

Research Report

“How Long Can I Carry On?” The Need for Palliative Care in Parkinson’s Disease: A Qualitative Study from the Perspective of Bereaved Family Caregivers

Herma Lennaerts-Kats^{a,b,*}, Anne Ebenau^b, Maxime Steppe^a, Jenny T. van der Steen^c, Marjan J. Meinders^d, Kris Vissers^b, Marten Munneke^a, Marieke Groot^b and Bastiaan R. Bloem^a
^a*Radboud University Medical Center, Donders Institute for Brain, Cognition and Behaviour, Department of Neurology, Centre of Expertise for Parkinson & Movement Disorders, Nijmegen, the Netherlands*
^b*Radboud University Medical Center (Radboudumc), Department of Anesthesiology, Pain and Palliative Care, Nijmegen, The Netherlands*
^c*Radboud University Medical Center (Radboudumc), Nijmegen, Department of Primary and Community Care, Nijmegen, The Netherlands; and Leiden University Medical Center, Department of Public Health and Primary Care, Leiden, The Netherlands*
^d*Radboud University Medical Center (Radboudumc), Radboud Institute for Health Sciences, Scientific Center for Quality of Healthcare, Nijmegen, the Netherlands*

Accepted 14 June 2020

Abstract.

Background: Family caregivers provide the majority of care for people with Parkinson’s disease (PD) in the palliative care phase. For many this is a demanding experience, affecting their quality of life.

Objective: We set out to map the experiences of bereaved family caregivers during the period of informal care in the palliative care phase as well as after the death of their loved one with PD.

Methods: Ten bereaved family caregivers participated in this qualitative study. Semi-structured interviews were conducted and interpretative phenomenological analysis was used executed.

Results: We identified four main themes. 1) **Feeling like a professional caregiver:** while caring for a person with PD, the family caregivers took over many roles and tasks of the person with PD. 2) **Healthcare professionals do not always know what PD really means:** most interviewees had negative experiences with knowledge and understanding of PD of, especially, (practice) nurses. 3) **Being on your own:** many respondents had felt highly responsible for their loved one’s care and lacked time and space for themselves. Grief and feelings of guilt were present during the caregiving period and after death. 4) **Being behind the times:** to provide palliative care in line with patients’ preferences and to feel prepared for the palliative care phase of PD, proactive palliative care planning was considered important. However, the interviewees told that this was most often not provided.

*Correspondence to: Herma Lennaerts; Radboudumc, ReinierPostlaan 4, 6525 GC Nijmegen, The Netherlands.

Tel.: +31 0 24 3614701; E-mail: herma.lennaerts@radboudumc.nl.

Conclusion: These findings indicate that caring for a person with PD in the palliative care phase is a demanding experience for family caregivers. They experience psychological problems for many years before and after the death of the person with PD. Increasing healthcare professionals' awareness of family and bereaved caregivers' needs may mitigate these long-term detrimental effects.

Keywords: Anticipatory bereavement, bereaved family caregivers, grief, palliative care, Parkinson's disease, post-caregiving

INTRODUCTION

Parkinson's disease (PD) is a progressive, neurodegenerative disorder, affecting approximately 1% of the population over 65 years in Western countries, the incidence increasing with age [1, 2]. As PD progresses, patients can experience a wide range of symptoms such as immobility, pain, fatigue, sleeping problems, cognitive deficits and dementia [3–5]. Furthermore, patients often increasingly become dependent on family members, especially spouses, for example, for physical care and support in social activities. Family roles change and family caregivers experience increasing demand [6, 7].

Family caregiving has been associated with negative outcomes such as social isolation, depression, reduced financial income, higher rates of psychiatric morbidity and a sense of guilt for feeling overwhelmed [8–11]. Therefore, we need a better understanding of the needs of family caregivers of patients with PD. Consequently, we must strive towards better understanding of the needs of family caregivers of patients with PD. This is even the more so because most people prefer to die at home and demand on informal care is increasing in Europe [12, 13].

Since PD is incurable, palliative care (PC) seems appropriate and beneficial. The World Health Organization defines palliative care as an “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment” [14]. During an incurable disease course, patients' care goals may gradually shift. More specifically, PC for people with PD can be seen from diagnosis onward as there is no cure, and care focuses on quality of life. However, often a late stage is defined to mark a phase in where care goals focuses more on comfort. A recent study highlights this as a palliative care phase in PD, in which care goals focus on comfort [15].

Studies about the palliative care phase of persons with PD, however, are scarce. Literature that is available shows that during this phase, family caregivers often fulfill their roles without receiving adequate information and support, particularly regarding the prognosis and what to expect of the disease course [6, 16–20]. They typically feel unprepared for their roles, and experience distress [6, 21]. Family caregivers of a person with PD often experience grief during the PC phase of their loved one, for example, when nursing home placement is inevitable, or when the loved one loses his or her personality [21–23]. Furthermore, PC for people with PD and their family caregivers is less commonly provided than for people with malignant diseases such as cancer [24].

Narratives of bereaved family caregivers can offer an understanding of the problems and needs related to the continuous support of a person with PD in the palliative care phase and the period of bereavement, i.e., after the loved one's death. In this study, which is part of the Dutch ParkinsonSupport project [25], we therefore collected the experiences from bereaved family caregivers to develop a better understanding of the PC phase, including the post-caregiving period.

