

Filling the gap in service provision. Partners as family carers to people with Parkinson's disease: A Scandinavian perspective

Chronic Illness

1–13

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Abstract

Objectives: The purpose of this study was to explore the expectations of and experiences with the public healthcare system of domestic partners of people with Parkinson's disease (PD) in Denmark and Norway.

Methods: A qualitative exploratory design was applied. The sample consisted of 14 people from Denmark ($n=9$) and Norway ($n=5$) living with a partner with PD. Semi-structured individual interviews were conducted between June and September 2020, digitally recorded, transcribed verbatim and analysed using a reflexive thematic analysis approach combining inductive and deductive approaches.

Results: The main themes were 'negotiating systems of support' and 'balancing being both a partner and a family carer'. Partners take responsibility for the people with whom they live and

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attempt to fill gaps in the public healthcare system. The most frequently described needs were more information, service coordination as the illness progressed and acknowledgement of the complex role.

Discussion: A recommendation for practice is recognition of the complex roles of partners to people with PD and reaching out to both regularly to determine needs. This may enhance the collaboration between partner carers, people with PD and healthcare providers, ensure sustainability of the system and optimise living with PD in the family.

Keywords

Parkinson's disease, family carer, caregiver burden, well-being, chronic illness

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Introduction

The experiences of family carers who live with people with Parkinson's disease (PD) are associated with challenges brought on by the disease.^{1–3} As the illness progresses, the person with PD becomes increasingly dependent on help; for many, the spouse or domestic partner becomes the primary family carer. This study investigates the experiences of partners serving as family carers to people with PD and their expectations of the public healthcare system in Denmark and Norway in that context.

PD is the second most common progressive neurodegenerative disease in the world⁴ and is characterised by the loss of dopaminergic neurons in the substantia nigra.⁵ Diagnosis is based on the presence of bradykinesia, tremor and rigidity.⁶ The functional decline of a person with PD is often linked to the presence of additional non-motor symptoms, such as sleep disturbance⁷ and cognitive decline.^{8–11} The trajectory of the illness varies, and the non-motor symptoms may be at least as disabling as the motor symptoms, seriously diminishing quality of life.^{6,12} PD symptoms can fluctuate on a daily or even hourly basis in an individual and thus require a range of caregiving approaches.²

Norway and Denmark are welfare states with a principle of universal health coverage regardless of geographic location, socioeconomic status, ethnicity and other factors. The

healthcare systems in Scandinavian countries are highly similar, with solidarity and equality as their ideological bases.^{13,14} A key characteristic is the fusion of welfare and work. The goals in the Scandinavian model are full-time employment and high taxes, which are important funding sources for health and welfare services.^{13–16} Most hospitals are publicly owned and funded. The primary care sector is strong and offers good access to general practitioners and other healthcare services; however, there are some geographical differences within both countries.^{13,16}

Residents of Scandinavian countries generally expect public health and social services to provide most of the care for family members who need it.¹⁷ However, the Norwegian and Danish welfare states have undergone transformations over the last 20 years, with the outsourcing and privatisation of services increasing. New public management reforms have been implemented, and patients and their family carers have not only gained more rights but also more responsibilities as recipients of health-related benefits.¹⁸ A strong emphasis on cost controls and efficiency has meant that healthcare professionals have to place a greater focus on goal-oriented and evidence-based work, including work process documentation.^{19,20} Increasingly, specialised caring tasks are the responsibility of healthcare professionals in the community,²¹ so it has become necessary for family carers

to take on a range of caring and helping tasks for which healthcare professionals were responsible in the past.

