

Perspectives of people with Parkinson's disease and family carers about disease management in community settings: A cross-country qualitative study

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Abstract

Aim: To explore perceptions of people with Parkinson's disease and family carers about the use and impact of health and social care services, community and voluntary sector resources for the management of Parkinson's disease.

Background: Resources from outside the formal health care system and collaborations between different levels and sectors could address the unmet needs of people with Parkinson's disease and their family carers and improve the management of Parkinson's disease in the community setting.

Design: A qualitative exploratory study was carried out in Denmark, Norway, Spain and the United Kingdom and was reported using the COREQ.

Methods: Individual semi-structured interviews were conducted with people with Parkinson's disease and family carers between May and August 2020. Interviews were digitally recorded, transcribed verbatim and analysed using thematic analysis. A meta-ethnographic approach was used to analyse and synthesise cross-national findings.

Results: Forty-seven people with Parkinson's disease and 39 family carers participated in the four countries. Four themes and eight sub-themes emerged: (1) Personalised care for needs throughout the Parkinson's disease journey; (2) Accessibility of different types of support systems (including initiatives to support emotional well-being, physical rehabilitation, information on the healthcare services, voluntary associations and community groups); (3) Multiagency collaborations, a more comprehensive

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approach; (4) Acknowledgment of people with Parkinson's and family carers own role in Parkinson's disease management.

Conclusions: An integrated and person-and-community-centred approach, which includes the participation of the health, social, voluntary and community sectors, is desired by people with Parkinson's disease and their family carers to improve the management of Parkinson's in the community setting. These findings could contribute to the creation of more sustainable care systems at the European level that would better respond to individual and changing needs in people with Parkinson's disease and their family carers, and in other long-term conditions.

Patient or Public Contribution: The Patient and Public Involvement groups contributed to the design of the study, the interview guides and validation of findings.

Relevance to Clinical Practice: This study will inform the management of Parkinson's disease at the community level and the use of resources not only directly linked to the health system. Taking into account all the actors that provide care and support to people with Parkinson's disease and family carers facilitates the creation of strategies that better respond to individual needs. Nurses and other health and social care professionals in the community and specialist levels of care should collaborate to develop multisectoral strategies that promote personalised and integrated care throughout the Parkinson's journey.

KEYWORDS

integrated care, long-term conditions, management, multisectoral action, nursing, patient experience, Parkinson's disease, patient involvement, personalised care, qualitative research

1 | INTRODUCTION

Parkinson's disease (PD) is one of the most common neurological disorders, and its prevalence has doubled in the last 25 years to reach more than 6 million people in the world (The Lancet Neurology, 2020). This rapid growth also corresponds to an increase in disability and mortality in the Global Burden of Disease (GBD) of 2015 with no clear relationship with increased life expectancy, geographical location, or early diagnosis (GBD 2016 Neurology Collaborators, 2019). To face this challenge, in addition to efforts to prevent the disease, improving living conditions and access to treatment and services for people with PD (PwPD) should be the priority (Dorsey & Bloem, 2018).

The complexity and progressive nature of PD are well documented. Among its consequences, non-motor symptoms (NMS) and psychosocial needs constitute a significant burden for patients and families and are the main causes of hospital admissions and decreased quality of life (QoL) (Chen, 2010; Rutten et al., 2021). Studies concerning the economic burden of the disease highlight the increase of indirect costs (in terms of loss of productivity), intangible (psychosocial costs) and personal costs (incurred by the patient and/or their family, when there is no support from private and/or public health care), increasing from 33%–61.5% (Bovolenta et al., 2017; Yang et al., 2020). Health related quality of life has been found to be poor in PwPD and their family carers and is associated with markers

What does this paper contribute to the wider global clinical community?

- Integrated care involving collaboration between health, social, community and voluntary sectors, and person-centred pathways, with the participation of people with Parkinson's disease (PwPD) and their family carers, are key elements in the management of Parkinson's disease (PD).
- Personalised care throughout the disease journey, greater accessibility of support, comprehensive care and acknowledgment of PwPD's and family carers' own role in PD management could be advantages of this multi-sectoral approach according to people with Parkinson's disease and family carers from Denmark, Norway, Spain and the United Kingdom.

of advancing PD severity, lower physical activity, higher depression severity and increased NMS, which affects their everyday life and the ability to manage and cope with PD (Lubomski et al., 2021). Thus, coping strategies and appropriate community resources for self-management in their day-to-day life could contribute to improving or alleviating the impact of the disease progression on patients

and families, enhance their QoL (Todorova et al., 2014), and reduce the majority of costs, which normally originate from outside the formal health care system (Chen, 2010). Collaboration between different levels (primary care, neurologists, stakeholders) and different sectors (health and social sectors, voluntary organisations, local community resources) is suggested to anticipate future health complications and improve coping skills (Fabbri et al., 2020).

1.1 | Background

Optimisation of community resources and implementation of multilevel and multisectoral approaches have provided broader forms of support in long term conditions (LTCs) (World Health Organisation, 2014), complimenting those in health services, promoting social support, sense of belonging and wellbeing and with a particular impact on deprived communities (Portillo et al., 2017). However, coordination between levels of actions and sectors is not clearly established, and the lack of acknowledgment, synchronisation and a shared agenda can lead to the overlapping of activities, limited use of community resources and gaps in action-planning (Portillo et al., 2015, 2017; World Health Organisation, 2014).

Most PwPD and their families describe wanting to feel in control of their disease, gaining power through information and resources provided by the health sector, but also in other sectors to address unmet needs (Wieringa et al., 2022). Among these unmet needs, therapeutic needs, including information about the effects, use and side effects of medication and ways to cope or nutritional changes and healthy eating strategies, are the highest (Lee et al., 2019). Therapeutic needs are followed by social/spiritual/emotional needs, need for certainty and physical needs (Lee et al., 2019; Navarta-Sánchez et al., 2017). Participation in support groups for PD or applying for community resources/financial assistance, long-term planning according to clinical status or challenges in the marital relationship, information about symptom management or about finding and applying for transportation services, are some of the expressed needs in these categories (Champagne & Muise, 2022; Lee et al., 2019; Tuijt et al., 2020).

However, different studies have highlighted the barriers that PwPD and their families encounter when it comes to accessing resources that could help them in the management of the disease. A key barrier could be the lack of coordination between different organisations and types of support (Zaman et al., 2021). For example, when information and resources are not provided by professionals, PwPD and their families may turn to online communities to find them (Chu & Jang, 2022), with a lack of coordination or support around which resources are most beneficial for each individual. Lack of access to face-to-face support for PwPD, may also lead to increased isolation and vulnerability, as shown during the Covid-19 pandemic (Soilemezi et al., 2022). The pandemic has raised barriers in access to care for disadvantaged populations, that in the present study are defined as immigrants and/or those from an ethnic minority background, older people, the socially vulnerable, those living with disabilities due to

long-term conditions and family carers. Online communities, on the other hand, helped to maintain social connections, which highlights the need to provide personalised and flexible support (Soilemezi et al., 2022). Personalised medicine and self-management have been posited as an important change in management of conditions such as PD, which is more than a genetic based approach and includes holistic strategies spanning genes, clinical subtypes, personality, lifestyle, ageing and comorbidities (Titova & Chaudhuri, 2017; van Halteren et al., 2020). This framework calls for a holistic, multidisciplinary and participatory approach to PD management. Multisectoral interventions could support and enhance the autonomy and QoL of PwPD and their families and should include a true dialogue between sectors and levels, placing PwPD at the centre of the decision making process.

