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Freedom and Imperative: Mutual Care Between Older Spouses With Physical Disabilities

Cristina Joy Torgé, MA¹

Abstract

This article explores mutual caregiving between older spouses aging with physical disabilities. Nine older couples, where both partners had lived long lives with physical disabilities, were interviewed as dyads about mutual caregiving. The couples not only had access to different kinds and degrees of formal support but also provided mutual care to each other in a variety of ways. Interview coding using grounded theory led to two overarching categories from which motivation for mutual caregiving could be understood. These categories were *Mutual care as freedom* and *Mutual care as imperative*. The results extend understanding about how older couples with disabilities attached meaning to their mutual caregiving, and why mutual care was sometimes preferable, despite the availability of other sources of help and despite practical difficulties of providing this help. These findings suggest that health care professionals need to be sensitive to the dynamics of the couple relationship and carefully explore the couple's preferences for how formal support can best be provided in ways that honor and sustain the integrity of the couple relationship.

Keywords

family caregivers, later life, couples, marital dyad, mutual care, grounded theory, conjoint interviews

Much of the informal care given to older people is provided not just by their children but also by their spouses (McGarry & Arthur, 2001; Pickard, Shaw, & Glendinning, 2000). Partners are often the first to provide care at the onset

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of impairment (Parker, 1993) and, with age, continue to evolve the caring role (Boeije & van Doorne-Huiskes, 2003; Lin, Macmillan, & Brown, 2012). The aging population and changes in family structure have resulted in an increase in the incidence of spousal caring, relative to other forms of help (Hirst, 2001; O'Connell, Bailey, & Walker, 2003; Sundström & Malmberg, 2006). Spousal caregiving in later life is also projected to be more prevalent and significant in the coming decades (Pickard, Wittenberg, Comas-Herrera, King, & Malley, 2007). However, like many other older informal carers in the community, spousal carers may experience their own health problems (Argyle, 2001; Corden & Hirst, 2011; van Dijk, Cramm, & Nieboer, 2013). How spousal carers with disabilities experience caregiving has not been extensively researched. Furthermore, literature on caring for an old spouse—for example in the context of cognitive disability or end-of-life care—may take for granted that the carer himself or herself is without disability. Although there is a reason to believe that many older couples age together with acquired or age-related impairments, there is still relatively little research on spousal care among couples in which *both* have disabilities. It is this group of older people, and how they experience mutual caring, who is the focus of this article.

This study is based on interviews with a group of older Swedish couples (60 years old and above) who had both lived long lives with physical disabilities and provided mutual care. They had access to different types and degrees of formal support such as medical support, transport services, home help, or personal assistance, but they simultaneously also provided each other with support in everyday tasks and caring activities. Elsewhere (Torgé, 2013a), I have explored how it is possible to be a carer despite also needing physical support. How caregiving took place and changed over time as the couples aged together with increasing or unpredictable disabilities was also described. In this present article, I explore how the interviewed couples gave meaning to the mutual care received and given. I also try to explain the motivations for providing this care, when other forms of help that were equally indispensable in making the couples' everyday lives work were available.

Why do couples experiencing physical disabilities provide different kinds of help for each other, including what may be considered as heavy care tasks, *despite* the existence of formal care and welfare systems aimed at them and those they care for? How does the relationship between them shape the experience of mutual caregiving? These questions are discussed in this article. A relational and family perspective was used to highlight the role of couplehood in shaping the experiences and expectations of mutual care. These insights, in turn, can help researchers and practitioners understand how couples with disabilities utilize different care resources (including one another) in various ways. In an aging population, where older spousal carers with disabilities are likely to be more prevalent (Hancock, Jarvis, & L'Veena, 2007; Pickard, Wittenberg,

Comas-Herrera, Davies, & Darton, 2000), understanding the significance of mutual helping despite formal support can provide direction for supporting older couples with disabilities in their desire to maintain mutual care.