A person with PD obtains health-related benefits by having a family carer living with them, while society reaps substantial economic benefits.²² Delaying or avoiding formal state-supported home care or institutionalisation is cost-effective for healthcare service providers and governmental funding bodies. Several policy documents thus advocate the increasing involvement of families in care.^{23,24} These initiatives are based on arguments related to healthcare service sustainability and the premise that informal caregivers may contribute to achieving that goal.^{23,24}

Research indicates that family carers may adjust their lives according to the trajectory of a loved one's disease, as they consider it their responsibility to care for and support them.^{25,26} As the illness progresses, partners may become increasingly involved in care and tasks related to supporting the patient and following up on the illness, and they are therefore at risk of experiencing caring for their partners as a burden.^{2,27,28} Failing to manage this caregiving burden may lead to burnout of the family carer and institutionalisation of the person with PD.²²

Making multiple adjustments for patients and family carers are important factors influencing caregivers' quality of life.²⁹ Family carers describe needs like services to support them as caregivers in coping with lifestyle changes and maintaining their own well-being.^{1,30} However, research addressing partners' expectations of and experiences with the welfare models of Denmark and Norway is scarce.

By examining the experiences of living with a person with PD as a partner in the welfare state models of Norway and Denmark, this study adds to the existing literature on caregiving by addressing the partner as family carer's perspective on healthcare provision as it is experienced in welfare states.

Materials and methods

Design

A qualitative exploratory design with semi-structured individual interviews was used, followed by a thematic analysis combining inductive and deductive approaches.^{31,32} The manuscript followed the consolidation criteria for reporting qualitative studies (COREQ).³³

Setting and sample

This interview study is part of the qualitative phase of the OPTIM-PARK study, a sequential mixed methods feasibility study conducted in Denmark, Norway, Spain and the United Kingdom. The OPTIM-PARK study aims to develop and evaluate an intervention to enhance the experience of living with PD for people with the disease and their family carers.³⁴ Qualitative interviews were conducted with people with PD, family carers, healthcare professionals, stakeholders and representatives from volunteer organisations across all four countries as part of the development of the intervention.^{35,36} This sub-study encompasses qualitative interviews with partners serving as family carers of people with PD in Denmark and Norway.

Recruitment to the study

In Denmark, family carers were recruited by sending information about the project to local units of the Danish Parkinson's Association. Subsequently, people could register to receive information and sign consent forms to participate. In Norway, family carers were recruited online and consented to participate digitally based on information provided via the Norwegian OPTIM-PARK website, social media and advertisements through the national branch of the Norwegian Parkinson's Association. Inclusion criteria for the present study were as follows: having a partner with PD, being able to give informed consent,

willing to participate and able to communicate orally in a Scandinavian language. In both countries, the interviewers contacted the participants and arranged the interviews.

Data collection

Data were collected from June to September 2020. Semi-structured interviews were conducted using a guide containing open-ended questions (Appendix 1). The interview guide was developed for the OPTIM-PARK project based on cross-national discussions, consultations with patient and public involvement (PPI) groups and a review of existing support services.³⁷ The complete cross-national findings from interviews with people with PD and all family carers are reported in a separate paper³⁵; this current paper focuses strictly on partners serving as carers in Denmark and Norway.

Four female researchers (EGH, HRS, SBH, and LKB) who were unknown to the participants conducted the interviews. All the researchers are trained professional healthcare personnel and had experience with qualitative interviews. The interviews were conducted face to face ($n=2$), by telephone ($n=10$) or via video conference ($n=2$), based on participant preference, enabling participation from different regions in each country and allowing the research to be conducted in accordance with Covid-19 restrictions.³⁸ The interviews, which lasted from 56 to 67 min, were recorded and transcribed verbatim.

Data analysis

Both inductive and deductive thematic analysis were applied to identify, analyse and describe essential themes in the interviews. For coding, familiarisation and thematic analysis, Braun and Clarke's^{31,32} six steps were followed: (1) familiarise yourself with your data; (2) generate initial codes; (3) search for themes; (4) review themes; (5) define and name themes and (6) produce the report.