METHODS

Design

We aim to identify individual perceptions of bereaved family caregivers of a person with PD, and conducted qualitative interviews, of which the outcomes were subjected to interpretative phenomenological analysis [26]. Phenomenological research aims to understand the essence and meaning of experiences and aims to grasp such ‘lived experiences’ in a narrative, descriptive manner [27]. This method fits our study, as it is suitable for small sample sizes and allows scrutiny of complex and emotionally-laden experiences which might be difficult to articulate [26, 28]. This type of analysis focuses on the internal psychological meanings

Table 1
Interview topic list

<i>Main topic</i>	<i>Sub topics</i>
1. Palliative care	<ul style="list-style-type: none"> ● Quality of life: psychological, spiritual, physical and emotional needs of patient and family caregiver ● Process of dying ● Identification of PC phase: care transition, information provision ● Meaning of palliative care: understanding and associations
2. Documentation of personal wishes	<ul style="list-style-type: none"> ● Introducing subject of dying and PC: who, when, how? ● Advance directives and other end-of-life preferences: which taken into account?
3. Professional support (during palliative and terminal phase)	<ul style="list-style-type: none"> ● Roles and knowledge of healthcare professionals ● Family caregiver involvement in decision-making ● Support: by and for whom, how? ● Care coordination and information provision ● Bereavement support/after care
4. Informal support	<ul style="list-style-type: none"> ● Who, what, how? ● Meaning of support
5. Support with end-of-life decisions	<ul style="list-style-type: none"> ● Conversations: with how, how? ● Realization of decisions ● Information provision

evident in the accounts [26, 29]. Data were collected from March until May 2017. The reporting is guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [30]. The methodology of this study has been described extensively in the published study protocol [25].

Sample

Bereaved family caregivers of a person with PD who died within the last five years, were invited to participate, primarily through a notice in a magazine of the Dutch Association of Parkinson's Disease [25]. Additionally, information sheets were distributed by PD nurse specialists who had regular contact with families.

Data-collection

Ten face-to-face semi-structured interviews were conducted by interviewers who were trained and experienced in qualitative research (HL and MS, both women). Given the aim of the study, this method was chosen because it provides room for the interviewer to prompt and explore, and for the respondents to talk freely about their experiences [31, 32]. The interviews were guided by a topic list consisting of five main topics and several sub topics (Table 1). The topics were based on a literature study, as well as on the expertise of the project group, including (senior) researchers with expertise in qualitative research, a PD nurse specialist, physicians and a (trained) family caregiver [25]. This family caregiver acted as a

(research) representative of the Dutch Association of Parkinson's Disease. Adjustments were made based on the suggestions that were provided by the project group. The interviews lasted one to two hours, were held at the respondent's homes, and were audio-recorded.

There was no prior relationship between the interviewers and the respondents; the interviewer stated only her name and occupation before the interview started. The interviewer first collected general information: respondent's age, gender, education, relation with patient, and moment and place of the patient's death.

Data analysis

HL and MS transcribed the interviews verbatim. Next, two researchers (HL and AE, both female) performed an interpretative phenomenological analysis. To comprehend the meaning of what the respondents relayed, the researchers maintained an open attitude towards the data [33]. The analysis consisted of five steps:

- 1) *Looking for themes in the first interview:* In a first reading, HL and AE independently wrote down in the left-hand margin what they found interesting and relevant for the main research question (What are the experiences of bereaved family caregivers of patients with PD when looking back on the palliative care phase?). These notes could be a summary, paraphrase, comment, association, connection or

Table 2
Characteristics of the interviewed bereaved family caregivers

<i>Bereaved caregivers (pseudonym)</i>	<i>Gender</i>	<i>Relationship</i>	<i>Time passed since bereavement (months)</i>	<i>Place where the loved one with PD died</i>
Laura	F	Spouse	46	Home
Janet	F	Daughter-in-law	12	Home
Jackie	F	Daughter	16	Home
Susan	F	Daughter	42	Hospice
Kate	F	Spouse	60	Home
Diane	F	Spouse	23	Home
Peter	M	Son	14	Nursing home
Marion	F	Spouse	20	Nursing home
Lydia	F	Spouse	32	Home
Thomas	M	Spouse	10	Nursing home

*Age was not included to reduce the risk of recognizability.

other insights and interpretations on the content of the story, but also on the way answers were expressed. Next, both researchers read the interview again and, in the right-hand margin, noted theme titles emerging from the initial insights. Theme titles were formulated in respondents' phrases or close to the original accounts. This contextual reading phase resulted in themes of a higher abstraction level.

- 2) *Connection of the themes*: HL and AE discussed their notes and themes derived from the first interview, and the connections between these notes and themes. Agreement on clusters of comments and themes was reached, although not yet solidified.
- 3) *Constructing a working document*: Themes and descriptions were written down in a table, and references to the primary interview material were included. This data analysis was done on paper, as computer software would not help to build a contextual narrative. The working document was constructed with the aim to check the researchers' interpretations against the original data, as well as to make up a detailed account of the respondent's experiences. This document was considered an initial list of themes. Each of the two researchers could add observations to this document during the entire analysis phase.
- 4) *Repeating for the second interview*: The above-mentioned steps were repeated for the transcript of the second interview. To refine the phrasing of the findings, the findings were added to or incorporated into the working document prepared in step 3. A list of all emerging themes across the two transcripts was compiled and clustered these into groups based on similarity and overlap. The preliminary theme list

(including six themes) was discussed with MJM and MG.

