh no, they’ll be here soon’ so I can’t do it any more. (Ellen, aged 76)

Ellen’s husband received home care several times a day. She described changing her morning routine, having to get dressed early and feeling worn down by having to welcome new people into her home on a daily basis. Ellen’s husband was one of about 250,000 people in

Sweden to have home care, many of whom live with a life partner.

Policies on ageing in place significantly impact elder care worldwide (Lehning et al., 2017). Several Western countries, including Sweden, have made the move from nursing home care to home-based care (Genet et al., 2011). As a result, more older adults remain at home longer, even when they have significant care needs. This also means that many older adults who may not require care themselves are living with partners who receive formal care daily in their home.

Home care in Sweden is provided according to individual needs and is heavily subsidised, making it affordable for users, who pay a maximum of 220 Euros a month, regardless of the services received. Home care is available day and night, every day of the year, up to

Data were based on qualitative interviews.

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2024 The Author(s). *International Journal of Social Welfare* published by Akademikerförbundet SSR (ASSR) and John Wiley & Sons Ltd.

about 10 times a day. Services range from help with personal hygiene, getting dressed, and medication to cleaning, laundry, social support, and outdoor walks. Many home care users have an electronic door lock installed, so care staff can enter without a key.

This study considers the experiences of cohabitating partners in the context of home care services. It examines how their lives are impacted by the presence of care workers and the adjustments made in the home environment. The introduction of home care services not only alters the life of the care user, but also significantly impacts the daily life of the cohabiting individual (Jarling et al., 2018). While existing research about spouses in the context of home care has emphasised their role as family caregivers (Jika et al., 2021), it is imperative to recognise they are also profoundly affected by the changes and may employ various strategies to navigate their evolving living conditions.

Previous research about care users and their partners

Home care allows older adults who would otherwise have required nursing home care to remain in their own homes (Ryan et al., 2009). While this is often in line with the wishes of older adults and their families alike, it also means a disruption when their private homes become a public arena for staff (Jarling et al., 2018). Studies have found older care users struggling with the spatial and temporal dimensions of daily life with home care (Doyle, 2012, 2014; Monrad, 2010; Palmqvist, 2020) and that care users may experience a loss of control over their daily lives and frustration when staff fail to show up as expected (Doyle, 2014; Palmqvist, 2022).

Research about the role of partners and spouses in home care has focused on them as caregivers and on aspects such as the caregiver's burden (Kim & Yeom, 2016; Lee & Marier, 2021) or care satisfaction (Compton et al., 2020). However, cohabitating partners are also directly affected by home care services, and partners' transitions from a life without home care to a life *with* home care has not been given sufficient attention. Partners may feel a weight lifted from their shoulders, yet they may feel overlooked when formal caregivers step in to interpret their partner's needs (Davis et al., 2014; Hunstad & Svindseth, 2011; Kalwij et al., 2014). The lives of care users and their cohabitant partners are 'linked' (Elder, 1994), and the relationship between the partner and home care staff can be described as a dynamic 'care convoy' that evolves over time (Antonucci & Akiyama, 1987; Kemp et al., 2013; Petersen et al., 2022). When a person begins to receive care from home care staff, the composition of the care convoy changes as

Key Practitioner Message

- The decision to apply for support from formal home care services is often made when the cohabitating partner is exhausted from the burden of caregiving. The care system should allow enough time and not require people to change their homes and habits in a rush.
- Care providers should acknowledge each 'ordinary couple biography' and 'family care biography'. The timing of their care visits must also take into account a cohabitating spouse's everyday life and routines.
- Care providers should develop termination and closure routines for cohabitating partners for when home care comes to an end because of the death or relocation of the care user.

formal and family care relationships develop. At the point when formal care is introduced, partners, often exhausted from the burden of caregiving, may experience it as respite care, but they may also need to be included in shared responsibilities from that moment on. Anker-Hansen et al. (2018) describe a 'failure over decades in meeting care partners' needs', which in Sweden has led to policies which hold local authorities responsible for providing support for family carers (Takter, 2017).

Alongside the changes in the cohabitant partner's role when formal care begins, their home will also be adapted. Like the care user, the cohabiting partner will be affected by the comings and goings of home care workers and the transformation of their home into a workplace. This is of particular relevance, given the ongoing changes to Scandinavian eldercare that have resulted in reductions in the number of nursing home placements, and ultimately to older individuals with extensive care needs living at home longer with support from home care services (Möllergren, 2024; Szebehely & Meagher, 2018; Vabø et al., 2012).

Aim and research questions

The aim of the study is to gain knowledge about the transition to living with formal home care for cohabiting partners.

- How is the partner's life affected by the presence of care workers and the arrangements for care in the home?
- What strategies do partners employ in the presence of care workers?