To become familiar with the data, the researchers read the text iteratively while extracting and noting relevant sentences or paragraphs. All interviews were transcribed in the participant's language, Norwegian or Danish, languages that are mutually intelligible. A detailed analysis of each interview was conducted to generate the initial codes, first separately by EGH in Norway and HRS in Denmark. The initial codes were then compared between countries, and tentative themes were discussed and agreed.

Second, a deductive approach was applied with a focus on relevant topics addressed by partner family carers. The next step was to collate the themes and codes and group them into overall themes and subthemes. The themes were discussed and reviewed iteratively by all the authors. When consensus was reached (Figure 1), the first (EGH) and second (HRS) authors drafted the interpretations of the findings and discussed them with all the authors through a sequence of video conferences until agreement was reached.

Ethical considerations

This study obtained the necessary approval from the Norwegian Centre for Research Data, reference number 986940. No ethical approval was necessary for the Danish part of the study. All participants were informed about confidentiality regulations and their right to withdraw from the study for any reason at any time. Subsequently, all participants provided informed consent to participate before the interviews began.

Patient and public involvement

PPI groups in the OPTIM-PARK study consisted of people with PD, family carers, healthcare professionals, stakeholders and representatives from volunteer organisations. The PPI representatives participated in the design of the study, in the development of the

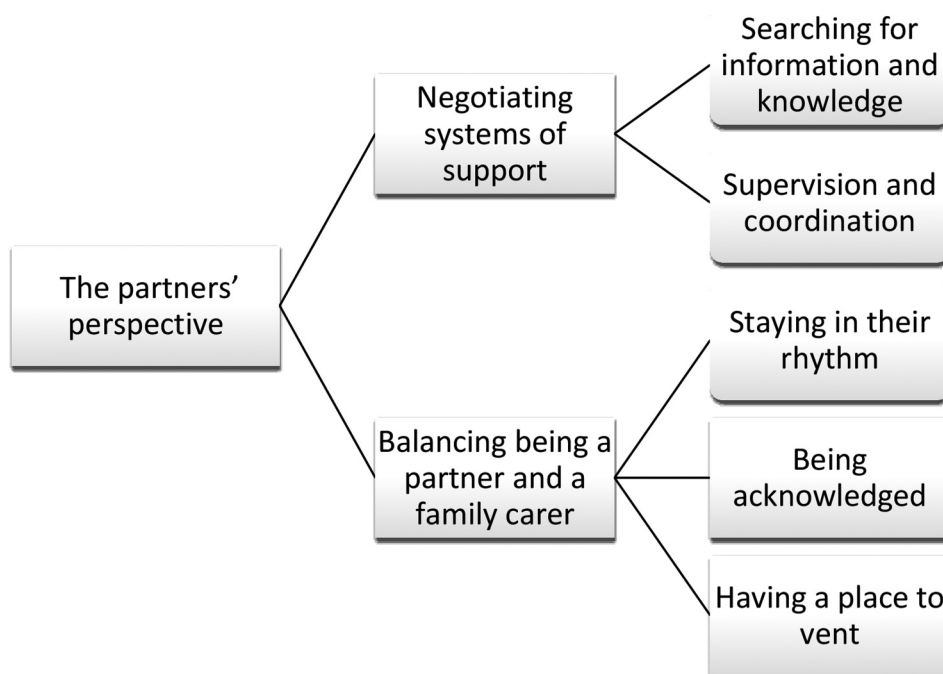


Figure 1. Themes and subthemes.

interview guide and in discussions and validation of the findings.

Results

The sample consisted of 14 partners who served as family carers for people with PD: five from Norway and nine from Denmark (age range: 51–84). The duration of their relationships varied from 2 to 18 years. Four partners were working; the rest were retired or receiving a disability pension, and 11 had health challenges of their own. The participants were numbered P1 to P14 to ensure anonymity. The characteristics of the participants are shown in Table 1.

