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Family caregivers' experiences of provided home care to persons with Parkinson's disease

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Family caregivers constitute an important part of the day-to-day service for persons with Parkinson's disease. As the disease progresses, the need for municipal home care assistance will increase. The aim of this study was to explore how family caregivers of persons with Parkinson's disease (PD-caregivers) experience their situation when they share caring with the home care services. Nine family PD-caregivers who were enrolled in home care units in one region in Norway were interviewed. Interpretive analysis was used.

The main interpretation of the caregivers' experiences was labelled: «Being on call around the clock despite providing home care». Three interpretations that highlight the meanings identified in different aspects of the informants' experiences contribute to the main interpretation: Challenges with clarifying and delimiting responsibility, Relief is not equivalent to feeling safe and satisfied, and Correct management of Parkinson's disease medication does not fit in with the routines of home care. This study suggests that taking advantage of professional home care does not excuse family PD-caregivers from their experience of being the overall responsible for the care and well-being of the care-recipient.

Keywords: competing needs, guilt, hermeneutics, responsibility, trust

Family caregiving constitutes an important part of the day-to-day management of persons with Parkinson's disease (PD) who live at home (Carter et al., 1998; Parrish, Giunta, & Adams, 2003; Whetten-Goldstein, Sloan, Kulas, Cutson, & Schenkman, 1997). Public health

care in Norway encourages people to live at home for as long as possible and provides them with the required services (St.meld. nr. 45 (2002–2003)). This may have positive implications for persons with Parkinson's disease and their caregivers, but it could also be burdensome for the caregivers.

Parkinson's disease is a chronic, neurodegenerative disease. The prevalence in industrial countries is about 0.3% of the entire population, increasing with age to 4% in the oldest age group (de Lau & Breteler, 2006). In addition to the more common motor symptoms such as tremor, rigidity, bradykinesia and postural instability, persons with Parkinson's disease often suffer from sleep problems, neuropsychiatric symptoms, and autonomic symptoms (Alves, Forsaa, Pedersen, Gjerstad, & Larsen, 2008). Up to this date, there is no curative treatment for Parkinson's disease. The main focus of disease management is drug treatment, the aim of which is to alleviate the symptoms. Disease progression is accompanied by functional decline, and many patients experience reduced benefit after some years on medication, with fluctuations between mobility and immobility. Consequently, many persons with Parkinson's disease need assistance in managing the activities of daily living. Time spent on providing informal care to persons with Parkinson's disease has been reported to an average of 22–96 hours per week (Whetten-Goldstein et al., 1997, Parrish et al., 2003) and the number of caregiving tasks increases as the disease progresses (Carter et al., 1998; Mangin, Lyons, & Carter, 2010). Many PD-caregivers bear a considerable emotional burden (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999; Aarsland, Marsh, & Schrag, 2009; Kim et al., 2007), and additional stress is placed on the caregiver as the Parkinson's disease progresses and its physical and mental complications appear (Ellgring, 1999; Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006).

Under Norwegian law (Lov om helsetjenesten i kommunene, 1982), any person in need has the right to municipal home care services which comprise nursing (medical, physical, and emotional) and domiciliary care. Nursing care is financed by the municipality and its provision is free of charge. The nursing team provides a day and night service. Professional carers in home care are registered nurses with a bachelor of nursing degree or nursing aides with a high school degree.

To the best of our knowledge there is no study that focuses on the experiences of PD-caregivers in home care. The aim of this study was to explore how family PD-caregivers experience their situation when they share caring with the home care services. The knowledge

gained may contribute to encouraging home care services to consider the situation and experiences of the family PD-caregivers when providing home care and thus help to develop further professional home care interventions.