Theoretical framework

Theoretically, the study applies the life course perspective found in ageing studies (Elder, 1994; Elder et al., 2003). Using this approach, studies have explored the pathways and trajectories, turning points, and transitions and other biographically significant events in the lives of individuals and members of their networks. Walther et al. (2022, p. 11) take a ‘doing transitions’ approach, using a life course perspective to describe transitions as ‘performative realities that are produced in discursive, institutional, and individual practices’. Transitions are not limited to individual experience, though; they are interpreted biographically, and actively negotiated with other actors in different contexts (Settersten & Thogmartin, 2018). With its focus on agency, process and interpretation, the ‘doing transitions’ approach highlights the way individuals position themselves on events and relations and acquire knowledge and skills as part of their new roles.

In the present study we focus on the transition to life with home care, but from the position of the cohabiting partner, occupying what Riley et al. (1988) call a ‘counterpart position’ because they are living with a person who has home care in a home where care is performed. The cohabiting partner is usually involved in the application for home care and welcomes it when it is provided, but even so the arrangements can be unwelcome in the broader sense of being prompted by the care user’s impairment.

The transition is engineered by a system of formal care, organised in a particular way, and often part of a family care biography that involves the care user, their partner, and the other members of the care convoy. The biographical interpretation individuals bring to their interactions with others can be likened to ‘lenses’ through which actions and arrangements are framed and evaluated. These lenses often include a ‘normal couple biography,’ characterised by established roles and routines prior to the transition into a caregiving dynamic, where one partner assumes responsibility for the care of the other. As caregiving evolves, this experience develops into a ‘family care biography,’ comprising new roles and habits. This family care biography then serves as a lens through which individuals interpret and assess formal caregiving arrangements.

METHOD

The study is part of a larger project about home care from the perspective of those who use it, mainly older care users, but also people living in the same home. The data for this study were collected between 2021 and 2023 and consisted of 14 interviews with the cohabiting partners of

home care users. Respondents were recruited through local authorities’ home care organisations, where staff provided written information about the project to older adults cohabiting with care users. Individuals who expressed interest in participating were contacted by researchers by phone to schedule an interview. Respondents lived in various geographical locations, ranging from large cities to rural areas. All interviews took place in the participants’ homes once both verbal and written consent had been obtained. In some instances the care user was present in another room during the interview.

The study had approval of the Swedish Ethical Review Authority (Dnr 2022-00829-02), and participants were informed about the study’s objectives and their right to withdraw consent at any stage. Participants were each provided with a lottery ticket as a symbolic honorarium. Half the respondents were male and half female, ranging in age from 64 to 85. The partners of all respondents had extensive care needs: a majority had dementia and used a wheelchair. Diagnoses varied from Alzheimer’s and Parkinson’s disease to multiple sclerosis and cerebral haemorrhage (see Table 1).

The interviews were digitally recorded and transcribed verbatim. They lasted about an hour, the shortest being 33 min and the longest 1 h 38 min. The transcribed material amounted to 487 pages. The interview guide had questions about the care provided and the impact of care

TABLE 1 Respondents (in alphabetical order) and their partners.

IP (Interview Pearson) pseudonym	IP age	IP partner’s condition
Anders	67	Cerebral haemorrhage
Annika	76	Stroke, paralysed. Died before the time of the interview
Beatrice	85	Dementia (not specified)
Catrin	80	Parkinson’s, dementia (not specified). Died before the time of the interview
Cecilia	72	Lewy body dementia
Edvin	82	Parkinson’s, cognitive impairment
Ellen	76	Parkinson’s
Frida	79	Spinal stenosis, Parkinson’s
Johan	75	Lewy body dementia
Kenneth	84	Dementia (not specified)
Monica	64	Stroke, paralysed, apraxia
Per	76	Multiple sclerosis. Died before the time of the interview
Rikard	81	Lewy body dementia
Ulf	74	Alzheimer’s

provision on the couple's lives, ranging from the impact on their home, daily routines, and habits to their personal appearance and relationships with care staff and others. The interview guide did not focus on the care provided by the cohabiting partner, but on how couples had lived at different stages of their lives and on the intersection of family and formal care.

Process of analysis

The analysis took the approach Braun and Clarke (2006) label 'theoretical thematic analysis', being driven by analytical questions about transitions that are anchored in a life course approach (Settersten & Thøgersmørtin, 2018). Following the usual steps of a thematic analysis, all interviews were transcribed verbatim and read by both members of the research team. Preliminary codes were constructed, and the entire dataset was coded in a process where new codes were added. The coding and recoding of data were facilitated by the NVivo software. The coded dataset was printed as a report and read by the members of the research team, who identified candidate themes, which were further investigated using the entire dataset, which brought overlapping themes together, excluded candidate themes that transpired to be marginal, and identified overarching themes of processes and relations.

The analysis resulted in two overarching themes, that were related to established roles and routines of the couple, and that represented modes by which cohabiting partners transitioned to life with home care: (1) adaptations and negotiations; and (2) new roles and positions. Each of the overarching themes comprised three subthemes:

Theme 1—Adaptions and negotiations:

- Routines and habits.
- Personal appearance.
- Home and objects.