Literature Review

In light of demographic trends of an aging population and the resulting policy and research focus on informal care for older people, it is necessary to understand caregiving in later life marriages. Despite the contributions of older people in informal caring, there has traditionally been a tendency to frame older people through a “decline and loss” paradigm, and consider the aging population as a social care burden (Oldman, 2002; Phillipson, 1998). Previous studies point out that the caregiving literature often ignores the fact that most of those providing care to older people are also old (Argyle, 2001; Dahlberg, Demack, & Bambra, 2007; McGarry & Arthur, 2001). In particular, married older people are most likely to get help from their spouses (Blomgren, Breeze, Koskinen, & Martikainen, 2012). Yet, mutual caregiving in old age may have particular challenges, as the caring spouse may also be experiencing disabilities or ill health (Ahn & Kim, 2007; Corden & Hirst, 2011; Jowsey, McRae, Gillespie, Banfield, & Yen, 2013; O’Connell et al., 2003). Because the risk of disability increases with advanced age, disability prevalence among older carers is also likely to increase (Hancock et al., 2007).

Previous research has shown that giving care to a spouse is often linked with psychological burdens and stress (Davis, Gilliss, Deshefy-Longhi, Chestnutt, & Molloy, 2011; Lavela & Ather, 2010). Other researchers have tried to understand what motivates family members to take continued responsibility for caregiving despite its burdens (Kuuppelomäki, Sasaki, Yamada, Asakawa, & Shimanouchi, 2004; McKee et al., 2003). Reported reasons for taking on caregiver responsibility include feelings of love or duty (Kabitsi & Powers, 2002), satisfaction, and pleasure from caregiving (Ribeiro & Paúl, 2008) and a sense of shared misfortune and inevitability (Boeije, Duijnstee, & Grypdonck, 2003). Relational and interpersonal dimensions seem to be prime motivators for why partners give long-term care (Beneken Genaamd Kolmer, Tellings, Gelissen, Garretsen, & Bongers, 2008; Boeije et al., 2003). Family caregiving is also complex and includes positive and meaningful experiences that can give satisfaction to those involved, despite physical or psychological constraints (Kuuppelomäki et al., 2004). Among older carers, caregiving can provide personal satisfaction such as a sense of personal growth and reciprocal engagement (Ekwall & Hallberg, 2007).

Why partners provide care, despite its burdens, is an especially relevant question to ask when the carer himself or herself also has disabilities and has to deal with the challenges of caring while also facing his or her own health problems and functional limitations. This question has not been sufficiently

explored as previous research has predominately focused on the motivations of carers without disabilities, regardless of age. Exceptions are Racher (2002) and Racher, Kaufert, and Havens (2000) who interviewed older frail couples about their access to health services and provision of mutual physical and social support. The present study addresses this gap by focusing on partners who both experienced long-term physical disabilities. Partners' experiences of aging and caregiving when both have physical disabilities need further exploration, especially because many older couples are likely to be in this situation.

A further point that this current study considers is that informal caring seldom takes place in a social vacuum. Informal caring for and by older people occurs alongside formal services such as home help services, disability benefits, or other formal support that are aimed at older people or the older carers themselves. The traditional way to understand the interaction between formal and informal care has been to see them as either complements or substitutes. Informal care as a complement suggests that formal and informal support sources provide different types of help, while the substitution model implies that family care decreases when the volume of formal care increases. However, the relationship between formal and informal care may be more complex, with substitution and complementarity often blurred or overlapping (Daatland & Herlofsson, 2001).

Family caregiving is also said to be a dynamic process that changes over time (Boeije & van Doorne-Huiskes, 2003). It includes dimensions of activity (such as doing chores) as well as more invisible types of support such as "being present" or "keeping an eye" out for the relative's well-being (Jeppsson Grassman, 2003). Likewise, spousal caring involves a variety of different types and levels of work that may have both physical and psychological components, and can even include "heavy" care tasks that may traditionally have been seen as work for professionals (Kitko & Hupcey, 2013; Pickard, Shaw, & Glendinning, 2000). In exploring the mutual caregiving between older spouses with disabilities, these forms of caring were considered, in light of the fact that the participants of this study also had access to different types of formal care that offered similar or different kinds of support.

Design

Research Method

The study on which this article is based was designed as part of a research program, *Forms of Care in Later Life: Agency, Place, Time and Life Course*, that aimed to explore the different situations and conditions of care for older people. The focus of the specific study was informal care between spouses with long-term or lifelong disabilities. As there is little previous research on

this area, an explorative and qualitative design based on grounded theory was used in this study.