Method

Participants and research ethics

Family caregivers of persons with Parkinson's disease enrolled in home care units in one region in Norway were asked to participate in this study. Inclusion criteria were: 1) taking part in the activities of daily living and caring for persons with Parkinson's disease for a minimum of six months prior to home care provision, and 2) the care provided consisted of nursing care over and above practical assistance in the household. The study was approved by the Regional Ethics Committee, University of Bergen (Project no. REK 3.2007.190). Approval to carry out the interviews was granted by the home care unit leaders. The caregivers were introduced to the study by an information letter from the researchers, given to them by a home care nurse. Caregivers who wanted to participate were asked to return a written informed consent form and a telephone number to the researcher, or to give this to a home care nurse who would hand it over to the researchers. The participants were contacted by the first author to arrange a time and place for the interview. Nine caregivers were interviewed: six women and three men, aged between 44 and 83 years (see Table 1). One eligible caregiver did not want to participate.

Table 1. Caregiver characteristics

Characteristics	Caregivers	
	N=6	N=3
Relation to care-recipient	Spouse 6	Adult child 3
Sex		
Female	4	2
Male	2	1
Age (years)	61-83	44-59
Living situation		
Cohabiting	6	
Living alone		3
Occupation		
Full time employment	1	2
Part time work	1	1
Retired	4	0

Data collection

An interview guide developed in advance directed the themes for the interviews. Examples of questions were: «What were the reasons for applying for home care?», «Could you describe

how your caregiving influence your life at the moment?», and «How does home care influence your caring situation?». The interviews, which lasted from 50 to 90 minutes, were audiotaped and transcribed verbatim by the first author.

Analysis of data

This study was inspired by Dahlberg, Dahlberg, and Nyström's (2008) description of lifeworld research based on phenomenological and hermeneutic philosophy, and their methodological guidelines for an interpretative approach to the analysis of qualitative data. Dahlberg et al. claim that to be in the world is to be in a world with others, and this is the starting point for all understanding of our self as well as of others. Due to our belongingness to the world, we experience that our surroundings are meaningful to us in one way or another. In general, human science research seeks to understand lifeworld meanings that are often implicit, tacit and taken for granted. Hermeneutics seeks to gain new understanding through interpretation (Dahlberg, Dahlberg, & Nyström, 2008). However, in our aim at understanding we are always in a danger of interpreting the phenomena of interest within a known context. In accordance with hermeneutics our pre-understanding is unavoidable and necessary preconditions for gaining knowledge, though we have to question our pre-understanding to see more clearly what prejudices there are and how they affect our approach to the phenomenon. An open approach to understanding is crucial when we want to discover something new (Gadamer, 2004). This attitude includes awareness of how our pre-understanding influences what we look for and a temporal withholding and restraining of one's pre-understanding. As the first author of this article has worked for several years in home care, it was necessary to bring attitudes and feelings regarding the phenomenon to the surface. In this study this was done by the first author having a brain storm and writing down as many prejudices as possible concerning the phenomenon in focus.

The initial phase of analyzing the transcribed interviews began by the first author reading the whole text several times in order to obtain a preliminary understanding of the phenomenon. Then, the data were organized into themes and sub-themes (see Table 2 for the framing of themes and subthemes).

Table 2. Visualizing the framing process from statements to themes and sub-themes

Themes	Variations/subthemes	Example of statements
The care-recipient's right to self-determinate is given priority	Cannot control an adult The wish of the care-recipient is in a strong position	It is her choice, I cannot force her. He wants to get up at 7 am as we have always done. Then I assist him before they (the nurses) arrive. She must find out by herself that she needs more help. At the moment she does not want assistance in the evening.
Disagreement between caregivers and home carers assessment	Fixed time Insufficient assessments Routines have high priority Phone calls Difficult to interfere	Their visits are so irregular and it wears me out more than anything else. I am comfortable with their acceptance of her telling them she is OK. She is not OK. It is 9 pm and time to go to bed, Mrs Olsen. How do they know her state when they don't see her? I tried to speak out, but the nurse defended herself immediately.
Bad conscience	Difficult choices Always responsible	I want him (husband) to live with me though I should have had the opportunity to come out of this house. These walls make me crazy. When he is in respite care, I feel as if I should have been with him.
Strain and burden	Lonely undertaking Heavy Anxious Always available Tied up	I do not blame him (the son). He is too busy to help us. I feel I am on duty 12 – 14 hours a day. I cannot keep on much longer. I could not let him stay by his own and me visiting a friend in the evening. I have no private time, he always want me to be around. I never go out just for fun, only when I have to.
Nonregulated medical management	Insufficient control Not fulfilled expectations Lack of knowledge	I must look after if he has got his medicine as they (the nurses) often tend to forget. She had to wait two months to get the prescribed medicines. I did not know the importance of