Theme 2—Managing new roles and positions:

- Guardians, witnesses and meddlers.
- Reluctant hosts.
- Friendships.

RESULTS AND DISCUSSION

The transition to living with home care was described as a process that included quantitative and qualitative shifts, typically when illness or an accident had resulted in an increase in care needs. Respondents described how their daily lives, routines and homes were transformed as a result of having home care staff coming and going daily.

An initial transition preceding formal care

Respondents had experienced care trajectories with an initial transition from 'normal' couplehood into couplehood with them being a family carer. This transition either developed gradually or came suddenly, conflated with the introduction of formal home care. Several respondents described being increasingly housebound, providing care beyond what was manageable. The interview with Johan (aged 75) was illustrative. His wife developed Lewy body dementia, and he gradually took over running the household; as his wife was steadily more dependent on him being present, so he was increasingly tied to the house:

So, as her illness gradually escalated, you could say, my own time was zero in the end and in order for me to be able to have some kind of social ... and my own time, we ended up getting help from the home care service.

Johan's situation illustrated how transitions are not merely individual experiences, but linked and embedded in social networks (Elder, 1994). At the time of the interview, the couple had daily home care and regular respite care, and Johan said they were considering a permanent move into a nursing home.

Johan and others interpreted their transitions with the 'family care biography' lens, which involved illness and accidents, encounters with healthcare, family care and an increasingly strained situation. The lens coloured their comparisons during the transition to life with formal home care. In several cases, respondents described a form of symbiosis that also affected their views on home care, where their relief and gratitude for the help—and the opportunity to leave the house—was mixed with their fear that the care user's unique needs would not be catered for in the right way.

The transitions are illustrated in Figure 1.

The transitions were not always distinct and as highlighted in the figure, the transition to formal home care was added to existing roles and relations. A third transition, where the partner moved into residential care or died, is not illustrated in the figure, but was described in several of the interviews.

Overarching theme: Adaptions and negotiations

The introduction of formal home care meant that activities and roles that had been challenged or lost could be regained once support and respite was in place. However, it presented new challenges. Respondents described a

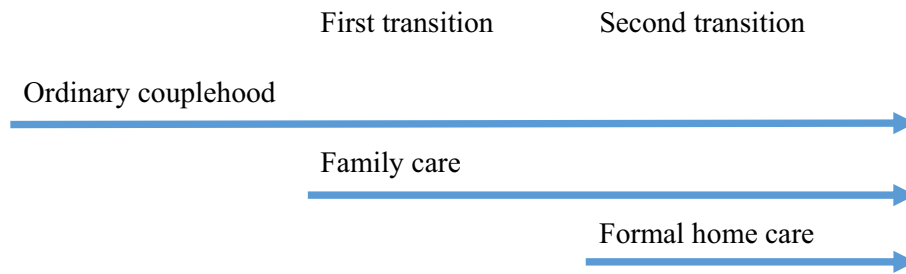


FIGURE 1 Couplehood transitions when living with home care.

transition characterised by a loss of agency and control over their home and their daily lives, and by having to adapt their habits to fit the home care schedule. Most viewed these adaptations as a reasonable trade-off, a natural consequence of their partners' condition, as when Beatrice mentioned that she had to be up and dressed early in the morning, before the home care staff arrived to help her partner get out of bed:

Yes, you have to, it's a change, it's part of this, absolutely. And that ... you have to see it like that ... they come to facilitate and help and not feel that they come and intrude in some way. (Beatrice, aged 85)

For Beatrice, the transition was also evident in a shift in how she thought about their home: where it had been their private sphere, it was now a semi-public arena where unfamiliar care staff came and went. Like several other spouses, her strategy included self-instruction—'You have to see it like that'—and agreed with what she saw as far-reaching changes in the way she lived her life. Beatrice set the alarm for 7:00 AM to get up and have a shower before the home care staff arrived. She said it would be nice to stay in bed longer sometimes, but she could not see life being any other way: 'it is like it is, you can't change that'. Beatrice's transition involved acquiring new skills and knowledge of how to adapt and negotiate to a life with home care.

Subtheme: Routines and habits

Like other respondents, the changes in Beatrice's life were linked to her husband's transition into being a care user and the institutional practices of the care provider. Spouses mostly complied with the provision of care, but that did not mean they appreciated it in every respect. Statements about irritations and problems with home care staff were common. What they found particularly intrusive was having to adapt to time adjustments that

kept couples from their preferred activities. While the introduction of formal care enabled couples to pursue activities that had been impossible after the initial transition, living with home care was also something that respondents felt prohibited them from keeping up with their work or their social life. Anders (aged 67) presented himself as a socially active person. For years he had thrown large parties within the ethnic group he belonged to. The transition to living with home care limited his social life and he could no longer spend time with his group of friends and acquaintances. When asked if his life had changed since his wife began having home care, Anders said their social life had shrunk. He described their old life, full of social obligations and their present life stuck at home:

Anders:

Before ... we have a lot of compatriots around here ... so they have parties and so, huh. Then when you have a party, I've said no to many parties because the parties start at six or seven o'clock. We have to be here at half past eight, so that time should ...