The aim of this study was to explore perceptions of people with Parkinson's disease (PwPD) and family carers (FCs) about the use and impact of health and social care services, community and voluntary sector resources for the management of Parkinson's disease in different European countries. Specifically, the research questions were:

- What role do different organisations (health and social care services, community and voluntary organisations) have in the management and daily life of Parkinson's and the care of people with Parkinson's from the perspective of PwPD and FCs?
- What systems of support and community resources are PwPD and FCs aware of for the daily management of Parkinson's?
- How accessible are health and social care services, community and voluntary sector resources for PwPD and FCs?
- How would PwPD and FCs like to receive support or access different resources in the community to help manage Parkinson's?

2 | METHODS

2.1 | Design

A qualitative exploratory study has been conducted, as the first phase of a mixed methods sequential study aimed to improve life with PD for patients and family carers by designing multisectoral care pathways to optimise the use of community resources in four European countries: Denmark, Norway, Spain and the United Kingdom (titled OPTIM-PARK project). This project provided findings for the development stage of The UK Medical Research Council framework for developing and evaluating complex interventions (Skivington et al., 2021)

The study was reported using the Consolidated criteria for reporting qualitative research (COREQ) (see Appendix S1) (Tong et al., 2007).

2.2 | Participants

Participants were PwPD and their FCs living in community settings. We used purposive sampling to ensure diversity of participants in

terms of age, sex, education, employment status, income, length of diagnosis and marital status. In addition, we also selected certain areas, which may be more disadvantaged to reach participants with vulnerable conditions (in terms of location, education, living with other health conditions, employment status, ethnicity and income).

1. The inclusion criteria for PwPD were: living at home, Hoehn & Yahr stage 1–4, cognitively able to participate, at different stages of PD (early, mid, later by years of diagnosis) and of all ages. We excluded hospitalised patients; patients diagnosed with PD <6 months ago to confirm the diagnosis and to allow them to have time to use the resources for PD patients; unwillingness to participate; living in nursing homes; not being able to communicate in and understand the language of the participating country.
2. The inclusion criteria for FCs were: caring for a relative with PD at different stages (early, mid, late), including those caring for patients with cognitive impairment. We excluded those not able to communicate in and understand the language of the participating country, and not being involved in direct care or support of PwPD. FCs did not need to have the person they care for also participating in the study and vice-versa.

The research team recruited PwPD and FCs who met the inclusion criteria through three main strategies:

- Healthcare services: PD specialist clinicians, PD specialist nurses, Primary Care health professionals.
- Community organisations and groups: Parkinson's disease national and local support groups, other local organisations, or groups with PwPD as members.
- Other strategies: adverts through social media (Facebook), local pharmacies, local media, other Parkinson's trusts or foundations.

A total of 86 participants (47 PwPD and 39 FCs) were interviewed in the four countries (Tables 1 and 2). There was a balance between women and men in the PwPD (49% women; 51% men) but not in the FCs group (70% women; 30% men). The average age was 62.2 among the PwPD and 59.5 among the FCs. The marital status was mostly married or in a civil partnership among PwPD and FCs in all four countries with 78.7% and 71.8%, respectively. Regarding work status, 61.7% of the PwPD were retired from paid work. As for the FCs, they were in full time paid work (33.3%), retired from paid work (25.6%) and long-term sick/disabled (17.9%). The PwPD had an average of 7.7 years living with their disease. When asked about their health perception on a scale of 1–10 (10 is an excellent perception of health), patients reported an average of 6.2. Only 36.2% of PwPD received any financial support due to disability. Regarding FCs, most were spouses (82%) with an average caring time of 9.2 years but sharing the experience of PD for 14.2 years.

2.3 | Data collection

Semi-structured individual interviews were performed in all four countries, supported by an interview guide (Table 3) co-developed by the research team and the Patient and Public Involvement (PPI) groups in Spain and the United Kingdom. Interviews were carried out by twelve researchers with extensive experience between May–August 2020, lasted between 23 and 120 min (on average 70 min), were digitally recorded and transcribed verbatim. No relationship was established between researchers and participants prior to the start of the study. No participant withdrew from the study.

The intention was to conduct the interviews face-to-face ($n = 18$), although due to the Covid-19 pandemic, most had to be carried out over the phone ($n = 55$) and by video conference ($n = 13$). At the time of data collection, there were no longer any lockdown measures, but there were restrictive recommendations regarding social gathering and social distancing in all four countries. All participants were asked to complete a socio-demographic form.

2.4 | Ethical considerations

Ethical approval was obtained from the required ethics committees (University of Southampton IRAS number: 265184; Research Ethics Committee in Hospital Universitario La Princesa number: 3995; Norwegian Centre for Research Data reference number: 986940). All participants were informed about the aim of the study, the methods and the plans to maintain the participants' confidentiality and anonymity. All participants signed an informed consent form. Interviews data (audio files, transcripts) were stored in a protected database and anonymised prior to analysis.

2.5 | Data analysis

We conducted a thematic analysis (Braun & Clarke, 2006) of the interviews, combining deductive and inductive approaches (Braun et al., 2016; Fereday & Muir-Cochrane, 2006; Nowell et al., 2017; Roberts et al., 2019). The analysis began with an inductive thematic analysis of the full transcripts of the PwPD interviews from Spain and FCs interviews from the United Kingdom. Multiple readings of the interview transcripts were developed by two researchers from these two countries. Initial codes were attributed to the data through this process. Upon reflection of the initial codes, themes began to emerge. This stage provided an opportunity to refine the analysis of the initial ideas and codes, at the broader level of themes. The themes were then reviewed and named and included in a report along with the codes and quotes.