- 5) *Continuing with the theme list for the remaining interviews*: the theme list guided the subsequent analysis. On two occasions, two themes were merged together. The researchers discussed the themes together until data saturation was reached: after six interviews no new themes emerged, and only slight adaptations to descriptions in the working document were made. The resultant four-item theme list was provided only with more nuances and examples. We labeled themes and subthemes as far as possible by using the respondents' own words in a representative quotation [26, 33–35]. HL and AE each independently and separately analyzed two of the four remaining interviews.

RESULTS

Table 2 shows the characteristics of the ten interviewees. Their ages ranged from 44 to 81 years; the time elapsed since the death of the loved one with PD ranged from 10 to 60 months. Analysis of the data revealed four themes: 1) "Feeling like a 'professional' caregiver"; 2) "Healthcare professionals do not always know what PD really means"; 3) "Being on your own"; 4) "Being behind the times". The themes are described in detail below with supporting quotes from the interviews.

Feeling like a 'professional' caregiver

"At home it was my job, I did nothing else." - Lydia

Bereaved family caregivers took over many, often time-consuming roles. Much of the support was related to helping the person with PD function on a daily basis. Reasons for caregivers to take over roles included the growing dependency of the person with PD on others and the drive to secure the loved one's well-being and dignity. Some felt forced to adopt these roles, to protect the person from falls/injury and further deterioration. Some bereaved caregivers, especially spouses, felt that they had become a 'professional' caregiver. This sometimes came with a sense of losing the partner role. We identified three specific caregiver roles.

First, being a 'spokesperson' was frequently mentioned: imparting information to others (neurologists, friends, family, homecare nurse) and, vice versa, receiving information concerning many aspects of life: from health status and medications to personal hygiene and recommended diet. The interviewees felt responsible to take over communication for their loved ones given the PD-related communication difficulties and cognitive deficits. Being able to observe subtle changes, they noted how the disease progressed overtime. The spokesperson role consisted of imagining oneself in the situation of the person with PD, and advocating the loved one's preferences if he or she had been able to articulate it. The interviewees often had the impression that healthcare professionals did not find their opinions about the persons' situation relevant. In some cases, opinions were not even asked for, even though they might have contained important information about the person with PD they cared for.

"I think it should have been a good thing to involve spouses more in the whole care trajectory. [...] With the two of us, we can understand better. However, I never had the impression that I was taken seriously as a conversation partner."
- Diane

Second, many interviewees acted as a 'case manager', but found it very hard to deal with the organization of care and administrative and financial issues. They were aware that they lacked specific knowledge about the range of services available for persons with PD. Thus, the case manager role often involved gathering information on available care services, medication, or arranging home modifications.

Third, the interviewees had an important role as 'daily caregiver'. Persons with PD needed help with all kinds of daily activities. A few interviewees mentioned that from the time that help was needed at night (due to frequent toilet visits; nocturia) they became

overburdened, which, among other reasons, triggered the need for transfer to a nursing home. Furthermore, they needed to ensure the loved one's safety and became anxious about possible falls. Caring for and supervising the patient, felt as a 24/7 job. The interviewees told that they could leave the person with PD alone only for short time spans. Jackie, for example, relayed that she felt like she was 'baby-sitting' her father. And Laura said:

"Well, if my husband went to the toilet, I was always keeping an eye on him. Because when he had a freezing moment, he couldn't come back. Thus, I was unconsciously remaining aware of what he was doing." - Laura

After death of the loved one, some bereaved family caregivers replaced their caregiving role with other meaningful activities, often in the context of PD advocacy. Laura and Peter, for example, began volunteering to help other family caregivers and professionals through support group facilitation, writing and public speaking.

Healthcare professionals do not always know what PD really means

"Every time somebody new had to learn about the advanced therapy for my mother. It was like she was being used as a guinea pig. Then they needed another needle. So many things went wrong; I could write a book about it." - Susan

Many respondents were dissatisfied with the care surrounding PD in the palliative phase. First, a lack of knowledge and understanding of PD of nursing staff (including practice nurses) was noted frequently, and medication management was part of the frustration. Nursing staff did not always recognize the importance of appropriate and timely medication administration. Susan and Diane had very negative experiences with apomorphine or Duodopa pumps at a nursing home and home, respectively. Nursing staff was not well equipped to provide for such advanced therapies. Second, besides these more technical issues, neurologists, among other healthcare professional, sometimes seemed to be unfamiliar with the lived impact of PD on family caregivers.

"My husband's neurologist said: 'I have been treating you for more than 15 years now. However, only after I stayed with a colleague with PD in a hotel room, I realized what PD really means'" - Laura

More specifically, bereaved family caregivers emphasized that healthcare professionals need to realize that a person with advanced PD is dependent on others for basic daily activities. Often, a person with PD cannot express what he or she needs as a result of apathy or cognitive impairment. In particular, this was often not recognized when the person with PD was in a nursing home or admitted to hospital. Trust in nursing staff decreased when a nurse repeatedly delivered insufficient care or if medications were not given on time. Consequently, many of the interviewees felt a greater demand for support.

Around 3 pm, my mother and I went to the hospital to visit my father. There was another female patient in his room, who told us that he had been in his wheelchair already from 9 am, facing the wall. During all that time, he couldn't communicate or had no idea of his situation. For my mother, it was so hard, she left, crying . . . - Jackie

"I was there [in a nursing home] eight hours a day to see to it that she would get the care she needed. Because it was often left undone." - Thomas

Respondents also talked about the limitations of services supporting people to continue living in their own homes. Even when services were available, they were often suboptimal or without sufficient knowledge of PD.