Interviewer:

Why do you have to be here at eight thirty?

Anders:

She needs help getting into bed. I can't do it ... there are two people coming, the last time is half past eight, nine o'clock or something, so at that time they come. They have other patients too.

Anders interpreted his situation through the 'ordinary couple biography' lens and the type of social life he and his wife had lived before, and could potentially have lived if the organisations would adjust some visits to the habits of the couple. His transition involved loss and agency. He clearly missed his old life, but complied and

changed his bedtime habits. From the early evening, Anders stayed with his wife in their bedroom and kept her company. They watched films together, but on a laptop because there was nowhere to have the television in the bedroom. Anders said that although he could not live in the way he wanted, his mission was to keep his wife happy, and this made the adjustments to their lifestyle tolerable. He framed this trade-off as reflecting his love for a wife who had become ill, but his situation was also shaped by the care provider and its schedules.

In several studies of care the unpredictability of visits was a common problem (Doyle, 2012; Palmqvist, 2022) and here too all respondents mentioned it. Spouses felt trapped at home, waiting for staff who arrived late or before the decided time. Catrin (aged 80) described a situation in which she never knew when staff would arrive: 'You have the feeling that soon they will come ... but will they come?' The couple were 'left in peace' in the morning until about 8:00 AM, but it was impossible to know when staff would arrive after that. Catrin was still working and had a home office, but her entire day was punctuated by unpredictable visits by staff, making work difficult. Catrin described a life which was 'on hold' for long periods.

Adaptions were not limited to compliance; they took the form of protests and negotiations, as when cohabitating partners requested that their established routines be accepted. Frida (aged 79) had repeatedly complained to staff about them being late for her husband's morning visits, as it disrupted the couple's entire morning.

It's every single day. Every day. They almost never come before eight thirty. And in my world, it's too late. Because when we've had breakfast, it's time ... we're sitting here eating breakfast and talking and reading the newspaper, yes, then it's ten o'clock. (Frida, aged 79)

She had asked to have the start time changed, but the response was there were not enough staff available and the care provider had to prioritise the 'insulin customers'. Her transition was not only linked to her husband, but also to the home care organisation and its 'insulin customers'. The home care organisation's staff shortages meant reduced agency for Frida and greater uncertainty about when staff would show up. Frida did not manage to change the arrival time of the home care staff, but several respondents described having some success in their negotiations to adjust the timings of home care visits to fit better with their established habits.

Subtheme: Personal appearance

The constant presence of staff and their shifting, unpredictable times of arrival were something which respondents handled differently. Some adjusted their appearance for a situation where the home had become a semi-public space, typically by getting up and dressed early, well before the first morning visit; others did not, as illustrated by Johan when asked whether the care staff arrived when he was still in his underwear:

Yes, in reality this is how it has developed. When it started, when we moved here, I didn't do that. But in practice now it's like, since I don't know when they're coming ... I can't be sure, I'm wearing pyjamas, often like that, even if I get up at five o'clock, huh, I'm still in pyjamas at eight, nine, something like that and then. I don't change just because they will come ... I still have it. So, I ... you ... you learn that more or less, you have to stop caring about it. (Johan, aged 75)

In Johan's case there were a couple of key moments in the transition process. The first was when the couple moved house and started to use home care and Johan changed his morning routine; the second was when he learned to stop caring about appearances. It could be interpreted as giving up his sense of dignity that he expressed by being properly dressed; alternatively, Johan's position could have been a way of reclaiming authority over their home and his own appearance in a situation when he had negligible control over the home care visits. What makes the latter interpretation credible is the description of his clear choice not to get dressed, expressed in the phrase: 'I don't change just because they will come.' He experienced multiple changes in his life linked to his wife's need for home care; his ability to remain indifferent about the way he dressed can be seen as a kind of skill he acquired over time.

Subtheme: Home and objects

Another type of adaption concerned the materialities of how people's homes were affected by the presence of care objects and traces of care. The provision of home care resulted in several changes that cohabitants described as necessary adjustments, minor nuisances, or intrusions. Examples of minor nuisances were problems finding items that staff had put in places that were not familiar to the spouse, medical items and protective equipment (PPE) lying around and incontinence

products thrown away in the normal bins. The realisation that staff were poking around, opening cupboards and trying to find items resulted in a sense of having lost control over the home. The transition to becoming an inadvertent care user involved a transformation of the home, from a private to a semi-public sphere.