Grounded theory is a research method first developed by Glaser and Strauss (1967). It emerged as a reaction to the dominance of quantitative social research and the tendencies of qualitative research to confirm already established theories. By laying out a set of tools for data investigation, they showed how qualitative analysis could not only be robust and grounded in data but also provide scaffolding for new theory-building. Following this method means constructing codes and categories from close reading of the data. This encourages exploration about a phenomenon not yet widely researched, instead of trying to comprehend the data using already established concepts. Throughout my analysis, I used the tools of grounded theory to raise the material from a descriptive level to a set of explanatory concepts. These tools—coding and constant comparison—consist of the basic operations for category-building (Kelle, 2007).

Participants

Participants were recruited through letters sent to local disability organizations, pensioner's organizations, and habilitation centers, although a majority of the respondents came from disability organizations in southeastern Sweden. Other respondents were further identified through snowball sampling (Atkinson & Flint, 2004). That is, couples provided information about other friends who met the participant criteria for the research. They in turn either contacted the author themselves or were contacted by the author.

The ethical principles outlined by The Swedish Council for Research in the Humanities and Social Sciences (The Swedish Research Council, 2008) were considered throughout the study. The participants were informed, both in writing and orally, about the study's aims and method. They also gave consent to participate in the study and were informed of their right to withdraw from the study at any time. Confidentiality was addressed by changing the names of participants in the transcripts and in writing the results.

In-depth qualitative interviews were conducted with, in total, nine older Swedish couples who fit the study criteria. At the time of the interview, the partners were between 60 and 83 years old and had lived for at least 12 years with physical disabilities, although most had disabilities for 20 years or more. The cause and severity of disabilities varied. Criteria for the study, however, were that couples with *physical* disabilities were recruited, and that both must have had their disabilities for a long period of time. The participants experienced disabilities related to, among other things, cerebral palsy, polio, childhood diabetes, rheumatoid arthritis, stroke, accidents, neurological diseases, and chronic illness. These disabilities had been present since birth,

youth, or middle age. Thus, all had lived a long life with disability and were growing old together with their partners who also had disabilities. Many of the interviewees also had secondary complications attributed to old age and which were experienced as a further cause of disability. The couples had been living with their partners from four to 45 years.

The different kinds of formal help received by the couples were not known at the time of recruitment, but all nine couples received different forms of formal support such as home help or a cleaning service, transport services, companion service for the visually impaired, help with technical aids, and help with making their homes more accessible. Some participants with lasting impairments also had personal assistance between 20 hr a week and 24 hr a day, which is a right for certain groups with disabilities under Swedish legislation (The National Board of Health and Welfare, 1993). Alongside this mixture of formal care, the couples also mobilized informal care from family and social networks. The couples all lived at home.

Data Collection and Analysis

To gain a fuller picture of the couples' mutual caring, interviews were conducted with both partners present in the same interview. Interviewing couples together—sometimes called conjoint, joint, or dyadic interviews—is an alternative method to individual interviewing, and may be used to gain further insights into the “we”-perspective of a shared experience (Eisikovits & Koren, 2010; Morris, 2001). This method has been found to be particularly useful and has produced rich data in studies of older couples' experiences of caregiving (Molyneaux, Butchard, Simpson, & Murray, 2011; O'Rourke & Germino, 2000; Racher et al., 2000; van Nes, Runge, & Jonsson, 2009). Employing this method also means that understanding the joint story of the dyad *as a unit* is central and permeates the study design, making it suitable for studying families' experiences (Eisikovits & Koren, 2010). In conjoint interviews, questions can be directed both at individuals and the couple, allowing the participants to frame themselves as concurrent actors in the relationship (Morris, 2001). In this particular study, the method also led to an analysis centered on relationality. Stories of “we-ness” and the interactive elements of the interview had to be taken into full account, instead of describing what has been said and experienced by the individuals alone (Torgé, 2013b). In this way, the study design was congruent with a family systems perspective, which holds that individual illness has an effect on the family as a whole, which in turn becomes the unit of analysis (Tomlinson & Åstedt-Kurki, 2008).

The conjoint and semi-structured interviews with the couples were conducted by the author in 2010. The interviews were between 2 and 3 hr long and conducted mostly in the couple's homes (except in one case, where

it was conducted in the university premises). An interview guide was used to explore themes such as own disability, how the couples met, everyday life with disabilities as a couple, the kinds of support they provide for each other, other sources of help and support, and aging together with disabilities. Follow-up questions could also be brought up during the interview, and the couples were also free to talk about related themes. The interviews were tape-recorded and transcribed by the author.