Being behind the times

"Yes, for a patient with PD it is [too late to talk about important things], because communicatively and with regard to writing, he is gone. The partner has to help continuously. In fact, this should be prevented." - Laura

The interviewees noted that healthcare professionals often did not recognize what disease phase the loved one had reached. For Marion this was particularly painful, as her husband was already in a palliative-terminal phase.

"I had an appointment at the other department. The manager enthusiastically explained about all the creative activities that he [the person with PD] could participate in. But I said, my husband is not able to do so anymore, he is confined to bed. The manager asked, why did you come here instead of a hospice?" - Marion

Most of the interviewees felt that the healthcare professionals used ad-hoc approaches instead of the

more proactive approaches that would have provided more of a future road map. Timely conversations about prognosis, future scenarios, medical options and care options were needed but found to be lacking. Peter, for example, was told that his mother was dying one day before she actually died. This news was shocking to him and his family. Care needs to be more proactive, he states.

"Proactively, there has to be somebody who is taking lead, a professional, taking the family by the hand and saying 'hey guys, this is the current situation. That means this and this and you have to bear in mind that so and so' ". - Peter

Furthermore, the loved one's preferences and wishes about future care often had not been documented at all, or only documented in general terms. In cases when the person with PD had lost the capacity to speak for herself or himself, the family caregivers found it very stressful to make treatment decisions. Some of them were aware that their preferences conflicted with those of the person with PD. As for Laura, she felt really guilty and disloyal to her husband when she repeatedly refused to call the general practitioner to speak about euthanasia, while he was dependent on her (her husband was not able to phone the general practitioner). In the Netherlands, only if the criteria of the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act are fully met, euthanasia and physician-assisted suicide are legal [36]. She also mentioned that helping him to complete his euthanasia form (because her husband could no longer write) was the hardest thing she ever had done in her life. Also, Lydia felt insecure and overwhelmed by making decisions for her husband about discontinuing artificial nutrition by a feeding tube in the palliative care phase; or more specifically, the palliative-terminal care phase.

Many bereaved family caregivers argued that they would have been willing to be engaged earlier in discussions about future care and treatment options—before cognitive deficits or communication problems arose. In some cases, the person with PD had not died at the preferred place of death because the palliative (including terminal) care phase had not been discussed when it was still possible to clarify this. However, discussing issues about death and dying was sometimes taboo. Marion's husband, for example, would not speak about PC issues, and Marion felt that he was in denial of the situation. This had eventually resulted in tension between Marion and her husband. But in the end, when her husband

was not able to speak for himself, it was Marion who had to make difficult decisions regarding PC. Marion explained that she had found this unfair.

Although the respondents talked about these matters with their families, they still would have liked professional support. Family members often had different opinions on ‘what is best’ for their loved one. Family dynamics can be delicate, and some respondents mentioned that they would have liked to discuss other options with someone outside of the family, especially in advance.

*“We were in doubt about palliative sedation, because it would hasten his death. **How did you deal with that?** We talked a lot in the garage, far away from him [person with PD]. That is, the children and the palliative team on what we should do. [...] **Do you keep on pondering as a family?** Yeah, it is difficult. I noticed that my mother-in-law was very overburdened. For her, the sooner palliative sedation was started, the better. We also noticed that he was anxious and restless and that was what he would not have wanted.” - Janet*

However, many respondents did not know whom they should turn to for advice, but ideally thought of one contact person. Some found this in the person of a ‘Parkinson disease nurse specialist’. For Jackie, this had worked out well because she and her mother could put any questions to the PD nurse specialist they had contacted. Other bereaved family caregivers had contacted various professionals whom they could turn to for support.

Being on your own

“I have been very depressed. As a spouse you are on your own in making decisions for him.” - Laura

Caring for a person with PD was portrayed as a lonely and very long journey. Often, the ‘external world’ did not have a clue of how bad the situation at home was. Some of the interviewees had received support from family members and friends, but still, many felt unable to talk with them about the impact of PD. Spouses were reluctant to ask their children for help in order not to burden them. Marion used metaphors to describe her feelings of being socially isolated as a consequence of caring for her husband.

“I cycled back from a St. Matthew Passion concert, thinking, this bird is going back into her cage again” - Marion

Peter relayed that he found it quite hard to connect with his mother, because she had lost verbal communication skills. Often, he was just sitting beside her to simply be there, but for him this was emotionally tough. Loss of connection constantly led to additional new roles and tasks and adaptation to a new situation. This was often a lonesome process in which healthcare professionals did not recognize enough the family caregivers’ grief or did not pay attention to it.

The interviewees struggled with balancing between ‘self-care’ and autonomy on the one hand and ‘taking care for the other’ on the other was often tense. Seeking professional help seemed inevitable, but they were ambivalent about accepting help with an increasing number of nurses visiting at home. Others tried to avoid placement in a nursing home by taking refuge in homecare; however, they struggled with the presence and the often-changing nurses.

“Just after homecare started, I went out of my mind. I think some 15 or 16 nurses came around during the week. They took over the entire house; they were everywhere.” - Marion

Providing care had affected the family caregivers’ own health in most cases. Being continuously attentive to the person with PD made them feel physically and emotionally exhausted. Some of them experienced ongoing physical or psychological health problems even long after the death of the person with PD. Only a few, however, eventually sought professional help. Laura, Diane and Lydia admitted that they had depressive symptoms for years after the death of their loved ones. In hindsight, some respondents doubted if they had done enough for the loved one, or felt guilty having left the loved one with people inexperienced to manage the complex care needs. Peter and Diane both concluded that, if they would have known more about the course of PD, they might have acted more compassionately or patiently with their loved ones at that time. More proactive and unambiguous information from healthcare professionals about issues such as cognitive changes, apathy, medication and possibilities for support would have been useful in helping family caregivers realize what might be expected in the future.