Two material objects were paid special attention in the respondents' accounts of living with home care: the electronic front door lock and the care bed, sometimes with a patient hoist. The installation of the lock had a double meaning, because it made it possible for respondents to leave the home when the care user could be left alone, since staff could access the home without a key; against that, there was a risk staff could enter the home when it was inconvenient for reasons of privacy. The care provider's demands to install a care bed and patient hoist could be controversial, and a few respondents described the negotiations with some bitterness. The timing was the problem, and a feeling that the care bed was being forced on them without them having the chance of getting used to the idea first. Per (aged 76) described the destructive dynamic that developed when the care provider demanded that a care bed be installed:

I fully respect the need to be careful with the backs and joints of the home care staff, I fully respect their need for a good working environment, but then there comes a safety representative and says that 'You must have a care bed here'. And Angela said, 'No I don't want any care bed'. And then she had the manager, the coordinator, and the safety officer on her back. And so they all came here with the coordinator to sit and talk about the bed and so on. [...] And they went on and on and then the manager said to Angela that 'If you say no to this, I can withdraw everything else that is not vitally important'. (Per, aged 76)

Per said he understood the practical reasons for having the bed, but it would result in the couple having to sleep in separate rooms. It was the timing of the demand and the care provider's attitude he found difficult to accept. Like other respondents, he described a need to get used to the rearrangement of beds. By interpreting the situation through an 'ordinary couple biography' lens, Per portrayed the care bed as an object that stood for the normalcy of the life he and his wife had lived together. Repeating his respect for staff working conditions, Per stated that 'one must distinguish a home from a hospital'.

The installation of a care bed can be interpreted as a symbolic transformation of the home and the relations between its inhabitants. A care bed is usually installed in a way that enables staff to work from a variety of positions, with or without a patient hoist. It is often impossible to fit another bed in the same room and spouses may therefore have to sleep in separate rooms. The separation of bedrooms challenged attempts to uphold 'normal' couplehood.

Overarching theme: Managing new roles and positions

The second main mode for the respondents' transition to a life with home care was that of managing new roles and positions. From being a spouse and family carer, when home care entered their daily lives partners found themselves taking on the role of guardians, witnesses and meddlers. Previous research has described how partners developed new roles (as adaptors, strugglers and managers) in handling caregiving situations (Davis et al., 2014). Our analysis shows that partners also developed new roles with home care staff, ranging from reluctant host to friend.

Subtheme: Guardians, witnesses and meddlers

Studies of residential eldercare have shown that the position of guardian is associated with attempts to get information about the arrangements and occasional conflicts which arise (Whitaker, 2009). The situation at home is governed by a different dynamic, where the partner is often present when care is provided, in sight or at least hearing. An episode related by Cecilia was typical of her overhearing problematic care:

Then they brought out ... they helped him take off his pyjamas and put on clothes that I had laid out as well as the night before that he was supposed to wear. And then I heard from inside, 'No, not that leg, no, now we'll take that leg!' (Cecilia, aged 72)

What made this part of Cecilia's transition challenging was the fact she was present, within earshot, in a situation when care was not provided in an optimal way. She could hear her husband protest and could choose to intervene. The experience of being a witness was often reported by respondents, and sometimes linked to their ambivalence about being relieved from the burden of care but still present and able to intervene. Respondents

described the worry and stress, and their attempts to control or compensate for the problems they saw. Annika (aged 76) said she had to act as an interpreter since many of the staff did not speak Swedish well enough for her partner to understand what they were saying. Rickard (aged 81) said the only time he could relax was when his wife had respite care 3 days a week, because then he knew she was being well cared for:

Then, then I can relax. It's those occasions. Otherwise, it is necessary that I am in some way some kind of back-up, by controlling; did you really get this [medication]? Did you get that and ...?

Rickard had put name tags on his and his wife's hearing aids but still, he said laughing, the home care staff put one of each in his wife's ears. Descriptions of problematic care usually included comments on differences among staff members, illustrating how their lives were linked with both those who knew the care user well and those who did not. From the perspective of the cohabiting partner, the latter had to be supervised, and the fact that new care staff sometimes asked for advice added to the uncertainty of the situation.

It is not our contention that these home care users were treated badly, but rather that the presence of others providing care was a source of worry and stress for several spouses. They took on ambivalent roles, witnessing glitches in care and feeling like unwelcome meddlers if they acted on what they saw. That first transition into the role and responsibility of a family carer resulted in a biography that included their preferred ways of caring, and that influenced their transition to home care use.

Subtheme: Reluctant host

The comings and goings of large numbers of staff members was remarked on as a problem by all the respondents. Part of the problem was the reluctant relationships where the spouse had to act as a host for unwanted guests. The appearance of new staff who did not know what care to perform was perceived as particularly frustrating, and it was difficult for spouses to relate to these visitors in a polite and relaxed manner. Some mentioned the summer times as difficult periods when care providers relied on substitute staff.

Cohabiting partners' living conditions were linked with the home care organisation, and mostly referred to the appearance of new staff as something that was inevitable. In many instances, introductions worked smoothly, but other respondents treated visits by new staff as an

intrusion. This was the case with Ellen and her husband, who talked of a staff member unknown to the couple entering their home during the interview, asking for directions to the medical cupboard. Ellen sent him back to the office, justifying her refusal to help him because he had no name tag and did not seem to know what he was doing in their home. Her husband thought that her approach was too harsh, and that they should have let the visit proceed. This instance could be described as a case of the cohabiting partner trying to send a message to the care provider—perhaps also as an illustration for the visiting interviewer. Ellen was clearly frustrated by the need to keep her eye on her husband's medication, since she had to engage socially with several care staff members in her home to an extent which on some days was beyond her:

Interviewer:

Do you try to set up your daily life so that there aren't situations where they come when you're not ready?