To analyze the interviews, the data were coded, first through open coding and then focused coding (Bryant & Charmaz, 2007; Charmaz, 2006). This method of analysis is frequently used in family research by Nursing and other practice professions, as explanatory concepts can be derived from the utterances and expressions of the informants themselves (Charmaz, 2006; LaRossa, 2005). In open coding, the author reads through the interviews in detail and tried to identify and “name” phenomena which packages of data may be about. This process initially led to diverse themes, of which some were more useful to conceptual and theoretical development than others. In focused or selective coding, core categories were identified. In particular, the different ways in which couples talked about different care sources, including each other, were further coded and compared, to derive stronger concepts and overarching categories that help describe the phenomenon of mutual care and its properties.

Results

Two overarching categories emerged in the analysis. The first category, *Mutual care as freedom*, discusses the ways in which caring had more than just an instrumental function. This category includes the subcategories *Freedom to do*, *Freedom from*, *Freedom to care*, and *Freedom to be themselves*. The second category, *Mutual care as imperative*, discusses how expectations and obligations to care stem from the relationship as a couple. This includes the subcategories *Caring as “a part of our lives,”* *Caring as “a moral obligation,”* and *Caring as “a job.”*

Mutual Care as Freedom

Freedom to do. In one sense, the couples’ combined use of formal care and mutual help was expressed merely as a pragmatic solution to allow them to engage in activities that otherwise would have been difficult for them. Care was thus used to gain the instrumental *freedom to do things*, and to solve practical matters. Many expressed everyday life with disabilities in terms of problem-solving. Not only activities of daily living, household chores, but also activities outside the home were mostly experienced as problems to be solved. Formal care sources, but also mutual caring, were seen as a part of the patchwork of help that made it possible for “everyday life to work,” because

the couples needed a lot of help to do the things they needed and wished to do. As one participant said,

You see, we live *restricted* lives, very restricted lives. There are a lot of things we can't do ourselves. There are a lot of things we need *help* with, you see? Our lives are different from a healthy person's life, even though we are out a lot, and do as much as we can, and are active people.

The couples combined formal care and mutual care in different ways. For example, a husband helped his wife to the toilet when her assistant was not around, but at the same time, his wife also said that "some things are better when my assistant does them."

Freedom from formal care. In addition to a *freedom to do*, couples also used mutual care in other ways, notably, as a *freedom from* the seeming inevitability of formal care. Although different forms and sources of care were a necessity in everyday life, there was also a value in being independent as a couple, and mutual caring was used to be, at times, "free from others' help."

Mutual care as *freedom from* was obvious in different ways regardless of the types and amounts of formal help that the couples received, but it was mostly expressed by the couples who had the most extensive disabilities. Despite the availability or presence of formal help, such as home help or personal assistance, these couples carried out care tasks for each other such as help with showering, dressing, eating, transport, or getting in and out of bed. Despite the fact that both partners had personal assistants, one woman repeatedly underlined the importance of her husband's involvement in everyday situations such as mealtimes and bedtimes. Although it was clear that formal assistance was invaluable, the sense of being alone with each other and being free from the assistants could be achieved by the act of caring for each other:

I want to emphasize that he is involved and helps me with a lot of mealtimes so we can be without help from assistants. We need to be alone with each other. And when I'm alone, he's always by my side, helping me with small and big things.

Formal help would sometimes even be used *to make spousal help possible*, pointing to an interaction between formal and informal care that cannot be merely understood in terms of complementarity or substitution. One couple used formal care in this way. When the couple went out to informal gatherings, they would sometimes ask the wife's personal assistant to arrange her clothes on her bed, so that the husband could help his wife to dress. This was thought to be more time-consuming and difficult compared with when

the assistant did it, but it was something the couple willingly did to do things for each other. The willingness to give care despite difficulties also represented something else for the couple: The freedom to give help just because one wants to.

Some couples, at the time of the interview, only needed formal care occasionally. For these couples, mutual care could be given with the intention of holding off what was thought to be the future inevitability of extensive help from others. They had worries that formal help would have an “anonymous” character, or that nameless carers would “come and go at all times of the day.” In contrast, mutual care had a more personal character and thus provided a feeling of security and integrity.