This report provided an exemplar framework of analysis connected to the research questions that the other participating countries (Denmark and Norway) could follow, thus using a deductive approach. However, the framework of analysis allowed teams to add

TABLE 1 Description of people with Parkinson's sample in all countries and cross-national

		UK	Norway	Denmark	Spain	Cross-national
Male, n (%)		6	7	5	6	24 (51)
Female, n (%)		5	8	6	4	23 (49)
Age, mean (min-max)		65.1 (49-83)	61 (45-73)	67(53-79)	55.8 (44-63)	62.2 (44-83)
Marital status, n (%)	Widowed	3			1	4 (8.5)
	Married or in a civil partnership	8	10	10	9	37 (78.7)
	Divorced		2			2 (4.3)
	Living with partner		3			3 (6.4)
	Single			1		1 (2.1)
Work situation, n (%)	Retired from paid work	8	6	7	8	29 (61.7)
	Full time paid work (30+ hours/ week)	3	2	2	1	8 (17)
	Looking after home/ family (full time)				1	1 (2.1)
	Long-term sick/disabled		6			6 (12.8)
	Part time paid work (8-30h/ week)		1			1 (2.1)
	Other			1		2 (4.3)
Income ^a , n (%)	Higher	5	4	3	4	16 (34)
	Average			3	1	4 (8.5)
	Lower	6	11	5	5	27 (57.5)
Area type, n (%)	Urban	4	8	4	9	25 (53.2)
	Semi-rural/suburban	2	3	5	1	11 (23.4)
	Rural	5	4	2		11 (23.4)
Live with, n (%)	Partner and child(ren)	6	12	10	7	35 (74.4)
	Partner	3	1		2	6 (12.8)
	On own	2	2	1		5 (10.6)
	Child(ren)				1	1 (2.2)
Years with PD, mean (min-max)	6.3 (0.5-13)	6.7 (1-22)	7.8 (1-18)	9.8 (3-17)	7.7 (0.5-22)	
LTC ^b or illness? n (%)	Yes	8	8	4	3	23 (48.9)
	No	3	7	7	7	24 (51.1)
Any financial support due to disability?, n (%)	Yes	3	9	2	3	17 (36.2)
	No	8	6	9	7	30 (63.8)
Perception of current state of health ^c , mean (min-max)		6.1 (3-9)	6.8 (5-8)	6.4 (1-9)	5.4 (1-10)	6.2 (1-10)
Structural hazards in the home?, n (%)	Hazards in the home	5	3	3	3	14 (29.8)
	No structural hazards	4	10	5		19 (40.4)
	Some adaptations have been made	2		2	4	8 (17)
	We have adapted the home		2	1	3	6 (12.8)
Have a carer?, n (%)	No	5	10	6	1	22 (46.8)
	Yes	Spouse (5)	Spouse (4)	Spouse (3)	Spouse (8)	20 (42.5)
		Children (1)			Children (1)	2 (4.3)
			Other (1)	Other (2)		3 (6.4)

(Continues)

TABLE 1 (Continued)

		UK	Norway	Denmark	Spain	Cross-national
Hoehn & Yahr ^d , (0–5), <i>n</i>	Stage 1	4			1	
	Stage 2	3			7	
	Stage 3				2	
	Stage 4	4				

^aAverage in UK (2019):£29.588; Average in Norway (2019):NOK 567480; Average in Denmark (2019):326048 DKK; Average in Spain per family unit (2019):19.479€.

^bLTC: Long term condition.

^cPerception of current state of health: range 1–10.

^dData were not collected in Norway and Denmark.

codes/themes when important themes that were not part of the initial framework were identified. To ensure transparency, an excel database for each analysed group of participants including codes, themes, quotes and a description of the themes was created and shared among all countries.

All the interviews were analysed in the original language of each country to enhance the researchers' sensibility to the original raw data, and country-specific reports were written in English explaining the process followed, including the findings with quotes for each particular group of participants. A total of 34 themes and 92 sub-themes emerged from the analysis across all countries.

The cross-national analysis based on the individual country reports, involved multiple readings and discussions across teams to synthesise the analyses. We applied a meta-ethnographic approach (lines of argument synthesis) (Noblit & Hare, 1988) to explain the results across groups and countries. The lines of argument strategy (Noblit & Hare, 1988) allowed us to identify the most powerful constructs representing the entire dataset from all four countries. This led to an agreed conceptual framework that incorporated a network of interconnected themes, which are presented in the results and enhanced understanding of the phenomenon studied. This process gave rise to comparative cross-national synthetic constructs.

2.6 | Rigour

To enhance methodological rigour, Lincoln & Guba's criteria for excellence in qualitative research were followed. Trustworthiness was achieved through different criteria based on the framework of Lincoln and Guba (1985). To ensure credibility, at least two researchers in each country were involved in data collection and analysis, data are presented as verbatim quotes and explained by the researchers' interpretation to illustrate the richness of the data. The researchers used reflexivity about their own position on the topic to ensure the confirmability of the data. The analysis began after the first interviews. Transferability was applied through purposive sampling and data saturation (Lincoln & Guba, 1985). The Patient and Public Involvement groups from each country contributed to the validation of findings.

3 | FINDINGS

Four themes and eight subthemes (Figure 1) emerged from the analyses of interview transcripts for PwPD and FCs in the four countries and illustrated the perceptions of PwPD and FCs about the health and social care services, and the community and voluntary sector resources available for PD management.

3.1 | Personalised care for needs throughout the PD journey (theme)

PwPD and FCs (in all four countries) commented that they would benefit from personalised care if information and support were more targeted for them. They expressed a need for both information and support to be given in a proactive and coordinated way. FCs would value receiving additional support when cognitive changes appear in PwPD. In addition, community organisations should provide peer support at the appropriate time.

3.1.1 | Unified, proactive and targeted information and support

PwPD in all countries called for more targeted information and support aimed at their individual needs throughout their journey with PD, for example in relation to medication, treatment side effects, how to prevent symptoms and promote their health. Although many resources were available, some PwPD were not informed of what was available in their area or who to ask to access support. Some PwPD discussed how important the point of diagnosis was for them and it seems that there was not enough support to help them deal with their emotional stress and concerns at that moment. Generally, participants stated that services should be tailored to personal needs given the variability of the disease.

I think the variability of the disease from one person to the next requires a real expert to find out what