Furthermore, many bereaved family caregivers found it painful having to witness the loved one deteriorate and gradually turn into a shell. This experience was not unique to spouses, but was mentioned as well by children of persons with PD. It was found difficult to deal with a person with PD who is ‘lost but not gone’; physically present but mentally absent.

“I wrote a piece about a living loss; on the one hand he is still there, and on the other hand he is gone” - Kate

Bereaved family caregivers also experienced difficulties after the death of a person with PD, which contributed even more to feelings of “being on your own”. Rebuilding their own lives after a prolonged period of caring was especially hard for spouses. Caring had gradually become ingrained in their lives, and was considered a meaningful daily task. Spouses in particular faced a prominent gap in their daily routines immediately following the death of the loved one, which made them feel uncertain. Accustomed to days filled with caregiving responsibilities, the caregivers in general recalled not knowing how to proceed with life as they grappled with deciding how to use their free time. Furthermore, interviewees mentioned problems that appeared related to their own senses of self and identity. Some needed to re-invent themselves, and to find new meaning for their own lives after years of caring. Spouses in particular said they had lost interest in social participation. The length of this period of adaptation was highly variable in this sample, ranging from a few months to over four years. Diane also talked about a sudden loss of contact with the nurses who had been involved intensively in the care for her husband; she felt lonely after this had happened. Most of the interviewees relied on support from family and friends after the death of the loved one with PD; only a few had sought individual bereavement support.

DISCUSSION

Our qualitative interview study provides a deeper understanding of how bereaved family caregivers of persons with PD experienced the palliative care phase of their loved ones, and how they interpreted their experiences. These caregivers described many roles and tasks they fulfilled to secure their loved one’s well-being and dignity. Many of them had felt lonely during the caregiving trajectory. Looking back, the family caregivers realized that they had, often subconsciously, been continually observing their loved ones for changes in symptoms or risk of falls, which was quite demanding. Especially spouses felt that they were on duty constantly. For some caregivers, the impact of caring for a person with PD in a PC phase caused health problems of their own, such as depression, loneliness and social isolation. Earlier studies on family caregivers in palliative care for patients with

PD showed this as well [6, 7, 16, 21, 37, 38].

The current study, however, shows that these problems could persist after the death of the person with PD, and that professional help might have been needed. Yet, none of the interviewees were referred to or received structural bereavement care services from a healthcare professional, which is not exclusive to bereaved caregivers from patients with PD. Notwithstanding that bereavement support is an integral part of PC, it needs improvement in general [39–44]. Several spouses mentioned issues related to their caregiver’s senses of self and identity. It appeared that the caregiving role specifically had gradually become a part of one’s own identity [45]. Some appeared to struggle in reinventing themselves and searching for new meaning in life after the loved one’s death. Some bereaved family caregivers reacted to the loss of the person with PD by replacing caregiving with another meaningful activity, e.g., helping other people with PD. Literature shows that volunteering after bereavement can enhance self-efficacy, protect against depressive symptoms, and reduce loneliness [46, 47]. Thus, with regard to bereavement care, volunteering might be of clinical relevance. However, we found no other studies in PD that reflect this finding, as this is one of the first qualitative studies [6, 37] of experiences from bereaved family caregivers of people with PD. Studies of dementia though also show that besides issues related to identity, bereaved family caregivers often have feelings of guilt and regret—persisting from months to years after the death of the person with PD. Furthermore, these studies describe similar experiences regarding the evolution of ‘losing the person’, with continuous loss, grief and emotional demand [48–50].

Professional psychological and spiritual support for the interviewees of the present study appeared limited, perhaps because healthcare professionals have little knowledge about family caregivers’ needs in a palliative care phase (including the terminal phase). Furthermore, the shortage of psychological and spiritual support might be related to the way the PC system in the Netherlands currently manifests itself. In the Netherlands, all healthcare professionals must be able to give basic PC. In more difficult situations, experts from external palliative care consultation teams (PCC teams) can be consulted. Care institutions may also have their own palliative care teams or units. Most advices from the PCC teams, however, still concern oncological cases. If PC expertise (either from the PCC teams or within-care settings) was involved in case of non-oncological

care, such as PD, it was at a late stage only [51, 52]. Since the knowledge concerning neuropalliative care is growing, it is crucial that further implementation into general and specialist palliative care services is needed. Furthermore, support for family caregivers might improve through raising awareness of the value of PCC teams for non-oncological patients and their proxies.

From this study, it appeared that respondents experienced ad hoc approaches in care, and that many found it essential to speak earlier in the disease trajectory with a person with PD about end-of-life wishes and preferences. They felt burdened and overwhelmed by making such difficult decisions on PC (including terminal care), issues without much preparation, support or guidance. Preparing for the palliative care phase before the person with PD develops cognitive deficits or communication problems was considered important, and this could be facilitated by better information provision and earlier attention to medical decision-making processes around PC issues. There is a clear need for proactive/advance care planning, in which decision-making and future planning is secured timely for people with PD [53–57]. Other studies also found that patients and caregivers need information throughout the PD trajectory [16, 20, 58]. More specifically, studies have shown that patients prefer a form of shared decision-making with family and physicians early in the PD trajectory [53, 59]. Still, patients do prefer that a physician takes the initiative to start the process of advance care planning [54, 59]. The family caregivers in our study often exercised the decision-making role if the person with PD had lost his or her decision-making capacity. Some had the impression, however, that healthcare professionals did not involve them in medical decision-making.