	Irregularity	taking the medicine at a certain time, neither did they (the nurses). They won't come regularly, which leads to terrible side effects.
Expect professionalism	Information Kindness Qualification / knowledge Responsibility	They could do better telling her about her disease. She get so upset when they are rude. They did not understand that she was really sick and decided myself that I had to take her to see a doctor. Once a day there must be a registered nurse to make sure that everything is ok with the patients.
Relief – for better or for worse	Accessibility Flexibility Safety Ambivalence Respite Freedom	Sometimes he has to wait for about an hour to access the toilet. It is difficult to fit in home care with a busy everyday family life. It would help me a lot if she accepted their assistance at evenings when I am not there. I do not like to many strangers coming to our house, but I cannot make it myself. I would love to have him in a nursing home for the night now and then. Without assistance we would feel more free. However, we could not take the risk of no assistance.

The sub-themes were compared and put together in new ways independent of the initial themes in order to search for underlying meanings. Tentative interpretations that could explain meanings in the sub-themes emerged. This process continued until all data of general importance for the research question were covered and temporarily explained. The criteria for a valid interpretation is based on Dahlberg et al. (2008): No other interpretations should to the same degree or more meaningfully explain the data; there must be no contradiction in the data, and considerable data must not be left unexplained. Interpretations that passed the evaluation were compared with each other and linked together in a comprehensive understanding; with a main interpretation concluding the validated interpretations (see Table 3 for the two levels of interpretations).

Table 3. Interpretations of the family PD-caregivers experiences of their situation when sharing care with home care

Main interpretation	Being on call around the clock despite providing home care		
Interpretations illuminating different aspects of caregiving	Challenges with clarifying and delimiting responsibility	Relief is not equivalent to feeling safe and satisfied	Correct management of Parkinson’s disease medication does not fit in with the routines of home care

The analysis was performed in collaboration between the two authors. The co-author independently read all the relevant transcripts and agreed that the themes were grounded in the data. Tentative interpretations were formulated by the first author and then validated in collaboration between the two authors.

Findings

The main interpretation was identified as family PD-caregivers experience of «Being on call around the clock despite providing home care». Three issues that illuminate the meanings identified in different aspects of the experiences contribute to the main interpretation: Challenges with clarifying and delimiting responsibility: Relief is not equivalent to feeling safe and satisfied, and: Correct management of Parkinson’s disease medication does not fit in with the routines of home care.

Main interpretation: Being on call around the clock despite providing home care

Unlike the home care nurses whose tasks are captured in a contract and restricted in time, the family PD-caregivers’ responsibility for the care-recipient is experienced as lasting night and day. Some had to look after their loved one the whole time, while others, due to the provision of home care, could on some days confine themselves to a phone call to make sure that everything was okay. However, home care does not take away the feeling of being on call around the clock. This feeling is strongly associated with Parkinson’s disease, which is described by the caregivers as a disease that makes their loved one’s condition unpredictable like, for instance, that immediate assistance is needed. A challenge according to the Parkinson’s disease sufferers’ mobility state is expressed like:

One day he (the husband) manages so well that you hardly notice he has Parkinson’s disease, while the next day he needs help with almost everything.

All caregivers in this study described being tied to the caregiving situation. Those living with the care-recipient were governed by his / her rhythm and needs more or less 24 hours in attendance. The following description from one caregiver is a typical example of how they experienced their feeling of being tied to the caring role:

He (the husband) is the central figure. I have no car, so I cycle to the grocery store, and if I meet someone I constantly watch the time, because I have to be back at two o'clock when he comes home from day care. It worries me all the time, and I always try to plan accordingly.... and I cannot go anywhere in the evenings.