TABLE 2 Description of family carers' sample in all countries and cross-national

		UK	Norway	Denmark	Spain	Cross-national
Male, n (%)		3	2	4	3	12 (30)
Female, n (%)		7	7	6	7	27 (70)
Age, mean (min-max)		64.2 (25–79)	54.4 (41–75)	68.4 (49–84)	51 (35–65)	59.5 (25–84)
Marital status, n (%)	Living with partner	1	2	1		4 (10.3)
	Separated	1				1 (2.5)
	Married or in a civil partnership	5	5	9	9	28 (71.8)
	Widowed	3				3 (7.7)
	Single		2		1	3 (7.7)
Work situation, n (%)	Full time paid work (30+ h/week)	3	5	3	2	13 (33.3)
	Unemployed	1			2	3 (7.7)
	Retired from paid work	4	2	2	2	10 (25.6)
	Long-term sick/disabled	1	2	2	2	7 (17.9)
	Part time paid work (8–30 h/week)	1		2		3 (7.7)
	Voluntary work			1		1 (2.6)
	Housewife				2	2 (5.2)
Income ^a , n (%)	Higher	3	1	4	5	13 (33.3)
	Average		2	4	2	8 (20.5)
	Lower	3	6	2	3	14 (36)
	Prefer not to say	4				4 (10.2)
Area type, n (%)	Urban	4	5	7	8	24 (61.5)
	Semi-rural	4	3	2	2	11 (28.2)
	Rural	2	1	1		4 (10.3)
Live with, n (%)	Partner	5	5	9	1	20 (51.3)
	Partner and children	1	2	1	7	11 (28.2)
	Children	1	2			3 (7.7)
	Partner and parents				1	1 (2.6)
	Parents				1	1 (2.6)
	On my own	3				3 (7.6)
Years sharing experience of PD? mean (min-max)		13 (5–41)	8.6 (2–20)	9.1 (1.5–18)	13 (2.5–20)	14.2 (1.5–41)
Years caring for? mean (min-max)		11.4 (1–39)	5 (1–14)	7.8 (1.5–18)	12.5 (0.5–20)	9.2 (1–39)
Relationship, n (%)	Spouse	9	5	9	9	32 (82)
	Other (parents, sibling)	1	4	1	1	7 (18)
Live with the PwPD?, n (%)	Yes	9	5	9	10	33 (84.6)
	No	1	4	1		6 (15.4)

Abbreviation: PwPD, People with Parkinson's disease.

^aAverage in the United Kingdom (2019):£29,588; Average in Norway (2019):NOK 567480; Average in Denmark (2019):326048 DKK; Average in Spain per family unit (2019):19,479€.

is going to be the best treatment for them. Because Parkinson's varies so much from person to person, different people have different problems. It is difficult to just give them a book on Parkinson's and say, "Read

that and do what it says" ...You need tailored advice and tailored management, tailored support services for each individual's needs

[UK-PwPD-009]

TABLE 3 Interview guide for the interviews with People with Parkinson's and Family carers

Topic fields	Questions
The role of professional and voluntary organisations	<ol style="list-style-type: none"> 1. What role do you think different organisations have in the management and daily living of Parkinson's and caring for people with Parkinson's? Professional organisations, voluntary organisations, the government, the national healthcare system, etc. 2. Where do you think the responsibility lies in the provision of care and day-to-day living with Parkinson's and caring for people with Parkinson's? The government? The national healthcare systems? Voluntary groups?
Available resources/services/ organisations	<ol style="list-style-type: none"> 1. What (other) community resources are you aware of for people with Parkinson's? 2. What (other) systems of support are you aware of for people with Parkinson's? <ol style="list-style-type: none"> a. Do you know if these are local, regional or national organisations? 3. Do you find the communication from professionals within any organisations you have contact with in regards to Parkinson's acceptable and helpful? <ol style="list-style-type: none"> a. If not, in what way do you find this unacceptable or unhelpful? b. How would you prefer communication and access to any support to be in regards to Parkinson's?
Care and resources management	<ol style="list-style-type: none"> 1. Have you experienced any problems accessing resources or services? <ol style="list-style-type: none"> a. What might have improved this access? <ol style="list-style-type: none"> (i) Do you have much access with professionals or groups? (ii) If not, why do you think this is? 2. What aspects of management of Parkinson's do you find more difficult? <ol style="list-style-type: none"> a. Are there aspects in which you need more resources or support? 3. Are there any relationships that would need to be focused on or strengthened in order for a new pathway to be helpful? 4. What kind of ways would you like to access support or different resources in the community to help you manage Parkinson's (e.g. online, telephone, through your general practitioner or clinic)? <ol style="list-style-type: none"> a. What would be most useful to you? b. What would you change about your current care? c. What do you like about your current care?

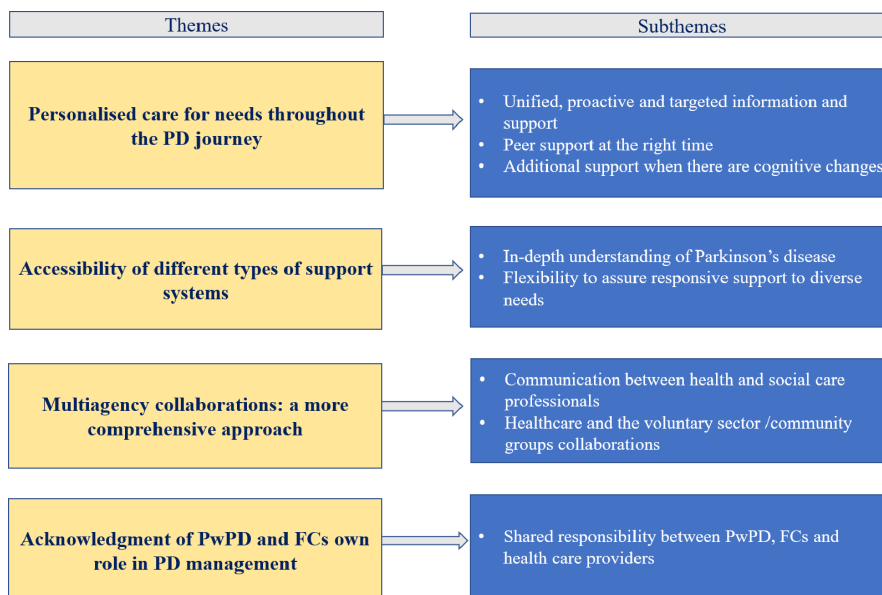


FIGURE 1 People with Parkinson's and family carers' perspectives on managing Parkinson's disease in the community.

† PD: Parkinson's disease; ‡ PwPD: People with Parkinson's disease; § FCs: Family carers.

Do you know what I miss? Information on whether there are studies on food for ... foods that I should avoid with this disease or foods that would be beneficial if I took more... conclusive studies on things that I do on a daily basis

[SP-PwPD-009]

Some PwPD in all four countries and some FCs in Norway, Spain and the United Kingdom pointed out that they would like to receive

unified information on the different support systems available for the management of PD (e.g. public, private, to address physical symptoms and psychosocial aspects) and on how to access them. Several PwPD and FCs in Denmark, Norway and the United Kingdom mentioned that they would prefer if there was one place or person where they could access all the information and support needed. That would make their life easier as they would be aware of what is available (from health and social care professionals, community organisations, voluntary sector) through just one appointment. This approach would enhance their

engagement with physical rehabilitation and community resources as part of PD management. Some participants pointed out the need for someone in charge of coordinating all types of support and that this could help PwPDs and FCs to receive support at the right time according to their different needs in the long term through a person-centred approach to care.

But we often find that these little pots of money and little pots of service there's nobody co-ordinating it and we encounter all kinds of barriers.