Strengths and limitations

This study tapped into the experiences of bereaved family caregivers after several months to years had passed after the death of the person with PD. Although in the cases of years passed since death, it may be questioned how well some respondents may recall their experiences, it is important to investigate how memories live on in the bereaved too [60].

The sample exists of seven bereaved family caregivers who were invited through an announcement in the magazine of the Dutch Association of Parkinson's Disease. The remaining respondents were invited by a PDNS. This might have a positive as well as a neg-

ative effect on our data. Our respondents might be highly satisfied or highly dissatisfied with their experiences and therefore feel the need for telling their story. Furthermore, since the interview guide did not explicitly focus on the rewarding, meaningful and other positive aspects of caregiving and bereavement, the interviews testified to more negative than positive experiences. However, other research has found that caring for a person with a chronic disease can also lead to a closer spousal relation, or to positive feelings of meaningful activities [61, 62], which are important facets for support during and after caregiving. Furthermore, it might be interesting to look closer at experiences of those care partners whose loved one died recently as compared with those for whom death was five years previously. Finally, generalizability is a matter of concern, as the sample size is small and the majority of the respondents were women. Still, our rich narrations can provide valuable data for the design of PC services which would seek to support the families in addition to the patients. Furthermore, we did not perform member checking with the respondents. However, to ensure validity of the analyses, the research team members regularly discussed data, coding and themes.

Clinical relevance and future perspectives

Living with a person with PD until death is often a lonely and difficult trajectory that encompasses many kinds of emotions. This study offers insights into the experiences of bereaved family caregivers during the care trajectory for a person with advanced PD and during the post-caregiving period. Although some previous studies have addressed the experiences of people with PD and their families in palliative care phases, ours is one of the first qualitative studies to collect experiences on the post-caregiving period [6, 37]. One of the contributions of this study is an improved understanding of the bereaved caregivers' experiences after the death of the person with PD. Yet, the study made clear that improvement is needed in different domains: information, education, psychological and spiritual support, anticipatory grief, post-caregiving, and advance care planning—all of which are encompassed in the specialty of PC. Implementing palliative care, including advance care planning, can help to offer support that meets the needs of persons with PD and their family caregivers. Another important message from the bereaved family caregivers in this study is that healthcare professionals' skills and understanding of PD need

to be improved. We suggest that the support for people with PD could be improved through setting a 'buddy' system linking experienced bereaved family caregivers to family members who are newer to the caregiving role.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethics approval was received from the medical ethics committee Arnhem-Nijmegen [file number; 2016-2424]. The bereaved family caregivers had received oral and written information about the study and had provided written and/or oral consent. To maintain confidentiality, we placed their names by pseudonyms in the documentation.

CONSENT TO PUBLISH

Consent for publication of the (anonymized) collected data was obtained by means of written and/or oral consent.

AVAILABILITY OF DATA AND MATERIALS

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

ACKNOWLEDGMENTS

We thank bereaved family caregivers who participated in this study and Marietta Eimers for transcribing one interview.

This study is funded by The Netherlands Organization for Health Research and Development (ZonMw) (Grant reference number 80-84400-98-086). Prof. Bastiaan R. Bloem was supported by a research grant of the Parkinson's Foundation. The funding party had no role in the design of the study, or in data collection, analysis or in writing the manuscript.

CONFLICT OF INTEREST

The authors declare that they have no competing interests.