Partners' perspectives

The partner carers described diverse experiences. Regardless of country of residence, the main disparities between the participants'

experiences related to the illness stage of the person with PD, with challenges increasing as the illness progressed. Two main themes and five subthemes were developed in the analyses; they are presented in Figure 1.

Negotiating systems of support. The partner carers described how they became not only essential helpers but also informal managers for their partners due to the lack of an established pathway for follow-up of partners with PD. They took on the role of seeking and assessing information and coordinating services through which they filled in the gaps between their partners' needs and the services provided by the healthcare system.

Searching for information and knowledge. Information needs were prevalent at all stages of the illness, and a contact person, either in the hospital or the municipality, was called for to help navigate the information flow. The

Table 1. Sociodemographic data.

Participant	Sex	Age	Years of having a partner with Parkinson's disease	Work situation	Own health challenges
1	Female	51	18	On disability benefit	Yes
2	Female	54	2	Full-time work	No
3	Female	58	2	Full-time work	Yes
4	Male	58	7	Full-time work	Yes
5	Male	58	7	On disability benefit	Yes
6	Male	71	15	Retired/part-time work	No
7	Female	71	2	Retired	Yes
8	Female	73	16	Retired	Yes
9	Female	73	7	Retired	Yes
10	Female	73	11	Retired	No
11	Female	75	8	Retired	No
12	Female	75	10	Retired	Yes
13	Male	76	12	Retired	Yes
14	Male	84	3	Retired	Yes

partner carers described a lack of knowledge about existing services and explained that they largely received the help they asked for, but they often did not know what to ask for or even whom to contact.

A common wish was for someone from the public healthcare system to provide information or relieve them of the stress of keeping track of everything: *'Just to know from one person whom we should turn to would be of great help'* [P13]. A more specific source of frustration was navigating the public healthcare system for services. The partner carers needed to be proactive: *'Yes, mmm, but you also have to ask for everything. It's kind of nothing, no unsolicited information is provided; you really have to be proactive to find it'* [P5].

At the time of diagnosis, some expressed a great need for information about the disease, its consequences and the medications to manage it, whereas others expressed that avoiding information overload was a deliberate strategy to maintain a sense of normality. However, as the illness progressed, the need

for information about services and help increased. The partner carers indicated that information distributed by healthcare services, in which all the services and contact information were provided, would be helpful:

'Get good advice in advance so that if something changes, you know how to respond. One thing that I think is important – when you first make contact, no matter how or when, it's much easier to make contact again' [P11].

In the absence of or in addition to information provided by professionals, the internet was frequently used as a resource. The advantage was that there were always people available to talk to online; however, the information and advice caregivers received could be overwhelming and even frightening.

Supervision and coordination. The partner carers described how they had to keep pushing and monitoring the healthcare system to avoid mistakes and ensure that their loved ones received the right examinations and

treatments. One participant explained this coordination role as follows: *'You can say that I'm the government, I'm the minister of finance and the minister of labour, and that whole government group'* [P3].

While different health professionals shared information with the person with PD and the partner carer, information was rarely shared among the different sectors of the healthcare service. Partner carers reported that professionals were organised in silos that operated separately from one another:

'If the professionals can talk together – "ok, now we discuss this patient, then we talk about him and then we give feedback" – like that, instead of them [professionals] sitting in their respective places and sending the medical record back and forth; there's no focus and progress in any way' [P11].

As a result, the person with PD or partner carer had to convey information between the different service providers. In several cases, the carers expressed a great need for information about what they should do to help handle symptoms and medication side effects. The uncertainty of when they would be able to address these challenges with a healthcare professional added to their worries. As one participant elaborated, *'Sure, you're told to come back for a consultation in six months, but you won't get to know exactly when'* [P12].

The partner carers found that when it was finally time for a consultation, the number of questions had built up, the time spent with the neurologist felt too short, and the problems that people with PD commonly experience when expressing themselves were not considered: *'There's a doctor who says a lot of things, but they often don't have time to listen to what my husband wants to tell them because he's slow. But Parkinson's makes you slow, so...'* [P8].