Ellen:

Yes, yes, I do. But it also happens that I walk away, because I think like this: I can't bear to meet more people.

Interviewer:

No, exactly.

Ellen:

So, I go away and then I check afterwards that he has received his medicine. So, me, I can be at home without showing myself.

The couple lived in a house with many rooms, which made it possible to apply this strategy on occasions when Ellen did not feel able to engage socially with staff. By interpreting her adaptations using a 'family care biography' lens, she portrayed them as understandable, as the staff had to come in the morning to help her husband. She did not manage to greet staff or act in the accepted manner when receiving visitors at home. She fell into the category of cohabiting partners who found it necessary to be properly dressed when 'visitors' arrived in the morning to care for her husband, and so had adjusted her habits to make this possible.

Subtheme: Friendships

Visits by home care staff changed the dynamics in the care convoy, with positive outcomes for cohabiting spouses, primarily the lifting of the burden of care. However, spouses and formal care staff also developed meaningful social relations that respondents described in positive terms.

Several respondents consciously adopted a positive and welcoming attitude in order to establish good relations. Catrin and Per put this at its plainest. Catrin described deciding to get to know the staff members who visited the couple, trying to find a personal connection for her own and her husband's sake. Per described a similar decision taken initially to 'put aside such feelings as if a stranger is coming into our home'. By interpreting the situations through the lens of a 'family care biography', the couple instructed themselves about how to interact with staff by being welcoming. They adopted new roles in their transition to a life with home care, and acquired skills and knowledge about how to develop friendships with visiting staff members. There were also cases where respondents struggled with this attitude, and once again the question of time and getting used to living with formal care was invoked:

I probably have to work ... work on this so that, purely mentally, I have to accept that these are people who come into my private bubble, and I know that it is a must. And it takes some time when you are used to fixing things yourself. (Frida aged 79)

Frida described visits as an intrusion into her private sphere and her established way of providing care, but reasoned that the arrangement had to be accepted as a necessary trade-off.

Interaction with staff was also described as something that added value to the social life of cohabiting partners. This theme was developed in descriptions of pleasant, interesting meetings with staff and as comments on friendships that had developed. Annika suggested that such positive encounters could compensate for a situation where everyday discussions with a partner were limited for reasons of illness:

I have had very nice people here in this house. ... I have to say that. We could talk about flowers, we could discuss wines and we could talk about anything, that is. And that, it becomes a little more natural then, when you are at a home and have a sick person, that you can talk about everything. And when they come and ask, 'What do you do with that plant, for example?' (Annika aged 76)

Annika commented on relations with staff members who had small children, asking after them: 'So you get to know about things and so part ... you participate in their daily life even when they are outside the home care'. This

additive aspect of home care was present in several interviews. It could solve problems associated with the first and second transitions, when their social lives were affected by being housebound or lacking interaction with a spouse with a cognitive impairment.

The importance of meaningful encounters and friendships was underlined by descriptions relating to the third or fourth transition, when the care user had died or was not present in the home during respite care or admission to a nursing home. Such turning points in respondents' transitions illustrate the intersection of linked lives (Elder, 1994). The friendship between the home care staff and the cohabiting partner depended on the care user: when the care user died or moved to a nursing home, the home care staff's link was lost not only to the care user, but also to the partner who remained at home. The three respondents whose spouses had died by the time of the interview considered it a period when they missed the social contact they had become used to when care staff visited daily. The contrast was striking where death or relocation to a nursing home had been preceded by intensive home care visits to the couple six to eight times a day.

Per described home care visits as an inevitable intrusion into their private lives, but added that the death of his partner had made him realise there were also positive aspects:

But I can say it now that now that Angela is gone, yes, then the escorted walks have disappeared, the respite care has disappeared, but the home care has also disappeared, so it is extremely quiet now. So now it's empty, now there are no people, there was both the escorted walks and respite care and a fantastically wonderful person who took care of Angela, I'm still in contact with her.

From 1 day to the next, several people the partner may have formed close friendships with were gone. The care bed and other devices were collected and their home was rearranged yet again.