REFERENCES

- [1] Bach JP, Ziegler U, Deuschl G, Dodel R, Doblhammer-Reiter G (2011) Projected numbers of people with movement disorders in the years 2030 and 2050. *Mov Disord* **26**, 2286-2290.
- [2] de Lau LM, Giesbergen PC, de Rijk MC, Hofman A, Koudstaal PJ, Breteler MM (2004) Incidence of parkinsonism and Parkinson disease in a general population: the Rotterdam Study. *Neurology* **63**, 1240-1244.
- [3] Lee MA, Prentice WM, Hildreth AJ, Walker RW (2007) Measuring symptom load in Idiopathic Parkinson's disease. *Parkinsonism Relat Disord* **13**, 284-289.
- [4] Higginson IJ, Gao W, Saleem TZ, Chaudhuri KR, Burman R, McCrone P, Leigh PN (2012) Symptoms and quality of life in late stage Parkinson syndromes: a longitudinal community study of predictive factors. *PLoS One* **7**, e46327.
- [5] Buter TC, van den Hout A, Matthews FE, Larsen JP, Brayne C, Aarsland D (2008) Dementia and survival in Parkinson disease: A 12-year population study. *Neurology* **70**, 1017-1022.
- [6] Hasson F, Kernohan WG, McLaughlin M, Waldron M, McLaughlin D, Chambers H (2010) An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. *Palliat Med* **24**, 731-736.
- [7] McLaughlin D, Hasson F, Kernohan WG, Waldron M, McLaughlin M, Cochrane B, Chambers H (2011) Living and coping with Parkinson's disease: perceptions of informal carers. *Palliat Med* **25**, 177-182.
- [8] Miyasaki JM, Kluger B (2015) Palliative care for Parkinson's disease: has the time come? *Curr Neurol Neurosci Rep* **15**, 26.
- [9] Coelho M, Marti MJ, Sampaio C, Ferreira JJ, Valldeoriola F, Rosa MM, Tolosa E (2015) Dementia and severity of parkinsonism determines the handicap of patients in late-stage Parkinson's disease: The Barcelona-Lisbon cohort. *Eur J Neurol* **22**, 305-312.
- [10] Goldsworthy B, Knowles S (2008) Caregiving for Parkinson's disease patients: An exploration of a stress-appraisal model for quality of life and burden. *J Gerontol B Psychol Sci Soc Sci* **63**, P372-P376.
- [11] Martinez-Martin P, Rodriguez-Blazquez C, Forjaz MJ (2012) Quality of life and burden in caregivers for patients with Parkinson's disease: Concepts, assessment and related factors. *Rev Pharmacoecon Outcomes Res* **12**, 221-230.
- [12] Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ (2013) Heterogeneity and changes in preferences for dying at home: A systematic review. *BMC Palliat Care* **12**.
- [13] van Groenou MIB, De Boer A (2016) Providing informal care in a changing society. *Eur J Ageing* **13**, 271-279.
- [14] World Health Organization (WHO), WHO definition of palliative care, <http://www.who.int/cancer/palliative/definition/en/>, Accessed February 11.
- [15] Lennaerts-Kats H, van der Steen JT, Vijftigschild Z, Steppe M, Meinders MJ, Munneke M, Bloem BR, Vissers KCP, Groot MM (2020) RADPAC-PD: A tool to support health-care professionals in timely identifying palliative care needs of people with Parkinson's disease. *PLoS One* **15**, e0230611.
- [16] Fox S, Cashell A, Kernohan WG, Lynch M, McGlade C, O'Brien T, O'Sullivan SS, Foley MJ, Timmons S (2017) Palliative care for Parkinson's disease: Patient and carer's perspectives explored through qualitative interview. *Palliat Med* **31**, 634-641.
- [17] Kluger BM, Fox S, Timmons S, Katz M, Galifianakis NB, Subramanian I, Carter JH, Johnson MJ, Richfield EW,