At times, mutual caring also seemed to actually lengthen the period of independence from formal help. As long as these couples had the capacity to help each other with activities ranging from small chores to extensive personal help, they had the option of not utilizing home help at all, despite increasing functional limitations. A couple, both of whom were dependent on mobility aids, compared themselves with an older neighbor, who used home help, among other things, to help her put on compression socks. Although this couple reported that their disabilities were getting worse over time, they relied on formal help to a lesser extent than their neighbor because they helped each other in activities of daily living, including dressing, even when they sometimes had difficulties doing this. They knew, however, that this relative autonomy was premised on their current capacity to help each other, and they might one day have to rely on more extensive home help services when one or both of them could no longer make it on their own, or provide help.

Freedom to be themselves. The *freedom from* others’ help and *freedom to give care* to a spouse was also related to another freedom felt in mutual caring, which is the freedom to “just be themselves.” To merely enjoy each other’s company was sometimes a reason that spousal help was given, and helping each other doubled as an expression of closeness and affection. Helping each other with activities was often retold as pleasant memories that gave satisfaction to both partners. These activities could be helping to curl a partner’s hair, cutting nails, cutting food into small pieces, helping to put on compression socks, or helping a partner in or out of bed. Other kinds of activities might not necessarily have an instrumental purpose at the outset, but were nevertheless important for maintaining a good quality of life. These included, for example, going for walks or to events together, which can be important for individuals who have mobility impairments. These activities had the positive consequence of enabling partners to remain active, but were done mostly because the couples just wanted to have a good time. A strong example of this comes from one couple, both of whom had suffered neurological impairments since their early years. Despite the husband having

assistance, they emphasized that they would probably not go outside their apartment very often if they did not do activities together.

Husband: I know that there's a person there, who I'm very fond of, that I can be with in sunny and stormy weather, and we can live with each other—it's very important. I think, if I didn't have her, I would have just sat indoors reading my books or using my computer. That would have been my life, apart from my meetings in the disability organization where I can meet people.

Interviewer: So are you outdoors more often, because you're together?

Wife: We go to the theater, to meetings, whatever. Go out, have some afternoon tea out on the green. It's a good feeling to have someone. Yeah, if I didn't have him, I would probably still be a bitch and would think that I have to fight through things by myself all the time. I wouldn't have this person who gives me a feeling of peace.

Interviewer: (to the husband) So, do you think that with her, your life has become less restricted?

Husband: Yes.

Wife: We listen to music, go out in nature, sit in nice places. In the summer, we sit out on the balcony and eat herring and potatoes. And just enjoy each other's company, you know.

There were other examples in the interviews of how pleasant activities also simultaneously became ways to increase activity and quality of life. Another couple, with different impairments leading to reduced mobility, had experienced repeated setbacks with surgery and hospital visits during the past years. Increased tiredness meant that they also had to give up physically demanding tasks that they used to enjoy, like gardening. Yet by encouraging one another to go on cookery and language courses, they felt that they could maintain a good quality of life despite their disabilities, and they felt no different from their peers. In this way, mutual care allowed them not only to maintain their independence as a couple but also contributed to their personal independence as they tried to live an active life with worsening physical disabilities.

Mutual Care as Imperative

The themes discussed above help us to understand the significance of mutual care in relation to other available forms of help. The category *Mutual care as freedom* shows that mutual spousal helping can be exchanged, because it provides a feeling of freedom, satisfaction, and liberation on different levels. However, motivation for spousal care may also be strongly connected to norms and expectations within the relationship itself. This next section, *Mutual care as imperative* discusses this aspect. Although freedom and satisfaction represents one side of how the relationship forms the experience

of mutual care, there is also another side, namely a sense of duty or a moral imperative that one *should* give help to one's partner. This appeared in the interviews, for example, when the couples mentioned caring not necessarily in liberating terms, but as something unquestioned, or as a moral obligation. This is not necessarily a negative dimension, but it provides another aspect for understanding mutual caring and how it is unique from other care sources.

Caring as "part of our lives." Helping and caring for each other was expressed by the couples as a part of their lives as married partners. The couples said that caring, most of the time, occurred "automatically" and was not "something that [they] had to think about." Supporting each other with tasks that they had difficulty doing seemed as natural as, in the words of one woman, "the right hand helping the left." That caring was part and parcel of their lives involves a different perspective from the *freedom to care* that appeared in other parts of the interviews. Rather than care appearing as something chosen or voluntary, caring, though this perspective, did not seem to have anything to do with choice but *just was*.