CONCLUSION

There are a number of studies about the role of spouses and other family members as providers of eldercare, and the need to provide support to reduce a caregiver burden has also been stressed (Kim & Yeom, 2016; Lee & Marier, 2021; Takter, 2017). This study adds knowledge by focusing on how the cohabiting partner's life is affected by the presence of care workers and the

arrangements for care in the home. The analysis took a social life course approach where transitions are seen as interpreted biographically, and actively negotiated with other actors (Settersten & Thogmartin, 2018). Using this approach, it became evident that a transition into being an ‘inadvertent’ care user was highly dependent on how the new situation was viewed through the established biographical lenses of being an ordinary couple or a family carer (Figure 1). These lenses were used in descriptions of a previously curtailed life, dominated by family care responsibilities, to which the introduction of formal care had restored some normality, as well as in descriptions of formal care as threatening established habits, privacy, and ‘normal’ couplehood, for instance by separating beds/bedrooms and disturbing the privacy of the couple. Respondents described the ‘ubiquity of formal care’ manifest in objects—care beds, lifts, and items such as gloves and rubbish—their home being rearranged, and the comings and goings of care staff. What gave the presence of staff an omnipresent character was the unpredictability of their visits and the realisation that staff were poking around when trying to locate items used for care. A particular dynamic was created by the spouse usually being at home, able to witness, feel and intervene from the established position as a family carer when formal care was performed.

From our findings it is possible to identify challenges and recommendations for care providers. Sweden and many other countries provide support for spouses in their roles as *family carers* (Lamura et al., 2008). The ‘doing transitions’ approach makes it possible to identify the challenges associated with *timing*. The decision to apply for support from home care services is often made when the cohabitating partner is exhausted from the burden of caregiving, giving the transition to home care use the character of a crisis (Anker-Hansen et al., 2018). The transition to inadvertent care user involves self-instruction, adjustment, acceptance and learning. It may take some time to come to terms with a situation that requires people to change their homes and habits. Based on the findings of this study, we recommend care providers should inform couples who will receive formal home care, enabling them to prepare and make adjustments. Depending on the situation it may also be necessary to support the development of strategies to handle situations that are particularly challenging: encountering many visitors in one’s home, finding time and space for one’s privacy, and acting as mediator when staff are new. All this increases the chance of home care being a relief that makes it possible to live a normal life, rather than an additional threat to established habits and relations.

Finally, there is clearly a need for further studies on termination and closure. Home care stops the day the

care user is no longer present in the home, which is rational from the perspective of the care provider but may come as a shock to the cohabiting partner, who may not even get the chance to say goodbye to staff they may have known for years. By understanding the transition to home care as a relational process, it is plain the care system should develop new means of supporting cohabiting partners throughout the entire care process.

LIMITATIONS

The home care systems in Scandinavian countries differ from many other countries. The transitions for cohabitating partners in countries with less extensive home care systems may be different, but equally they may still involve the negotiation, adaptation and management of new roles and positions. Another limitation is that the voices of care users and staff are absent.

ACKNOWLEDGEMENT

The authors would like to thank Alexander Fäldtman, Marianne Granbom and Glenn Möllergren for their contributions.

FUNDING INFORMATION

This study was funded by Forte, Dnr 2021-0815; 2021-00506.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The transcribed interviews analysed in this article are not publicly available, since participants did not give written consent for their data to be shared publicly.

ETHICS STATEMENT

The project was approved by the Swedish Ethical Review Authority, Dnr 2022–00829-02.

ORCID

Tove Harnett  <https://orcid.org/0000-0002-2868-5369>

Håkan Jönson  <https://orcid.org/0000-0003-2347-7656>

REFERENCES

- Anker-Hansen, C., Skovdahl, K., McCormack, B., & Tønnessen, S. (2018). The third person in the room: The needs of care partners of older people in home care services: A systematic review from a person-centred perspective. *Journal of Clinical Nursing*, 27(7–8), e1309–e1326.
- Antonucci, T. C., & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. *Journal of Gerontology*, 42(5), 519–527.