[UK-FC-001]

Had it at bit more like, a place to gather things, have one day to take the examination for that and that and that, and then you wouldn't have to go back and forth and back all the time. You use up all your strength on that. There is so much waiting. Then someone must look at that, and then it ages to get a reply. And the next one is doing that. More sort of coordination

[NO-FC-001]

Receiving information about available support after diagnosis, automatically, without having to request or search for it, was expected by some participants in Denmark, Norway and the United Kingdom. These PwPD and FCs commented that they would benefit if different support systems were offered to them proactively. These participants considered that the social and health system should check that PwPD and FCs are aware of the resources available and are receiving those they need. This should not depend on the ability of PwPD and FCs to perform that function since not all people are as communicative as others regarding their needs.

And the fact of the matter is that it is those who need the most help, maybe isn't the ones who seek out. Is my suspicion and thought. So it has been a big question, how do we reach those who does not show, that is the invisible ones

[NO-PwPD-003]

He follows those annual examinations by the neurologist. After such consultations, he gets a little more pills and a little more pills. So... we thought it was not good enough for a specialist just to prescribe pills. Much more is needed than pills [...]

[DK-FC-001]

3.1.2 | Peer support at the right time

Voluntary groups and community organisations were considered essential by many participants in Denmark, Norway, the United Kingdom and some in Spain when it came to providing important information and support for PwPD and FCs, often substituting or

complimenting support provided by or lacking from the health service. Participants in all four countries expected to meet people of a similar age or with similar symptoms in community organisations, from whom they would receive significant practical and emotional support. When this was not the case, it was a barrier in terms of using the resources of these community organisations.

There is an association for us who have Parkinson's, where we meet twice a year. Where we talk about how are doing. We sit and have a cup of coffee together. I'm probably not the person who gets the most out of it, but I think such an association is a very good idea. Other people and find out what kind of problems they are facing

[DK-PwPD-001]

I'm on a Facebook support group, um, which is, has been very, they've been supportive as well. There's lots of people on there able to, you know, give you help and suggestions, and same again, they're just a shoulder to cry on. They've been very supportive on, on my initial diagnosis... they've been very supportive and we support each other, because we're all in the same boat, if you like

[UK-PwPD-007]

A few PwPD in Spain and the United Kingdom acknowledged that they were avoiding some aspects of the illness, perhaps because they were not ready to accept or make decisions. Therefore, they were not interested in what voluntary associations and community groups could offer them and did not want to learn about resources other than their own (family, personal network) or to seek other support.

The doctor told us that there was a Parkinson's Association but the truth is that I didn't want to, I don't know, I didn't see myself ready to go (...) I don't want to see more things, because you see many people who are better but you see many others who are worse.

[SP-FC-005]

3.1.3 | Additional support when there are cognitive changes

FCs in all four countries indicated that cognitive changes in PwPD gave them much greater cause for concern than the physical changes. These changes were in most cases referred to as personality changes, which could often lead to disagreements, strain or loneliness among relatives. While medication and its effects (or lack of effects) were considered a driving force within their day-to-day activities, cognitive changes were reported to be the most difficult aspect to live with.

Physically I could deal with it, really, because of my background [nursing]... It was the mental bit, that he had addictive behaviour, he was quite abusive... and that was the most difficult thing for me, because nobody would talk to me about it

[UK-FC-009]

The nonmotor symptoms are far worse than tremor and bradykinesia. The psychological things. I felt they took a lot energy for some years

[DK-FC-003]

PwPD and FCs in all four countries expressed that initiatives to support the emotional well-being of FCs would be desirable. These participants explained that FCs often feel concern, tension and uncertainty about the status of their relative with PD and their progress in the future. They felt it was essential for FCs to receive support to maintain their health and emotional well-being, and their ability to help PwPD.

I was thinking about my husband and also the carer situation. Quite simply. It can also be, or is that they also need to be taken care of, and we have talked about that, during this process when the diagnosis is given. And they are also, I think, probably insecure, worried about what happens next

[NO-PwPD-005]

There are days when I am saying "oh my goodness, what awaits me later" (...) That she cannot feel independent, that is the worst thing she could take, because she is very independent. And... well I have strength, but there are days when I say eh! this is not easy, it is not easy because I also have to make my life, and she occupies my life a lot

[SP-FC-004]

3.2 | Accessibility of different types of support systems (theme)

In all four countries, there were PwPD and FCs who explained that an in-depth understanding of PD across sectors was essential to increase the accessibility of different resources in the healthcare system and in community organisations. In addition, they pointed out the need to assure the accessibility of all types of support systems to any geographic area and at the right time and in the right format.

3.2.1 | In-depth understanding of PD

There was a general feeling that a more in-depth understanding of PD was required among non-PD specialist health care professionals

according to some PwPD and FCs in all four countries. Participants explained that only PD specialist healthcare professionals could provide the support and understanding of PD that was needed, which could mean that interactions with general healthcare and external formal services were quite limited. "General health care professionals" were described as having a lack of understanding and comprehension about PD and the different types of support available for PD management.

In relation to knowledge, then my opinion is that she knows nothing about Parkinson. And if one the believes that it is the GP who is meant to coordinate, then I think that is just not.

[NO-PwPD-005]

We also see it in the GP, who has also told him that if he has Parkinson's that they cannot give him guidance

[SP-FC-001]

A few PwPD in the United Kingdom and Spain mentioned that one barrier to getting the right information and support was sometimes misconceptions or generalisations about PD in the health and social care, voluntary sector and community resources (e.g. PD only affects older people). As a result, PwPD and FCs may be missing valuable support related to financial, emotional, social or rehabilitation needs from the voluntary sector, community organisations and healthcare.

I think the nurse did mention looking on Parkinson's UK, which I did to a certain extent, but they didn't seem to think people could travel anywhere, so they only said there was nothing really, because they didn't seem to think that I would be able to get to Cardiff you see, I think that's why... They were a bit staggered that I would go to Cardiff for a dance class, but I don't find that staggering, I don't mind doing that

[UK-PwPD-001]

My husband was referred to a hospital who didn't dare to treat him, so he was referred to another hospital. But, they did not want to treat him either, so he was referred to a third hospital which finally agreed to treat him. This was two years ago, and they kept saying, because of PD we did not dare to perform surgery

[DK-FC-005]

3.2.2 | Flexibility to assure responsive support to diverse needs

In line with the previous theme, many PwPD in all four countries highlighted the clinical expertise and support that they received from health care specialists in PD. Neurologists (in all four countries), physiotherapists and PD nurses (in Denmark, Norway and the United Kingdom) were pointed out as important sources of support

for managing their individual symptoms, treatments and addressing their concerns. However, according to many PwPD and FCs in all four countries, more flexible access to PD specialists was necessary to respond to symptoms that arose unexpectedly (e.g. adverse effects after treatment adjustments). Many participants desired easy access to responsive health and social care, accessing support when they need it (flexibly rather than in a regimented way), at different times (diagnosis, stages of progression) to ensure that people access the support that is right for them at any given time.