The expression that care was part of their lives did not necessarily mean that couples felt forced to give care. Indeed, they provided care despite, at times, not needing to ("She can take care of herself when I'm away, and I can take care of myself when she's not around"). Some dimensions of caregiving had just grown to become routine or had become a part of the pattern of their everyday life. Caring and servicing became intertwined in this way as the couples helped each other not only with personal or instrumental caring tasks but also with things that had to be done around the home anyway, and where evaluation of a help need was difficult to establish. Instrumental help-giving and everyday living were blurred, as this couple said:

Husband: [What we help each other with] are not things that we absolutely *must* do to make things constantly work. But that can occur.

Wife: I always used to take out the pots and pans myself and spread them out when I was preparing to cook. But my arms are getting weaker. And I need a little help with that. To take out the heavy things. To take out items from the refrigerator, for example.

...

Husband: She can get dressed by herself, but compression socks are pretty tricky. When you have to remove them, I help you.

Wife: Yes, it's a lot of work to remove them. It takes forever. So he helps me with that.

Interviewer: And besides showering, do you need any other help?

Wife: No, no, no. But I've got a little weaker since October. So he has to help me lift my feet up onto the bed at nights. He still helps me with that, but mostly because we've gotten used to it. I think I might be able to do it now (*husband chuckles*), if I could manage to hold on to something.

Caring as “a moral obligation.” When the couples compared mutual caring with help from others, what stands out is how they described care from their spouses as having a higher level of dependability. However, this sense of dependability and immediacy of help is closely linked with a sense that helping *should* take place—it is a *moral obligation* embedded in the relationship—and thus can be expected to be received or given by both parties. The relationship becomes a kind of mold for what can be expected of the caring role, as this man says,

Yes, I mean . . . it’s obvious, in the family situation. She and I, we’re sticking together our whole life. We promised to love each other in sickness and in health. And there’s been a lot of sickness [*Wife laughs*], but that’s no reason to give up.

The relationship is thought to involve a moral imperative to care for one’s partner. This mutually understood expectation to give and receive help was a significant aspect of why couples continued to provide care, despite or besides other help being available and despite their own health setbacks. The common life together—which meant that they dealt with “the same problems” of life with disability—also demanded solving those problems together, which included the willingness to provide mutual help:

I mean, I wouldn’t say, “No, no, stay there!” I mean, because we are two and live with the same problems, of course, if I *can* help her, I will. If you’re in a relationship—and this is precisely what a relationship is—that’s how it should be. Otherwise, there’s no point being in it, right?

In the interviews, this mutually understood moral obligation to help was often translated into a feeling of security in knowing that help was never far away, and that it was always available. Compared with help from others, which had to be organized, planned, scheduled, and demanded communication with other people, spousal care was described as not only something natural but also most of all as spontaneous, immediate, and reliable. At times when formal help did not work as expected, when other sources of help were not available, or at times of emergency when one could have been in a very vulnerable position, there was a feeling that one could *always* rely on one’s partner for help. Most respondents said that they did not even have to ask for help from their partners, as helping was a way of life. Asking for help, regardless of the situation or time of day, did not involve the same inhibitions that one might have when requesting help from others, which at times was “cumbersome” and “demanded much explaining.”

There are, of course, also limitations to this sense of security, which was also emphasized in the phrase “if I *can* help her, I will.” Partners, in reality, may not be able to provide help when expected to. In that case, the moral

obligation to care could instead be experienced as an unreasonable burden, when one also has physical disabilities oneself. This is when caring could be experienced as “a job.”

Caring as “a job.” What made the interviewed couples in this study different from those in many other studies on spousal care is that both partners had had physical and disabilities for a long period of time and were aging with these long-term disabilities. These individuals’ lives had been marked by health setbacks of different kinds, and they were also starting to think about age-related impairments that they anticipated or knew they had. The long life lived with disability and the “normal” effects of aging were sometimes hard to distinguish from one another, for example in the experience of increased tiredness. At least two informants reported that they had started feeling increasingly tired over the years and they needed to nap two to three times during the day to feel rested. For others, aging meant that their already limited mobility became even more limited, such that they needed more help to perform daily activities or were considering using mobility aids. It is possible that these factors could affect their willingness and possibilities to give help in the future. What this implies is that reliability, dependability, and immediacy of help—although shown in the interviews as important characteristics of spousal and mutual care—are not complete, and are indeed limited by time and by physical capacity. Accordingly, relying on each other for help appeared to involve negotiation between partners. Although the moral imperative to help one’s spouse remained as a mutually understood ideal and as part of their lives, the practice of mutual caring was a balance between “making things work” and the partners’ actual abilities and willingness to be involved in caring. One woman said,