Family PD-caregivers who did not live with the care-recipient and those who had a job were worried about how things were at home if there was nobody around. They appreciated the home care nurse's visit although it did not reduce the burden of being the overall responsible of the care-recipients' well-being and the fact that they were left unattended most of the day. Worries described in the interviews were particularly associated with sudden stop in the ability to move and the risk of falling. Caregivers' anxiety about the care-recipient's condition influenced their everyday life in different ways. One caregiver expressed the situation as:

I have felt as if my wings have been clipped for a long time.

Although he knew that his spouse was doing well most of the time when he had left home for work and the home care nurse had finished his / her visit, he found it difficult to give priority to his own hobby in the evenings:

When you know she has been sitting at home for ten hours, you don't go off cycling with a clear conscience.

To apply for and receive help from home care is experienced as a threshold for the family PD-caregiver as well as for the care-recipient. Hence, the caregivers acknowledge their loved one's right to limit the extent of assistance from home care, as one caregiver said:

It is her choice, I can't force her. She is an adult.

It might, however, not necessarily be that the care-recipient does not want help from home care, but the home care nurses may not be available at the time the care-recipient wants or

needs help. Like the persons with Parkinson's disease, the family PD-caregivers also found it difficult when assistance with bathing and dressing was provided at different times from day to day. This often led to the caregivers taking the responsibility for the care, as expressed in the following:

Due to their (the nurses') irregular visits, we never know exactly when they will arrive. Then he always keeps questioning me; when will they come, when are they coming? I am sure they have forgotten me, couldn't you better do it? – Then I have to do it.

Love, compassion and faithfulness were the words the family PD-caregivers used to describe what kept them going. One of the six caregivers who lived with the care-recipient was encouraged by other family members to do things on her own and to let one of the children look after the ill parent. The other spouse caregivers whose adult children lived in the same area made the excuse that their children were too busy to assist in caring for their father or mother. They were grateful that home care saved them from asking their children for assistance.

Challenges with clarifying and delimiting responsibility

To acknowledge the care-recipient's right to decide the extent of assistance from home care does not free the family PD-caregivers from worries concerning their responsibility. One caregiver described this the following way:

... So what is my responsibility towards her (the mother)? She is not my daughter... I feel she is pushing me to make decisions for her which I actually should not, should I? ... This makes me feel guilty about her. I don't have to, but it's a problem.

This caregiver struggled with her responsibility for her mother as well as her expectations from the responsibility of the home care service. She wished that the home care nurses could increase her mother's acceptance of more help. For this caregiver, as for all with the exception of one, the main reason for applying for professional help was their experiences of feeling unable to handle many of the problems concerning the Parkinson's disease. Thus they wanted support from professional carers who were more experienced and knowledgeable about the disease. The extent to which their expectations were met by the home care nurses varied. One caregiver said:

They are all nice and some are well trained, but too many seem to know nothing about the problems related to Parkinson's disease.

Another participant told about his mother suffering greatly due to home care nurses not being qualified to nurse persons with advanced Parkinson's disease. He would appreciate internal control. Nevertheless, the family PD caregivers are careful about making demands and trespassing on the professionals' territory. One woman who had cared for her frail spouse for several years excused her involvement in the caring, saying:

I hope they are not offended, because I have to keep an eye on what they do.

Increased need for assistance, due to the progression of Parkinson's disease and the care-recipients' fluctuating function, implies difficult decisions for the family PD-caregivers concerning the well-being of the care-recipient and their own conscience. They try to act in the advantage of the care-recipient, despite knowing that it may be against his/her will. One caregiver cried when she said that she recently had to implore her husband to accept three weeks in a nursing home. Several caregivers described how their conscience bothered them and they blamed themselves for not always doing their best. The tension between the care-recipient's and the caregiver's needs as well as other commitments is by one caregiver summed up in the following comment:

At present, nothing is good. I always feel guilty. That makes it difficult.

Relief is not equivalent to feeling safe and satisfied

Receiving home care was at first experienced as a well needed support for the family PD-caregivers. To have someone with whom to share the workload was a relief. One caregiver expressed her satisfaction this way:

They (the nurses) seem to have a lot of experience of Parkinson's disease and are very well qualified. They know exactly what to do and are very attentive to their job.