We basically needed someone to tell us like, "This is what we're going to do in six months' time if this hasn't changed," and we never kind of got that. But that's who referred us to the... yeah... And the most frustrating thing is he's gone downhill a long time in that gap as well, so yeah, that's an annoying thing.

[UK-FC-002]

In addition, some participants in Norway, Spain and the United Kingdom mentioned that accessing certain healthcare services and community resources varied between PwPD and across geographical areas. This means that not all areas offer the same level of support services, and there are inconsistencies and potential delays in getting seen. These PwPD explained that in some rural areas there was lack of staff or fewer health professionals than in larger research hospitals. Difficulty accessing community resources was the case for PwPD who lived in rural areas, had given up driving or did not have enough energy/time to engage with activities.

And then I am thinking, yes it is important but still, seen against a patient pathway, what happens after you have received the diagnosis. When I talk to others with Parkinson, it is so different. Once a year, twice. Right. Some have to call and nag themselves others get a notice. In my opinion there should be a standardized pathway for everyone to follow

[NO-PwPD-004]

Some PwPD and FCs in Norway, Spain and the United Kingdom thought that the flexibility to choose the right format (online, face-to-face, both) for them was crucial and enabled them to get the support they needed and avoid delays/bureaucracy of the system. Similarly, some participants mentioned that they had other conflicting personal commitments, so when designing pathways, it was considered important to take into account other factors such as personal preferences, work and family commitments or ability to drive. These participants pointed out the need for a more coordinated and flexible pathway for PwPD to assure access to all services at the right time and in the right format from all geographical areas.

Many times we go to the hospital and everything could be solved over the phone and there are times when there are consultations that it is not necessary to go to

a hospital. And I think that, even for the health system, is being seen now, that many times it is not necessary to go, that simply with a phone call it is solved

[SP-FC-003]

3.3 | Multiagency collaborations: a more comprehensive approach (theme)

Some PwPD and FCs in Denmark, Norway and the United Kingdom considered that greater communication between social and health professionals was necessary and proposed the creation of collaborations between the social and health system, the voluntary sector and community groups to promote comprehensive care in the management of PD.

3.3.1 | Communication between health and social care professionals

In Denmark, Norway and the United Kingdom the importance of a smooth and clear communication between healthcare professionals who provide different services from the healthcare system for the management of PD, was noted as particularly important by some PwPD and FCs. These participants felt that each healthcare professional was exclusively focused on addressing health problems related to their specialty, but they did not pay much attention to the recommendations they were receiving from other healthcare professionals. Some PwPD and FCs in Denmark, Norway and the United Kingdom perceived that regular communication and cooperation between health and social care professionals would facilitate the continuum of care in PD management.

That the professionals can talk together, okay now we take this patient, then we talk about it and then we give a reply like that, instead of them sitting at different places sending the patient records back and forth and then there will be no focus or progression sort of

[NO-FC-001]

According to some PwPD and FCs in Denmark, Norway and the United Kingdom, it would be necessary for the social and health care professionals involved in the care of a PwPD to carry out a joint assessment of their individual situation. In this way, PwPD would receive an integrated and comprehensive care plan that would make it easier for them to manage PD and navigate the different services of the social and health care system. The large number of disciplines that may be involved in the long-term management of PD complicates navigating the social and health care system. This situation is aggravated for PwPD who have other long-term conditions or acute complications, which they might experience as being 'caught' in the health care system because of the lack of collaboration and knowledge exchange between the health care professionals attending PwPD.

the day I got diagnosed they gave me some medication. I came home and read the leaflet that comes in with the medication and there were so many things in there that affect my other problems that I have that I didn't start taking it

[UK-PwPD-008]

I don't think the different parts of the health service really communicate with each other. For example, if they're going to give me a diagnosis there are a lot of people involved and they don't sit down together after every consultation and talk about me all with me. I'd also appreciate better communication with the physiotherapist.

[DK-PwP-002]

3.3.2 | Healthcare and the voluntary sector/ community groups collaborations

Some participants also highlighted the need for a care plan that focused not only on pharmacological or rehabilitative treatment, but which also included participation in social, informative, or physical activities organised by community organisations.

Parkinsonians and their carers don't have to take this up but they do need to have the information given to them that there are support groups out there and people that will help. And it is just not happening.

[UK-FC-007]

These participants discussed the need for national or local governments to support voluntary organisations and community groups to complement the role of the healthcare system to provide more comprehensive care. Thus, a collaborative structure between health and social care professionals, the voluntary sector and community groups to improve the support offered to PwPD is a desirable scenario, as they would receive more comprehensive care in the management of PD in the community.

The carrying-out, the public can use volunteer organizations, for example such as the (Parkinson) Association, by supporting the association then the public will use the association to, kind of keep up their responsibility or contribute

[NO-PwPD-003]

3.4 | Acknowledgment of PwPD and FCs own role in PD management (theme)

Many participants highlighted their own role in the management of PD shared between PwPD and FCs. Some PwPD and FCs expected

to be more involved in the treatment and follow up in collaboration with health care providers.

3.4.1 | Shared responsibility between PwPD, FCs and health care providers

Many PwPD in the United Kingdom and some in Denmark, Norway and Spain considered themselves to be jointly responsible in the management of their condition and making decisions to adapt their everyday activities and improve their physical condition. These PwPD were interested in the support that health professionals and voluntary organisations could offer them and getting the support of their own family and social networks. However, they also recognised that they themselves had a role and a responsibility in their PD journey. These PwPD seek to remain active, participating in group or individual activities or accounting for their own hobbies or work. They are not prepared simply to wait for what is to come in the future. The decision to be co-responsible and remain active seemed to be personal, since participants did not indicate that it was a recommendation suggested by healthcare professionals.

I discovered that the heat was very good for me, I have not only already put the heated seats on the new car, I have even fitted a heated steering wheel for my hands [laughs], that is, I have adapted

[SP-PwPD-009]

I box and work out and I have attended online training, for instance with [regional] boxing club, If you know that group? So I try to be active and challenge my brain a bit

[NO-PwPD-003]

Overall PwPD in all four countries and some FCs in Denmark, Norway and Spain stressed that FCs (spouses in the majority of cases) were the most important source of support for PwPD. According to these participants, FCs were, together with PwPD, those who bore the burden of the disease due to their involvement in many aspects of daily life (e.g. medication, emotional support, housework, economic affairs, attending clinic appointments).

She [the spouse] helps with all the practicalities of pensions and unemployment benefits, and such. There was a lot to be arranged, things to be applied for. She is also with me when I meet the social worker. She is a great support and help in everyday life.

[DK-PwPD-004]

Well, I would have difficulty if my wife went into hospital or died. I would be in great difficulty fending for myself on my own

[UK-PwPD-009]

Some PwPD and FCs in all countries asserted that the voice and needs of PwPD and FCs needed to be involved in a more direct and person-centred way in the management of PD. These participants expected to be involved in the treatment and follow up and to be treated as equals by health care providers. These participants would welcome more communication between health professionals, PwPD and FCs. According to these participants, respect for their voice and needs would facilitate their PD journey.