We have to respect each other too. Otherwise we can’t live in this sort of dependency-relationship, where we can be independent of each other in this relationship but still be—*nevertheless* be—dependent. We need mutual respect. For what the other can, thinks he can, or is willing to do, and so on. So that we can make it. Find solutions. When things don’t work, and when things become hard, or when we wish to do different things . . .

Having said this, there were also examples in the interviews of when negotiation did not go smoothly, or when there was an experienced imbalance between expectations on one hand, and ability or willingness on the other hand. When this imbalance was experienced, mutual caring was not seen as a joy or freedom, but as an unreasonable constraint or an imperative that one could not live up to. This was expressed by a man with chronic pain who said that caring for his ill wife sometimes felt “like a job for me.” His wife needed much help with eating, brushing teeth, showering, and other activities of daily living. Although she had hours of formal help during the daytime, her husband helped

her in the evenings and at nights, for example in using the toilet. They tried to sleep in different bedrooms so that the husband could get some sleep, but the practical difficulty of ringing for formal help at nights meant that he felt obliged to offer nightly help anyway, being the only other person around. For him, the expectation to care that was embedded in the relationship left him feeling rather ambivalent. Although he felt that he was doing the right thing as a dutiful husband (“you stick together, you’re a family”), giving care was not easy in practice as he had to deal with his own health problems:

Say the assistant has gone home and my wife is up late doing something. Then she suddenly becomes dead tired. I’d have to help put her to bed and fix everything around that. And it takes time, and it gets pretty late. And I get tired myself. But, it’s precisely that. In a marriage, you stick together, you’re a family. But I feel that it becomes like a job for me, then. And when the job is done, I can’t relax. Like people who work in restaurants, who go home at one in the morning and are so awake they can’t go to sleep.

In other parts of the interview, the same man described helping his wife in terms of exercising a freedom to care for her. In the above example, however, he also described the social and moral imperative to care as something that constrained him. Mutual caring thus seems to involve both aspects. On one hand, caring for each other can be experienced as a freedom, and gives reliability and security. On the other hand, difficulties can arise when one feels that one cannot live up to caring expectations because of one’s own disability. Caring in this case could be experienced as demanding.

Discussion

This research report examined the following questions: Why do couples, who themselves have impairments and disabilities provide different kinds of help for each other, including what may be considered as heavy nursing tasks, *despite* the existence of formal care and welfare systems aimed at them and those they care for? How does the relationship shape the experience of mutual caregiving with disabilities? The categories *Mutual care as freedom* and *Mutual care as imperative* help shed light on these questions in that these categories help us understand that mutual caring is performed not only for its instrumental value and not primarily because formal help is lacking. The participants in this study gave care despite not needing to, and despite the availability of other help sources. They provided mutual care to feel free to be themselves as a couple. At the same time—and not necessarily contradictorily—they also provided help because it was what this type of relationship demanded of them. In this respect, this study echoes what has been found among other caregiver groups: that caregiving burden and well-being are two sides of the same coin, rather than distinct concepts (Chappell

& Reid, 2002). What this study shows is that the same experience can also be relevant for carers who have disabilities themselves, and who, because of these impairments, have unique experiences of caring.

The findings from this study also suggest a more complex relationship between formal and informal help than as substitutes or complements for “task-specific” or “time-equivalent” helping (see Jegermalm & Jeppsson Grassman, 2011; Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000). Naturally, elements of substitution and complementarity are also present in the interviews. One interviewee, for example, pointed out that other forms of help gives him a “rest” from caring. Another said that she did not want to “meddle” with the partners’ assistance. Yet, besides substitution or complementarity, formal and informal care interact in other ways, such as when it feels better for a partner to either choose formal help or spousal help for reasons *other than the nature of the task*. What could be derived from the informants’ responses is that formal and informal care are distinct types of caring, in that they develop from partly different premises. Motivations for caring for a spouse can stem from the pleasures, demands, and logic of the relationship itself, which formal care cannot possibly recreate. Mutual caring, as the interviews also show, can be important in maintaining other dimensions of autonomy—such as being independent as a couple and free from dependence on extensive help from others.