Balancing being a partner and a family carer. The interviews gave the impression of people who

went to great lengths to help and support their loved ones. They adjusted to the changes that occurred and to the fluctuating needs of the person with PD, simultaneously balancing being partners and family carers. They lacked recognition from the public health services but found support from other family members, friends or peers to cope with their new roles.

Staying in their rhythm. The partner carers expressed that flexibility in the way they organised their everyday lives and plans was important in adapting to the daily variations in PD partners' function. Maintaining a positive spirit and a balance between optimism and realism was important, and taking one day at a time was a common coping strategy: *'We've decided that this is the day we have; it's today we're alive, and we'll enjoy this day'* [P12]. The partner carers tried to stay active, focus on problem solving and, as one put it, stay in the *'rhythm'* of the person with PD [P5]. In some instances, the adjustments were small, such as changing the lighting in the living room; in another case, one partner declined a rehabilitation stay for her own illness because her partner with PD was reluctant to be left home alone.

The unpredictability of PD as an illness, including cognitive challenges, personality changes and sleep problems, required the caregivers to be constantly attentive and adjust their lives to the needs of the person with PD: *'But you never know when a situation arises ... that's what I mean; you don't know which man is present [at any given time]'* [P7]. It was difficult for the caregivers to prepare for the unknown and make firm plans of their own; if they did, they had to be prepared for sudden changes in those plans.

The partner carers' roles involved being supportive, taking over tasks, making adjustments to planning for future problems and, for many, ignoring their own needs:

'Everyday life is about being considerate and always being available. Be patient, very

patient and set yourself to the side a bit. That's my daily life' [P1].

The reason for suppressing their own feelings and needs was that they perceived their partners' needs to be more important than their own. However, some expressed that it could feel both heavy and unfair to bear the entire burden of making the partnership work:

'I'm thinking, should I bear the entire burden? You know what I mean? I should always be the supportive and calm one. I sometimes feel that I'm a little angry myself. Not like it affects anything, but sometimes I get a little discouraged' [P3].

The slow progression of the disease was positive in the sense that partner carers had time to adapt to the changes and maintain as normal a life as possible. On the other hand, the person with PD's gradually increasing need for help made it difficult to identify the point at which the burden became overwhelming:

'When I think back now, I see that I'm very limited compared to a few years ago, but it progresses so slowly that you don't suddenly get that kind of shock; oh, God, is this how it is for me now? It's terrible' [P11].

Being acknowledged. When the partner carers attended consultations, the focus was on how the person with PD was doing. As the illness progressed, the need for help increased accordingly, which also restricted the partner carers' lives, but most caregivers did not experience being asked how they were doing: *'It means something to have someone like that. It's common to ask the person who's ill, "How are you, and how is it going?" But the caregivers, they're not acknowledged' [P11].* This caregiver elaborated, *'I don't want anyone to feel sorry for me. That's awful; it is. Because it's not pity for me. But at the same time, I'd like someone to ask me how I'm doing'.*

Several participants indicated that their efforts were taken for granted by formal caregivers. For example, in most cases, it was expected that the partner carer would drive the person with PD to appointments, even if that meant taking time off work: *'Sometimes, I have to take time off work to attend meetings. It's not like I don't want to do it, but it's just one more thing I have to do' [P12].*

Having a place to vent. Support in coping with the partner carer role was commonly sought and found through family networks, the Parkinson's Association or through their own initiatives to find peers, typically through social media. The partner carers appreciated having someone to talk to, regardless of whether or not those interlocutors had any particular or expert knowledge of PD. Close family and friends were often cited as important individuals in these networks.