After the first period of home care, the caregivers' experiences are more diverse:

They could be three hours late for the meal. So she gets her breakfast at 11.30 and dinner at 13.00.

This caregiver did not trust the service. Still, he appreciated having home care, as it relieved him from caring tasks. Relief is thus not necessarily associated with feeling safe or satisfied with the care provided. In order to feel safe, the service has to be trustworthy and predictable. An example of an insecure situation was the flexibility of home care i.e. if the decision whether to give a visit was made during a telephone conversation between the care-recipient and a home care nurse. Caregivers question the nurses' ability to make a qualified decision when they cannot see their patient. However, a flexible service is something caregivers also appreciate and ask for. When there was a lack of flexibility, the caregivers did not get the kind of relief they needed, as pointed out by one of them:

What would have benefitted me was if there was some flexibility in the home care service. My impression is that their time schedule is fixed. If it happened that one day I want them to help her when I am busy at work, I can't ask on that same day. I have to fill in an application in fourfold, five days in advance. I just couldn't be bothered.

For this caregiver, as for several others in this study, the way in which the home care helps them is important for their experience of relief: *«To me, they (the nurses) mean everything. They look after me and tell me when I forget that I should not lift due to my aching back»* is how one caregiver expressed her satisfaction and the importance of relief from home care, despite the fact that her caregiving obliged her to stay with her husband whenever he was at home.

Correct management of Parkinson's disease medication does not fit in with the routines of home care

For a long period the family PD-caregivers had experienced the importance of being accurate in administering medications to maintain the care-recipient's most optimal functional ability. However, persons with Parkinson's disease who need to have their medication at a certain time cannot be met within the framework of the home care schedule. The home care nurses were often late and sometimes twice in a row. This irregularity led to increased Parkinson's disease symptoms and complications. Hence, some caregivers hesitated to let home care have responsibility for the medication in order to feel safe. One said:

I need to have full control over his (the husband's) medicine.

The family PD-caregivers did not expect the home care nurses to visit the care-receiver's home each time he / she needed medication, which could be up to eight times a day. They did their best to facilitate their loved one's cognitive and practical limitations in order to make him / her self-reliant concerning medical management. One described it as follows:

I'm afraid that if she (the mother) lets the nurses take responsibility for her medication, she is at risk of being sent to a nursing home. They won't come regularly and that will lead to terrible side effects She can only live at home on condition that she manages her own medication.

Discussion

This study aimed to explore how family caregivers of persons with Parkinson's disease experienced their situation when they share caring with the home care services. The main theme from the interpretation of the interviews is the family PD-caregivers' experience of being on call around the clock despite the home care provided. It is a relief when caring tasks are taken from their hands though it did not reduce the burden of being the overall responsible for their loved ones' care and well-being. This experience is to a considerable extent associated with the complications of Parkinson's disease, causing fluctuations in functional ability on a daily or even hourly basis. The family PD-caregivers feel tied up, even when not assisting, and are anxious about what could happen in their absence.

Several studies focus on competing needs faced by family caregivers (Beach, 1993; Shyu, 2000). In a study of family caregiving to frail elders, Shyu (2000) found that the sources of competing needs faced by caregivers could be characterised by three main categories: 1) competing family and care-receiver needs, 2) competing caregiver and care-receiver needs and 3) competing care-receiver needs. The present study reveals that a fourth category emerged: competing needs between family PD-caregiver and home care. The home care services' need for a flexible schedule, to employ unprofessional assistance, and to plan activities in advance competed with the family PD-caregivers need of a professional, trustworthy, predictable, and flexible service. These findings suggest that although home care assists the family PD-caregivers, it is also a source of new competing needs, which in turn limits the possibility of obtaining relief.