These insights raise awareness of the significance of mutual caring, even for people who might have difficulty in performing this care. Perhaps it is all the more important to understand the significance of mutual care to individuals when partners, despite their own health difficulties or other help sources, persist nevertheless in providing and receiving spousal care. These insights can be used to reflect on how to best help older carers with disabilities to improve their capacity to provide care when they wish to. The example of the assistant laying out the wife’s clothes so that the husband could help her to dress is an example of this.

Having said this, to understand the complexity of family and spousal care, it is necessary to look at both the positive and negative aspects of caring. As McKee and colleagues (2003) point out, practitioners have mostly focused on mitigating the effects of the caregiver’s burden, at the expense of ignoring positive aspects that make the caregiving relationship work. They argue that “directing supportive efforts only towards the reduction of burden may actually serve to make a caregiving relationship more problematic, while ignoring opportunities to enhance the satisfactions gained from the relationship” (p. 39). In the same light, support directed only at improving the capacity to care must consider the effects of the couples’ failing or unpredictable disabilities over a time-perspective, when partners may be less willing or less able to provide help. Supporting older caregivers with disabilities is bound to mean different types of interventions for different individuals.

Limitations

This qualitative study was limited to couples who had been living for a long time with *physical* disabilities. An exception was an informant who also had an autism spectrum disorder. The results of the study may not necessarily be transferrable in the context of aging partners with cognitive disabilities, such as dementia. It is possible that the dynamics, significance, and problems of mutual caregiving can have a different character when partners with cognitive disabilities are studied.

Due to the wide spectrum of physical disabilities experienced by the participants in this study, the couples required different types and intensities of help at different periods; yet the data for this research report was based on interviews from one period in time. Spousal caregiving is not static and can mean different things at different times for the couples. Their differences also meant that experiences of caregiving were unique for each couple and that not all were constantly engaged in providing physical support. The unstable and shifting nature of disability implies that judgments about the levels and intensity of caring were closely tied to past situations that were explored in the interviews, or based on the couple's situation during the interviews. How spousal caregiving develops or changes as the couples continue to age with their disabilities was not the focus of this study but would be an interesting topic for future research, perhaps using follow-up interviews with the same dyads.

Implications for Practice

This study underscores the importance of acknowledging and supporting older people with disabilities as family carers. There are two important points that may be significant for practice. First, it is necessary to reflect on which groups are often considered as “family carers” to a client or help receiver, as it may not be apparent at first hand that older family members, who also need support and assistance, provide different kinds of help and support themselves. This means having to particularly recognize older family members with disabilities as active or potential caregivers of different types and levels of care. Nurses and caregivers who work with families can play an important role in identifying this undervalued group of older carers. Support can then be provided to enable them to continue to provide mutual care if they wish to do so (McGarry & Arthur, 2001). From a demographic perspective where people are living longer, older people and especially *older people with disabilities* might represent the bulk of society's informal caregivers, and they need to be further recognized and acknowledged not only as receivers of social care but also as providers of invaluable care.

Second, some of those growing old in the population and providing mutual care for older people may also be—like the participants in this

study—aging with their *long-term* or *lifelong* disabilities. According to Putnam (2012), this group of people aging *with* disability may already have had lengthy experience with a variety of medical and social services, and thus represent a unique client group in elder care, compared with those aging *into* disability. How to acknowledge this group's willingness and capacities to provide care for others, while also recognizing their specific needs, is a further challenge.

In this study, participants described how mutual caring can have a liberating aim, especially if one has received formal care for a long period of time. However, when identifying this group as willing caregivers, there must also be sensitivity in recognizing when providing caring for a spouse or family member becomes no longer possible, and when it might become a burden instead of liberation.

Conclusion

A relational and family perspective was used in this grounded theory study to account for the role the dyadic relationship in shaping experiences and expectations of mutual caregiving in older couples who both experience long-term physical disabilities. The results extend understanding about how older couples with disabilities attached meaning to their mutual caregiving, and why mutual care was sometimes preferable, despite the availability of other sources of help and despite practical difficulties of providing this help. These findings suggest that health care professionals need to be sensitive to the dynamics of the couple relationship and carefully explore the couple's preferences for how formal support can best be provided in ways that honor and sustain the integrity of the couple relationship.

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