I want the patient up, at the same level and that we are sitting and looking into each other's eyes. That we are equal and that the doctor or therapist or whatever, is my adviser

[NO-PwPD-002]

4 | DISCUSSION

In this cross-national study, we have explored the perceptions of PwPD and FCs about the health and social care services, and the community and voluntary sector resources available for PD management. To our knowledge, this is the first European study in which the management of PD has been explored in-depth through a multisectoral perspective (i.e. considering organisations and types of support from different sectors and community groups) based on the experiences of PwPD and FCs in four countries (Denmark, Norway, Spain and the United Kingdom). The results of this research identified four issues to be considered in the provision of services for PwPD and FCs: personalised care for changing needs throughout the PD journey; accessibility of different types of support systems (at the right time and in the right format from all geographical areas); comprehensive care across sectors through regular communication and collaboration between health and social care professionals, voluntary organisations and community groups; acknowledgement of PwPD and FCs roles in managing their health. These issues were found essential in the development of integrated and person-centred care pathways for PwPD and FCs in the management of PD.

Our findings showed that PwPD and FCs desire to receive personalised care for their needs throughout the PD journey. There is significant consensus regarding the need for health and social services to adopt a person- and community-centred approach in PD (Bloem et al., 2020; Dorsey et al., 2016; Fabbri et al., 2020). There is growing evidence that moving away from a traditional model of outpatient-hospital care towards a model centred on the individual and their community setting would bring many benefits. Although more conclusive studies are needed, preliminary research in other chronic conditions suggests that a person-and-community centred approach could improve clinical outcomes, enhance patient health, well-being and satisfaction, improve service sustainability and reduce costs in healthcare (Dorsey et al., 2016; Shepperd et al., 2009; Wood et al., 2016). A main finding from our study was a wish to receive personalised care according to symptoms, age, preferences, family and work responsibilities, and level of acceptance of the

situation in three areas: information and support; peer support; cognitive changes. Regarding targeted information and support, our research findings coincide with a recent study that identified PwPD as having unmet information needs on treatments and their effects (including adverse effects) (Chu & Jang, 2022). In our study, in addition to information needs related to treatment, information needs on the different support systems available to manage PD (public, private services, to address physical symptoms and psychosocial aspects) were identified. According to our results, this lack of knowledge about services could make it difficult for PwPD and FCs to seek the necessary support at the right time, which is compounded when they have difficulties expressing their needs, and also when, as indicated by another European study (Merritt et al., 2018), there is a lack of awareness about the symptoms. Therefore, it would be advisable for PwPD and FCs to receive individualised information about the disease, treatment and various sources of support available throughout the PD journey. Our results propose that this information be provided in a proactive and unified way through a single appointment, with the coordination of a social and health professional, who ensures that PwPD and FCs receive the support they need at any given time and could help provide a more integrated vision of the supportive process and other services, professionals and community groups involved in the PwPD care. This PD coordination role leads to other areas of need that need reinforcement such as personalised support through self-management programmes. In line with previous research (Wieringa et al., 2022), our findings indicated that PwPD want to have greater self-management of their disease and involvement in decision-making. Relevant interventions in the self-management of PD include: the provision of information about resources, training in psychological strategies, the promotion of social support networks, lifestyle counselling, medication management, physical exercise, self-monitoring techniques and maintaining independence (Pigott et al., 2022; Tuijt et al., 2020).

Support from peers and patient organisations has also been highlighted as being important in the management of PD in our study and previous research (Merritt et al., 2018), which need to be more clearly incorporated in community care. Based on our findings, peer support in the community could be enhanced and perceived as a more helpful source of support if it were adapted not only to the type of disease, but also to the symptoms, age and preferences of individuals. Peer support could be discarded by PwPD who do not feel they need it, do not want to face their possible future or have not accepted their disease, as was noticed in our study. Promoting other coping dynamics for these people that would facilitate their process of accepting the disease is an essential step, since acceptance promotes adjustment to the new situation and improves their well-being (Navarta-Sánchez et al., 2017). In addition, support for FCs of PwPD suffering from cognitive decline should be increased through personalised care, to decrease their burden and the impact on their health, and to help them cope and adapt throughout the PD journey (Hulshoff et al., 2021; Navarta-Sánchez et al., 2017; Vatter et al., 2018). Our findings and earlier research (Vatter et al., 2018) have shown that cognitive changes in PwPD are more difficult to

manage and live with for FCs than the physical symptoms of PD. It is important for the identification of cognitive changes in PwPD to be linked to an individualised assessment of the FCs' needs in terms of supporting their role as carers and their emotional well-being.

From a community care perspective providing individualised information, promoting peer support, self-management and addressing the individual needs of FCs should be priority strategies for PwPD and their FCs as this facilitates the development of person and community-centred approaches (Fabbri et al., 2020; Wood et al., 2016). However, our findings revealed that this is not sufficient to manage PD in the community setting. A multisectoral integrated care approach needs to be adopted, which is aligned with recent health policies (Department of Health & Social Care, 2021; WHO, 2018). Fragmentation in health care has been associated with high economic costs, low quality of care and negative health outcomes (Kaltenborn et al., 2021; McAlister et al., 2017). Integrated care aims to bring health services together to respond efficiently to the individual needs of each person throughout their life, improving their experience and health outcomes (Thorstensen-Woll et al., 2021). Different authors (Bloem et al., 2020; Fabbri et al., 2020; Rajan et al., 2020) have stressed that the care model in PD must evolve towards integrated care. Our results are consistent with this shift but contribute to further understanding. While health professionals from different disciplines need to work collaboratively with each other and with PwPD, care plans also need to be coordinated by health, social, volunteer and community resource professionals. This multisectoral integrated care approach should place the needs and voices of PwPD and FCs front and centre. Studies that have evaluated integrated care strategies in PD are very heterogeneous, limiting knowledge about the scope of their results in improving quality of life for PwPD and the sustainability of services (Rajan et al., 2020). In addition, no randomised clinical trials have yet been conducted to evaluate multisectoral integrated care strategies for PwPD and FCs.