Our findings support previous studies reporting that caregiving in Parkinson's disease often results in limitations in social and leisure activities (Lökk, 2009) and that family PD-

caregivers experience less control and predictability in life as the demands increase (Carter et al., 1998). In addition, caring for a frail person can be a lonely undertaking (Beach, 1993; Fjelltun, Henriksen, Norberg, Gilje, & Normann, 2009a; Mott, Kenrick, Dixon & Bird, 2005) and caregivers are often reluctant to ask other family members for assistance (Beach, 1993; Harrison & Neufeld, 1997), which was also found in the present study. Likewise, respite and emotional support have been reported to be among the most important needs of family PD-caregivers (Parrish et al., 2003). Consequently, Norwegian municipalities have a legal duty to offer respite care to families providing particularly burdensome care (Lov om sosiale tjenester, 1991), although the opportunity to use this right depends upon the care-recipient accepting such care. Caregivers in the present study give several examples of their difficulty in taking advantage of municipal services when the care-recipient only reluctantly accepts it. These findings are in accordance with previous studies reporting that caregivers in general experienced respite care as supportive if it benefited both him- / herself and the care-recipient (Fjelltun, Henriksen, Norberg, Gilje, & Normann, 2009b; Winslow, 2003) and that care-recipients' resistance is a barrier to the caregivers' opportunity to take advantage of such relief (Hudson, Toyne, & Kristjanson, 2006; Winslow, 2003). Our study gives support to previous research (Beach, 1993; Carmack, 1997; Shyu, 2000) showing that «finding a balance» is a demanding process in caregiving.

The family PD-caregivers in the present study utilized various strategies for dealing with the different competing needs and difficulties regarding their responsibility. Nevertheless, they were bothered by a troubled conscience for not being good enough and felt guilty when giving their own needs higher priority. Similarly, several other studies confirm that a guilty conscience is a feature of caregiver experiences (Guberman, Maheu, & Maille, 1992; Mott et al., 2005; Spillers, Wellisch, Kim, Matthews, & Baker, 2008). According to Noddings (2003), caring challenges the relationship between the caregiver and care-recipient in ways that may induce guilt in the former.

The present study reveals that family PD-caregivers may experience considerable responsibility for their loved one's care and well-being. Love, compassion and faithfulness are what sustain them. Similarly, in other studies caregivers expressed their caring for family members as self-evident (Wennman-Larsen & Tishelman, 2002), a normal stage of life (Beach, 1993), and a loving and satisfying act (Mott et al., 2005). Unlike reports in previous studies (Fjelltun et al., 2009a; Harrison & Neufeld, 1997; Wallhagen & Yamamoto-Mitani,

2006), the caregivers in our study did not talk about their duty to care. These differences might be a coincidence, although they possibly also reflect the fact that the caregivers in the present study knew that, according to Norwegian law, they have a right to receive assistance with caring tasks (Lov om helsetjenesten i kommunene, 1982). Nevertheless, caregivers in the present study showed that they devoted a lot to caring although there was an issue regarding professional assistance.

When handing over caring activities for a loved one to home care nurses, the caregivers need to trust the nurses and the service. Grimen (2009) claims that trusting is a way of acting towards others, and when trusting another person this person is given a space for acting towards the one who trusts him /her. Trusting someone is thus always associated with a certain danger. The cost of relinquishing control is making oneself vulnerable to the consequences of the other's choice. Those who feel they have no other choice than to trust others and those who leave someone who is important to them in the hands of others are most vulnerable (Grimen, 2009). This is in line with how the caregivers in the present study characterized their situation. In all caregivers except one, their loved ones had applied for home care when he / she was unable to meet the need for professional care. When something of special value is handed over to another person, the giver often takes steps to protect against the harmful effects of relinquishing responsibility (Grimen, 2009). In the present study, the caregivers described several precautions taken in relation to the home care service in order to make their own situation less vulnerable. Concerns about patient safety and quality of care have similarly been reported as a barrier by caregivers who utilize little or no support from the municipal services (Winslow, 2003). To trust someone is associated with being less cautious and functional institutions have control systems aimed at reducing co-operator vulnerability (Grimen, 2009). Accordingly, in Norway there is a «Regulation of quality of care in health and social services» (Forskrift om kvalitet i pleie- og omsorgstjenestene, 2003), which describes the service that should be provided by the municipal health care in order to safeguard the client's right to qualified care. The family PD-caregivers' precautions in relation to the home care service might be a result of their experiences of few control routines. They are concerned about the quality in a service characterised by unpredictability, frequent problems with medication compliance and lack of knowledge in Parkinson's disease among nursing staff. As reported in previous studies (Habermann & Davis, 2005; Hudson et al., 2006), the PD-caregivers in our study expected appropriately skilled professional carers. During their experiences in caregiving, these caregivers have probably learnt to interpret the