At the same time, it was important for partner carers to maintain what they considered normal relationships with their family and friends. This involved not always asking them for help with practical problems and not sharing all their problems with those who also knew and had relationships with the person with PD. Support from someone neutral or a professional was valued. This could be an individual who understood the challenges of the disease or a therapist with experience in helping clients cope with challenging life situations:

'It's like you're saying that if you could've talked to someone the way I'm talking to you now, it's recognisable to the recipient, then they can compare it to something familiar: "Oh, this is perfectly normal". So, I wouldn't think I'm all alone. It's just to have someone [to talk to]' [P11].

Peer support groups were important arenas for venting frustration, sharing experiences and seeking support outside the family, friends or formal healthcare. The Parkinson's

Association webpages or Facebook groups were regarded as good starting points for meeting peers who shared caregiving experiences. After meeting through digital channels provided by the Parkinson's Association, partner carers could form personal networks:

I found a support group. I thought I would go crazy. It was worth its weight in gold. There, we can share our experiences and support one another. I might have some blowouts, meet others and not feel completely alone because I'm in the same situation as the others' [P1].

Discussion

Summary of main findings

This study highlights key aspects in the experiences of partners of people with Parkinson's disease in Denmark and Norway and their expectations of the public health care system. Partners take on caregiving responsibilities for the people with whom they have built lives and often families and attempt to fill the gaps in the public healthcare system. The most frequently described unmet expectation from healthcare services was a lack of information. The partner carers sought information from healthcare services to understand, help and support their partners with PD. They expected the information regarding services to be more routinely presented as a menu of what could be useful to them. This view does not accord with the guidelines from the health authorities, in which the partner or other family carer is expected to take on the responsibility for non-specialised tasks, including finding out about available services.^{23,24} The public welfare systems in Denmark and Norway are not built around the idea of advertising and encouraging the use of services but are based instead on parsimony: that is, the use of services should be determined by what is needed.¹⁵ Consequently, the system is not transparent to users, and help is generally

not offered in advance. This may result in less use of the services that are available because some potential users do not know they exist.

The substantial strain placed on family carers identified in previous research^{18,19,24} was also found among the partner carer participants in the present study and may involve issues with coordination, medication administration, prompting for self-care, communication and advocacy on behalf of loved ones, surveillance of falls and provision of emotional support.^{22,25} The experienced obligation to support and help their partners may place stress on partner carers and compromise their self-care. Most of the partners had health challenges of their own that they downplayed or even ignored. Theed et al.³⁹ found that the need to provide care may be the primary focus of caregivers and influence decisions about their own lives, and burnout among family carers may cause premature institutionalisation of people with PD.²² Ageing in place is a goal of both the Danish and Norwegian welfare models, as it involves substantial cost savings for the state over institutionalisation in nursing homes.^{23,24} Supporting and helping family carers to cope with various tasks should therefore be an intermediate goal to ensure a sustainable welfare system. Instead of the partner being in charge of all follow-up, however, our participants expressed the need for a central coordinator or navigator to offer help as the illness progressed, challenges increased, and the need for services rose accordingly.

As partners and family carers, the interviewees wanted to be acknowledged by the healthcare system as part of the treatment course. However, this is not the same as assuming that partners do not have any needs of their own or do not find their responsibilities problematic or even overwhelming. The need to be seen, recognised and supported was found in the present study as it was in previous research.^{1,3,24} The partner carers were proactive and did what was necessary to try to

maintain normality in their lives, staying focused on the present and keeping pessimistic thoughts regarding the future at a distance. In line with the findings in Haahr et al.,²⁶ partners put the needs of the person with PD ahead of their own and were deeply involved in their partners' illnesses. The partners acknowledged their marital commitments, demonstrated acceptance and adjustment and made efforts to control their emotions in order to avoid upsetting their partners while experiencing disruptive emotions.^{26,40}