- Braun, V., & Clarke, V. (2006). Using hematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Compton, R. M., Owilli, A. O., Caine, V., Berendonk, C., Jouan-Tapp, D., Sommerfeldt, S., McPhee, D. J., & Walz, D. (2020). Home first: Exploring the impact of community-based home care for older adults and their family caregivers. *Canadian Journal on Aging/La Revue Canadienne du Vieillessement*, 39(3), 432–442.
- Davis, L. L., Chestnutt, D., Molloy, M., Deshefy-Longhi, T., Shim, B., & Gilliss, C. L. (2014). Adapters, strugglers, and case managers: A typology of spouse caregivers. *Qualitative Health Research*, 24(11), 1492–1500.
- Doyle, S. (2012). ‘Being-in-the-world-of-care’: The lived experiences of older people receiving community aged care packages in Queensland. *Health Care for Women International*, 33(10), 905–921.
- Doyle, S. (2014). The impact of power differentials on the care experiences of older people. *Journal of Elder Abuse & Neglect*, 26(3), 319–332. <https://doi.org/10.1080/08946566.2013.875970>
- Elder, G. H. (1994). Time, human agency, and social change: Perspectives on the life course. *Social Psychology Quarterly*, 57(1), 4–15.
- Elder, G. H., Johnson, M. K., & Crosnoe, R. (2003). *The emergence and development of life course theory*. Springer.
- Genet, N., Boerma, W. G. W., Kringos, D. S., Bouman, A., Francke, A. L., Fagerström, C., Melchiorre, M. G., Greco, C., & Devillé, W. (2011). Home care in Europe: A systematic literature review. *BMC Health Services Research*, 11, 1–4.
- Hunstad, I., & Svindseth, M. F. (2011). Challenges in home-based palliative care in Norway: A qualitative study of spouses’ experiences. *International Journal of Palliative Nursing*, 17(8), 398–404.
- Jarling, A., Rydström, I., Ernsth-Bravell, M., Nyström, M., & Dalheim-Englund, A. C. (2018). Becoming a guest in your own home: Home care in Sweden from the perspective of older people with multimorbidities. *International Journal of Older People Nursing*, 13(3), e12194.
- Jika, B. M., Khan, H. T., & Lawal, M. (2021). Exploring experiences of family caregivers for older adults with chronic illness: A scoping review. *Geriatric Nursing*, 42(6), 1525–1532.
- Kalwij, A., Pasini, G., & Wu, M. (2014). Home care for the elderly: The role of relatives, friends and neighbors. *Review of Economics of the Household*, 12(2), 379–404.
- Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies*, 27(1), 15–29.
- Kim, E. Y., & Yeom, H. E. (2016). Influence of home care services on caregivers’ burden and satisfaction. *Journal of Clinical Nursing*, 25(11–12), 1683–1692.
- Lamura, G., Mnich, E., Nolan, M., Wojszel, B., Krevers, B., Mestheneos, L., & Döhner, H. (2008). Family carers’ experiences using support services in Europe: Empirical evidence from the EUROFAMCARE study. *The Gerontologist*, 48(6), 752–771.
- Lee, K., & Marier, P. (2021). Aging in place with a spouse in need: Neighborhood cohesion and older adult spouses’ physical and mental health. *International Journal of Aging and Human Development*, 93(4), 1012–1030.
- Lehning, A., Nicklett, E., Davitt, J., & Wiseman, H. (2017). Social work and aging in place: A scoping review of the literature. *Social Work Research*, 41(4), 235–248.
- Möllergren, G. (2024). The home care home—An un-total institution. When the care home logic permeates the private space. *Socialine Teorija, Empirija, Politika ir Praktika—Social Theory, Empiries, Policy and Practice*, 29, 39–55.
- Monrad, M. (2010). Eldres oplevelse af at modtage hjælp [Older people’s experience receiving help]. *Dansk Sociologi*, 21(4), 9–24.
- Palmqvist, L. (2020). *Ålderdom, omsorg och makt: Gamlas situation och omsorgsrelationer i nyliberala tider* [Old age, care, and power. Elderly people’s situation, and care relations in neoliberal times]. Göteborgs universitet.
- Palmqvist, L. (2022). Crippling time in eldercare: Waiting for the home care service. *European Journal of Social Work*, 25(6), 957–968.
- Petersen, M., Winterton, R., Warburton, J., & Wilson, J. (2022). Negotiating the care convoys for a diverse group of older Australians living in rural communities: A large qualitative study. *Ageing & Society*, 1–21.
- Riley, M. W., Foner, A., & Waring, J. (1988). *Sociology of age*. Sage.
- Ryan, A. A., McCann, S., & McKenna, H. (2009). Impact of community care in enabling older people with complex needs to remain at home. *International Journal of Older People Nursing*, 4(1), 22–32.
- Settersten, R. A., & Thogmartin, A. (2018). Flux: Insights into the social aspects of life transitions. *Research in Human Development*, 15(3–4), 360–373.
- Szebehely, M., & Meagher, G. (2018). Nordic eldercare: Weak universalism becoming weaker? *Journal of European Social Policy*, 28(3), 294–308.
- Takter, M. (2017). *Vem är den enskilde i ett gemensamt hem? En studie av hur biståndshandläggare förhåller sig till anhörigas möjligheter till frivillighet, autonomi och personlig integritet* [Who is the individual in a shared home? A study of how aid workers relate to relatives’ opportunities for free will, autonomy, and personal integrity]. Malmö Universitet.
- Vabø, M., Szebehely, M., & Anttonen, A. (2012). A caring state for all older people. In A. Anttonen, L. Häikiö, & K. Stefánsson (Eds.), *Welfare state, universalism and diversity* (pp. 121–143). Edward Elgar.
- Walther, A., Stauber, B., & Settersten, R. A. (2022). ‘Doing transitions’: A new research perspective. In A. Walther, B. Stauber, & R. A. Settersten (Eds.), *Doing transitions in the life course: Processes and practices* (pp. 3–18). Springer International.
- Whitaker, A. (2009). Family involvement in the institutional eldercare context: Towards a new understanding. *Journal of Aging Studies*, 23(3), 158–167.

How to cite this article: Harnett, T., & Jönson, H. (2024). Becoming an inadvertent home care user: The transition for cohabitating partners. *International Journal of Social Welfare*, 1–11. <https://doi.org/10.1111/ijsw.12703>