Our findings indicated that the development of a multisectoral integrated care approach could bring the following benefits in the management of PD: in-depth understanding of PD; flexibility of access to a variety of support; comprehensive care. Our results highlighted that an in-depth understanding of PD across all sectors is essential to increase access to resources offered by the social and health system and the community setting. Ultra-specialisation in PD, often located within large tertiary hospitals in cities, may limit the availability of treatment in other areas (Giacobbe et al., 2021). Some community initiatives require knowledge about PD so that PwPD can safely benefit from them (Domingos et al., 2019). It is, therefore, necessary to continue training efforts in PD, such as ParkinsonNet (Ypinga et al., 2018), to address the dearth of PD experts in many countries and to provide PwPD with the best possible care. Extending this training on PD to the social sector, volunteering and community organisations are future lines of action to prevent underuse of these resources by PwPD and FCs due to misconceptions surrounding PD. The flexibility of access to support is another finding in our study. Telemedicine and new technologies could speed up consultation times in the onset of unexpected symptoms and address the imbalance of

resources between geographic areas, bringing PD experts to areas with smaller populations (Giacobbe et al., 2021). However, some PwPD may encounter barriers to using telemedicine and new technologies (e.g. lack of internet, difficulties using it, lack of confidence in the care received) (Giacobbe et al., 2021; Lubomski et al., 2021). Exploring strategies that combine face-to-face care and telemedicine can facilitate the development of a person-and-community-centred approach in PD (Fabbri et al., 2020; Lubomski et al., 2021). Moreover, due to the high level of specialisation in the management of PD, providing coordinated and personalised care throughout the different stages of PD is a challenge (Fabbri et al., 2020). This makes it difficult to meet the needs of PwPD. Working on clinical and professional coordination, key dimensions of integrated care, could help tackle this situation (Valentijn et al., 2019).

Future lines of research should include studies that evaluate integrated and person-and-community-centred care pathways for PD management, involving the health, social, voluntary and community sectors. Understanding how to integrate and coordinate this approach at the level of PwPD, FCs, professionals and organisations could generate more sustainable and effective care structures. Exploring how this approach could be implemented in clinical practice, how this could be evaluated and if digital tools could help sustain this approach. Studying the benefits and impacts of this approach to care in PD could identify new possibilities in the care of people with other neurodegenerative or long term conditions. To provide robust answers more quickly, studies should be based on clear definitions of person-centred outcomes and integrated and multisectoral care, such as those offered by the Rainbow Model of Integrated Care Measurement Tools (RMIC-MTs) (Valentijn et al., 2019) and the WHO (2018), respectively. RMIC-MTs, which have not yet been validated for PD, would allow us to understand how the approaches to care evaluated fulfil the requirements of integrated care. Exploring the experiences of the users and professionals involved, through questions focused on different areas of integrated care, such as those proposed by Thorstensen-Woll et al. (2021), would complement the quantitative analyses provided by the measurement tools. Including economic analysis and implementation projects is necessary for emerging multisectoral integrated care approaches to be sustainable. Exploring how bridging roles (particularly in nursing) could be developed in this approach in PD would facilitate its implementation. Comparing traditional care with the use of tools such as Chat &Plan (Corbett et al., 2020) for personalised care among PwPD and other long term conditions could guide the integration of multiple services. This would help us to make specific decisions about which resources to mobilise to develop integrated and person-and-community-centred care pathways for PD management across sectors.

4.1 | Limitations

Findings could have been influenced by professional background and personal experiences of the researchers. In addition, cultural

differences and variability in health and social care systems between countries could have been underestimated in our results. However, this might have been avoided by the analysis of interviews by at least two researchers in each country, the use of a meta-ethnographic approach and the Patient and Public Involvement groups (who participated in design of the study, the interview guides and validation of findings).

5 | CONCLUSIONS

Our findings have pointed to the importance of moving towards an integrated and person-and-community-centred approach in the management of PD in the community, involving the health, social, volunteer and community resources sectors. These results have provided an international perspective to improve the usability (effectiveness, efficiency, satisfaction, user-friendliness) of the different supports needed to move towards this approach in the management of PD. This has been made possible by analysing the experiences of users themselves, PwPD and FCs in four countries: Denmark, Norway, Spain and the United Kingdom. These findings could be used to inform more sustainable systems of care at a European level that respond better to individual needs among PwPD and their FCs, and in other chronic diseases.

6 | RELEVANCE TO CLINICAL PRACTICE

Our study suggests that integrated care involving cross-sector collaboration could change current care (which focuses almost exclusively on drug treatment and rehabilitation therapy), moving towards a multiagency approach, in which participation in social, physical and cultural activities in community organisations and the voluntary sector is equally relevant. This approach would emphasize complications prevention and health promotion through education and self-management, which have been recognised as key elements of the person- and- community-centred approach in PD (Fabbri et al., 2020). An example of health promotion is exercise, where PwPD who are more physically active are more likely to perceive a higher quality of life and be less affected by non-physical symptoms (Lubomski et al., 2021). However, achieving these goals are complex. Thus, it is important that relevant support, information and resources are provided by nurses and other healthcare professionals and reinforced in different settings, such as community and voluntary groups. In addition, it is paramount to identify a single point of access or care coordinator to play a leadership role across agencies. Rehabilitation therapies (Lubomski et al., 2021), frequent participation in physical (Fabbri et al., 2020), social and cultural activities in the community and the voluntary sector should be promoted in a multiagency care treatment for PwPD.

AUTHOR CONTRIBUTIONS

MVNS involved in conceptualization, project administration, data curation, formal analysis, funding acquisition, investigation,

methodology, validation, visualization, resources, writing original draft, review and editing. APS involved in formal analysis, investigation, methodology, validation, visualization, writing original draft, review and editing. APM involved in formal analysis, investigation, methodology, validation, visualization, writing original draft, review and editing. CR involved in data curation, formal analysis, investigation, methodology, validation, visualization, review and editing. DiS involved in formal analysis, investigation, methodology, validation, visualization, writing original draft, review and editing. AH involved in conceptualization, project administration, data curation, formal analysis, funding acquisition, investigation, methodology, validation, visualization, resources, review and editing. DoS involved in formal analysis, investigation, methodology, validation, visualization, review and editing. HRS involved in data curation, formal analysis, investigation, methodology, validation, visualization, review and editing. LKB involved in funding acquisition, project administration, data curation, formal analysis, investigation, methodology, resources, validation, visualization, review and editing. EGH involved in data curation, formal analysis, investigation, methodology, validation, visualization, review and editing. SBH involved in data curation, formal analysis, investigation, methodology, validation, visualization, review and editing. MCP involved in conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, resources, validation, visualization, supervision, writing original draft, review and editing. All authors have contributed to the manuscript substantially and have agreed to the final submitted version.

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CONFLICTS OF INTEREST STATEMENT

The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.


ETHICAL APPROVAL

This study obtained ethical approval from the required ethics committees: University of Southampton, number- HRA: IRAS number: 265184; Research Ethics Committee in Hospital Universitario La Princesa number: 3995, CEIm 02/20; Norwegian Centre for Research Data reference number: 986940. Participants gave informed consent before taking part in this study.

THE NUMBER OF REFERENCES

We would like to clarify that our manuscript has more than 25 references. These references were used to explain the international relevance of the topic, the previous research and the gap, the methods and to discuss the results. We could reduce the number of references if this is compulsory in this journal. Although, taking into account what is indicated in the author guidelines, we would appreciate it if you would consider the specific case of this work.

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