The partner carers turned to friends and other family members for support. However, to ensure normal relationships with family and friends, the partner carers described how they found it inappropriate to ask family or friends for help with practical tasks. They felt that this should be the responsibility of the public healthcare service. This notion of finding it easier to ask the healthcare service rather than family or friends for help may be due to cultural differences between countries that favour a family-oriented model (e.g. Spain) and Scandinavian countries, which use the welfare model.¹⁵ The partner carers expressed that they expected to receive the help they needed automatically from the public healthcare system, without having to ask for it, as a kind of readily available safety net. However, as this view did not fit with the goals and guidelines of the welfare state,²⁴ this expectation was not met and led to disappointment with the services. This may contribute to the notion of partners struggling to completely accept the caregiving role. These expectations of the provision of services might be more profound because they are related to the family carers' expectations of the welfare state and the idea of getting value for all the taxes paid over the years.^{15,41} Within the Scandinavian welfare model, which legitimates high taxation by the provision of a high-standard universal healthcare system, partners may feel reluctant to fully embrace all the emerging caregiving expectations and adjustments.

The trend of transferring care to the families of people with chronic conditions may cause a strain on those assuming caregiving roles; when the family carer is the life partner of the person with PD, expectations may become overwhelming. Recognising that there may be a mismatch in expectations between family carers' involvement in the healthcare system and their actual motivation and resources to handle the burden is crucial to ensuring sustainable cooperation between the public healthcare sector and families.

Strengths and limitations of the study. The sample consisted of partners who voluntarily self-recruited to participate in the project. This may have resulted in a sample that was particularly opinionated or had challenges they wanted to express. Merging the sample from two countries may have reduced this potential limitation, as the number of participants increased, and the different recruitment strategies used in Denmark and Norway may have led to a more heterogeneous sample.

This is a sub-study of a larger study focusing on the experiences of family members living with and caring for people with PD. Perspectives from other family carers, such as adult children, are covered in a separate cross-national paper from the OPTIM-PARK project.³⁵ The interview guide was developed to obtain knowledge regarding available services and cooperation between different services and service levels, and none of the questions focused specifically on the burden of partners as carers (as opposed to, say, adult children in that role). However, the interview guide and the researchers' choice to use open-ended questions enabled enough flexibility to allow topics that emerged during interviews to be explored.

The sample in the present study includes partners of people with PD with a broad range of characteristics and experiences as family carers and partners. This, along with the progressive nature of the disease, meant different caregiver experiences and burden levels

among participants. The progressive nature of PD may also have led to changes in symptom burden during the study period. The interviews were conducted in Norwegian and Danish, with quotes translated into English. Some of the quotes were challenging to translate because of the use of language-specific expressions and incorrect grammar, which entailed a risk that nuances were lost. To limit elements from getting lost in translation, several of the paper's authors verified the translations.

Conclusions and implications for future research and clinical practice. This study provides a rich description of the many challenges and needs related to the role of partner carers of people with PD. Healthcare services must recognise the complexity of being both partners and family carers for people with PD to improve the collaboration between partners, people with PD and the healthcare system. A recommendation for practice is to be more proactive towards partners as family carers by recognising their particular burden and reaching out to them regularly throughout the illness trajectory to determine and respond to their needs.

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Authors' contributions

All the authors (EGH, HRS, AH, SBH, DS, MVNS, MCP and LKB) made substantial contributions to this work. The study was conceptualised by EGH, HRS, AH, SBH, DS and LKB. EGH and HRS were in charge of the analysis and drafting of the manuscript. All authors critically reviewed the analyses and provided comments on the first draft. The content of the manuscript was discussed and determined in close collaboration with all authors. All authors critically revised subsequent drafts and approved the final draft to be submitted.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethical approvals

This study obtained the ethical approval necessary from the relevant ethics committees. (Norway: Norwegian Centre for Research Data reference number: 986940).

Guarantor

EGH

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Informed consent

Written informed consent was obtained from the participants for their anonymized information to be published in this article.

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Supplemental material

Supplemental material is available online for this article.

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