- Bekelman D, Kutner JS, Miyasaki J (2017) Palliative care and Parkinson's disease: Meeting summary and recommendations for clinical research. *Parkinsonism Relat Disord* **37**, 19-26.
- [18] Bouça-Machado R, Lennaerts-Kats H, Bloem B, Ferreira JJ (2018) Why palliative care applies to Parkinson's disease. *Mov Disord* **33**, 750-753.
- [19] Richfield EW, Jones EJ, Alty JE (2013) Palliative care for Parkinson's disease: a summary of the evidence and future directions. *Palliat Med* **27**, 805-810.
- [20] Giles S, Miyasaki J (2009) Palliative stage Parkinson's disease: Patient and family experiences of health-care services. *Palliat Med* **23**, 120-125.
- [21] Goy ER, Carter JH, Ganzini L (2008) Needs and experiences of caregivers for family members dying with Parkinson disease. *J Palliat Care* **24**, 69-75.
- [22] Fox S, Cashell A, Kernohan WG, Lynch M, McGlade C, O'Brien T, O'Sullivan SS, Timmons S (2016) Interviews with Irish healthcare workers from different disciplines about palliative care for people with Parkinson's disease: A definite role but uncertainty around terminology and timing. *BMC Palliat Care* **15**, 15.
- [23] Carter JH, Lyons KS, Lindauer A, Malcom J (2012) Pre-death grief in Parkinson's caregivers: A pilot survey-based study. *Parkinsonism Relat Disord* **18**(Suppl 3), S15-18.
- [24] Walker RW, Churm D, Dewhurst F, Samuel M, Ramsell A, Lawrie C, Hill J, Threapleton CJ, Wood B, Gray WK (2014) Palliative care in people with idiopathic Parkinson's disease who die in hospital. *BMJ Support Palliat Care* **4**, 64-67.
- [25] Lennaerts H, Groot M, Steppe M, van der Steen JT, Van den Brand M, van Amelsvoort D, Vissers K, Munneke M, Bloem BR (2017) Palliative care for patients with Parkinson's disease: Study protocol for a mixed methods study. *BMC Palliat Care* **16**, 61.
- [26] Smith JA, Osborn M (2009) Interpretative phenomenological analysis. In *Interpretative phenomenological analysis: Theory, method and research*, Flower P, Larkin M, Smith JA, eds. SAGE, Los Angeles, pp. 53-80.
- [27] Kafle NP (2011) Hermeneutic phenomenological research method simplified. *Bodhi* **5**, 181-200.
- [28] Smith JA, Osborn M (2015) Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *Br J Pain* **9**, 41-42.
- [29] Smith JA, Jarman M, Osborn M (1999) Doing interpretative phenomenological analysis. In *Qualitative Health Psychology: Theories and Methods*, Murray M, Chamberlain K, eds. Sage, London, pp. 218-240.
- [30] Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* **19**, 349-357.
- [31] Boeije H (2014) *Analyseren in kwalitatief onderzoek: Denken en doen [Analyzing in Qualitative Research: Thinking and doing]*, Boom Lemma Uitgevers, Den Haag, the Netherlands.
- [32] 't Hart H, Boeije, Hox J (2005) *Onderzoeksmethoden [Methods of Research]*, Boom onderwijs, Amsterdam, the Netherlands.
- [33] van der Meide H (2018) Niet coderen maar schrijven: Data-analyse in fenomenologisch onderzoek [Writing instead of coding: Data-analysis in phenomenological research]. *KWALON: Tijdschrift voor Kwalitatief Onderzoek* **23**.
- [34] Gobo G (2008) *Doing Ethnography*, SAGE, London.
- [35] Fusch PI, Ness LR (2015) Are we there yet? Data saturation in qualitative research. *Qual Rep* **20**, 1408-1416.
- [36] Government of the Netherlands, Euthanasia, assisted suicide and non-resuscitation on request, <https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request>, Accessed February 11.
- [37] Goy ER, Carter JH, Ganzini L (2007) Parkinson disease at the end of life: Caregiver perspectives. *Neurology* **69**, 611-612.
- [38] Miyasaki JM (2013) Palliative care in Parkinson's disease. *Curr Neurol Neurosci Rep* **13**, 367.
- [39] She WJ, Prigerson HG (2018) "Caregrieving" in palliative care: Opportunities to improve bereavement services. *Palliat Med* **32**, 1635-1636.
- [40] Hudson P, Hall C, Boughey A, Roulston A (2018) Bereavement support standards and bereavement care pathway for quality palliative care. *Palliat Support Care* **16**, 375-387.
- [41] Aoun SM, Rumbold B, Howting D, Bolleter A, Breen LJ (2017) Bereavement support for family caregivers: The gap between guidelines and practice in palliative care. *PLoS One* **12**, e0184750.
- [42] Guldin MB, Murphy I, Keegan O, Reverte MAL, Benkel I, Monroe B (2015) Bereavement services in European palliative care: A descriptive study by the bereavement taskforce of the European Association for Palliative Care. *Psychooncology* **24**, 23-23.
- [43] Breen LJ, Aoun SM, O'Connor M, Rumbold B (2014) Bridging the gaps in palliative care bereavement support: An international perspective. *Death Stud* **38**, 54-61.
- [44] Distelmans W, Bauwens S (2008) Palliative care is more than terminal care. *Belgian J Med Oncol* **2**, 19-23.
- [45] Eifert EK, Adams R, Dudley W, Perko M (2015) Family caregiver identity: A literature review. *Am J Health Educ* **46**, 357-367.
- [46] Li YQ (2007) Recovering from spousal bereavement in later life: Does volunteer participation play a role? *J Gerontol B Psychol Sci Soc Sci* **62**, S257-S266.
- [47] Carr DC, Kail B, Matz-Costa C, Shavit YZ (2018) Does becoming a volunteer attenuate loneliness among recently widowed older adults? *J Gerontol B Psychol Sci Soc Sci* **73**, 501-510.
- [48] Almgren BE, Grafstrom M, Winblad B (2000) Caregivers of relatives with dementia: Experiences encompassing social support and bereavement. *Aging Mental Health* **4**, 82-89.
- [49] Corey KL, McCurry MK (2017) When caregiving ends: The experiences of former family caregivers of people with dementia. *Gerontologist* **58**, e87-e96.
- [50] Sanders S, Ott CH, Kelber ST, Noonan P (2008) The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Stud* **32**, 495-523.
- [51] van Drielen E, Tummers RM, Brom L, Klinkenberg M (2019) Integraal Kankercentrum Nederland (IKNL).
- [52] Stichting Fibula, Het landschap van palliatieve zorg [The palliative care landscape], https://iknlsawebprod.blob.core.windows.net/mediacontainer/iknl/media/pdfs/palliatieve%20zorg/pznl_landschap_palliatieve_zorg.pdf
- [53] Kwak J, Wallendal MS, Fritsch T, Leo G, Hyde T (2014) Advance care planning and proxy decision making for patients with advanced Parkinson disease. *South Med J* **107**, 178-185.
- [54] Lum HD, Jordan SR, Brungardt A, Ayele R, Katz M, Miyasaki JM, Hall A, Jones J, Kluger B (2019) Framing advance care planning in Parkinson disease: Patient and care partner perspectives. *Neurology* **92**, e2571-e2579.

- [55] Tuck KK, Brod L, Nutt J, Fromme EK (2015) Preferences of patients with Parkinson's disease for communication about advanced care planning. *Am J Hosp Palliat Care* **32**, 68-77.
- [56] Tuck KK, Tarolli CG (2019) Palliative care and advance care planning in Parkinson disease. *Neurology* **92**, 1039-1040.
- [57] Walker RW (2013) Palliative care and end-of-life planning in Parkinson's disease. *J Neural Transm* **120**, 635-638.
- [58] Boersma I, Jones J, Carter J, Bekelman D, Miyasaki J, Kutner J, Kluger B (2016) Parkinson disease patients' perspectives on palliative care needs: What are they telling us? *Neurol Clin Pract* **6**, 209-219.
- [59] Kluger BM, Shattuck J, Berk J, Sebring K, Jones W, Brunetti F, Fairmont I, Bowles DW, Sillau S, Bekelman DB (2019) Defining palliative care needs in Parkinson's disease. *Mov Disord Clin Pract* **6**, 125-131.
- [60] Hassan E (2005) Recall bias can be a threat to retrospective and prospective research designs. *Internet J Epidemiol* **3**(2), <http://ispub.com/IJE/3/2/13060>.
- [61] Andrén S, Elmståhl S (2005) Family caregivers' subjective experiences of satisfaction in dementia care: Aspects of burden, subjective health and sense of coherence. *Scand J Caring Sci* **19**, 157-168.
- [62] Wawrziczny E, Antoine P, Ducharme F, Kergoat M-J, Pasquier F (2016) Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia* **15**, 1082-1099.