needs of the care-recipient, which might have influenced the difficulties in delimiting their responsibility and their need to control the caring situation. In addition, family PD-caregivers' precautions in relation to home care could be explained in the light of their engagement in caregiving and the importance they attribute to their responsibility to attend to the care-recipient's wellbeing. This is supported by other studies, where caregivers describe their role as intimately related to their sense of self (Guberman et al., 1992) and self-esteem (Harrison & Neufeld, 1997).

Methodological considerations

First, the authors acknowledge that pre-understanding might have impaired the data collection as well as the analysis. However, according to a lifeworld approach to research, pre-understanding could as likely facilitate as constrain understanding (Dahlberg et al., 2008). Knowledge and experience within the research field have given an access to the phenomenon in focus in a way that was impossible if the research field was unknown. However, the researcher's pre-understanding might also have been an obstacle for being able to look behind what is already known and to find something new that was not expected from the start. In this study, openness and curiosity is endeavored during the data collection by making an effort to minimize the interviewer's impact on the family PD-caregivers' responses to the questions by encouraging them to narrate their experiences freely in response to the interview guide and by restraining specific and concrete questions on subjects which were not initiated by the family PD-caregivers themselves. In addition, the tentative interpretations were confronted against the prejudices of the researchers and thoroughly discussed in a continual hermeneutic movement between single statements and the whole text – the parts and the whole – and finally rephrased until the interpretations were judged to represent the meaning of family PD-caregivers' situation when sharing care with the home care services.

Second, the authors are aware that the findings in the present study are based on a small sample of family caregivers of persons with Parkinson's disease. Nevertheless, we believe that the knowledge that emerged from the interviews illustrates central aspects of family PD-caregivers' situation when caring for a person who is allocated to home care. However, in addition to the generalisation based on each of the informants' personal experiences as expressed in the main interpretation, the research must gain knowledge that extends beyond the experiences of the individuals in a single study (Dahlberg et al., 2008). In line with the lifeworld theory, understanding of the particularity of individual experiences provides

an opportunity to gain knowledge of general relevance in a shared lifeworld. Consequently, the findings may be applicable to caregivers of persons with Parkinson's disease in similar settings outside the study area as well as to family caregivers of people with other chronic diseases who share caring responsibility with home care nurses.

Third, a limitation of the present study is that it only reports on the family PD-caregivers' experiences. Docherty et al. (2008) addresses this problem and emphasises the importance of focusing on the triad of patient, caregiver and service provider to fully understand the complex dynamics of the caregivers' situation in home care.

Conclusion

Caring for persons with Parkinson's disease is a complex undertaking, experienced by family PD-caregivers in the present study as being the overall responsible for their loved ones' caring and well-being, and on call around the clock. This could be understood as family PD-caregivers' protection against the vulnerability in delegating responsibility with home care nurses without getting sufficient insurance that the service is satisfying. Although home care to some extent is considered relieving, the service is also a source of competing needs. The findings indicate the importance of a professional, predictable and flexible home care service in which the family PD-caregiver can trust.

Nurses in home care services must be appropriately trained to care for persons with Parkinson's disease. When assessing the needs of the person with Parkinson's disease, the family caregivers' perspective, their workload and informal contribution to the treatment unit must be considered. Also caregivers' access to practical and emotional support and how they are coping with the situation must be addressed. Further, home care must be organised in a way that meet family PD-caregivers' need for a service that supports in balancing competing needs and eases troubled conscience. Additionally, the home care nurses must encourage the person with Parkinson's disease to accept the assistance offered from municipality services in order to enable his/her caregiver to obtain the relief and respite care needed to continue the significant caregiving function.

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