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| Title                       | Palliative care for Parkinson's disease: Patient and carer's perspectives explored through qualitative interview                                                                                                                                                                                                              |
| Authors                     | Fox, Siobhán;Cashell, Alison;Kernohan, W. George;Lynch, Marie;McGlade, Ciara;O'Brien, Tony;O'Sullivan, Sean S.;Foley, Mary J.;Timmons, Suzanne                                                                                                                                                                                |
| Publication date            | 2016-09-28                                                                                                                                                                                                                                                                                                                    |
| Original Citation           | Fox, S., Cashell, A., Kernohan, W. G., Lynch, M., McGlade, C., O'Brien, T., O'Sullivan, S. S., Foley, M. J. and Timmons, S. (2017) 'Palliative care for Parkinson's disease: Patient and carer's perspectives explored through qualitative interview', Palliative Medicine, 31(7), pp. 634-641. doi: 10.1177/0269216316669922 |
| Type of publication         | Article (peer-reviewed)                                                                                                                                                                                                                                                                                                       |
| Link to publisher's version | <a href="http://journals.sagepub.com/doi/abs/10.1177/0269216316669922">http://journals.sagepub.com/doi/abs/10.1177/0269216316669922</a><br>- 10.1177/0269216316669922                                                                                                                                                         |
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| Download date               | 2026-10-31 23:34:59                                                                                                                                                                                                                                                                                                           |
| Item downloaded from        | <a href="https://hdl.handle.net/10468/5557">https://hdl.handle.net/10468/5557</a>                                                                                                                                                                                                                                             |

**Title:** Palliative care for Parkinson’s disease: Patient and carer’s perspectives explored through qualitative interview.

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**Counts:** Word count paper (excl. quotations): 3149

Number of tables: 3

Word count abstract: 235

Number of figures: 1

Number of references: 22

**Running title:** People with Parkinson’s disease and their carer’s perspectives on palliative care.

**Keywords:** Parkinson disease; Caregivers; Palliative Care; Qualitative Research; Quality of Life.

**Conflict of interest:** None of the authors have anything to disclose concerning the research related to this manuscript.

**Funding:** This research was supported by a grant from the Irish Hospice Foundation.

## 25    **Key statements**

### 26    **What is already known about the topic?**

- 27        • An integrated palliative care approach is recommended in all life-limiting diseases,  
28           including Parkinson's disease (PD).
- 29        • People with PD and their families are not currently accessing Specialist Palliative  
30           Care services and unmet needs have been reported.
- 31        • Previous qualitative research has focused on the views of healthcare workers and, to a  
32           lesser extent, carers.

### 33    **What this paper adds?**

- 34        • An exploration of the palliative care needs of people with Parkinson's disease, from  
35           the perspectives of the people themselves, and their carers.
- 36        • Contrary to finding stigma or fear, many people with PD and carers were simply  
37           unfamiliar with palliative care and would appreciate any extra support.
- 38        • Key crisis times when extra support may be needed from palliative care are at  
39           diagnosis and at advancing illness.

### 40    **Implications for practice, theory or policy?**

- 41        • *Practice.* Healthcare workers may overestimate the fear and stigma associated with  
42           palliative care and should be mindful of cues from their patients that they want to  
43           discuss palliative or end-of-life issues.

- 44       • *Practice.* A palliative care approach should be adopted by all healthcare workers;  
45       formal needs assessments are vital to identify people with PD who may benefit from  
46       referral to Specialist Palliative Care.
  
- 47       • *Policy.* The provision of palliative care to people with PD requires a multi-  
48       professional and integrated approach, with guidelines required to guide service  
49       provision and individual healthcare worker's practice.

50

## Abstract

**Background:** Palliative care is recommended for non-malignant illnesses, including Parkinson's disease (PD). However, past research with healthcare workers highlights unmet palliative needs in this population and referral rates to Specialist Palliative Care (SPC) are low. Some healthcare workers perceive a 'fear' in their patients about introducing palliative care. However less is known about the views of people with PD (PwPD) and their carers about palliative care.

**Aim:** I: To explore the palliative care and related issues most affecting PwPD and their families; II: To examine perceptions about/understanding of palliative care.

**Design:** This was a qualitative study; semi-structured interviews were conducted, transcribed, and analysed using Thematic Analysis.

**Setting/Participants:** Thirty-one people participated, both PwPD (n=19) and carers (n=12), across three movement disorder clinics in Southern Ireland.

**Results:** PwPD and their carers were unfamiliar with the term palliative care. When informed of the role of palliative care, most felt that they would benefit from this input. PwPD and carers experienced a high illness burden, and wanted extra support. Crises requiring SPC involvement may occur at diagnosis and later, with advancing illness. Participants wanted more information about palliative care, and especially further supports to address their psychosocial needs.

**Conclusions:** A holistic palliative care approach could address the complex physical and psychosocial symptoms experienced by PwPD and their carers, and PwPD and their carers are open to palliative care. Further research needs to explore how palliative care can be introduced into the routine care for PwPD.

## Introduction

Parkinson's disease (PD; see abbreviations table 1) is the second most common neurodegenerative disorder after Alzheimer's disease<sup>1</sup>. PD is life-limiting, with complex and progressive symptomatology; thus a palliative care approach is appropriate. People with advanced PD share some symptoms and have an equivalent overall disease burden to people with metastatic cancer<sup>2,3</sup>. There has recently been increasing recognition of the palliative care needs of people with neurological illnesses, nationally<sup>4</sup> and internationally<sup>5</sup>.

All people with PD (PwPD) would benefit from a palliative care approach throughout their illness, which involves all HCWs practicing palliative care principles as a core skill. A proportion of PwPD may experience more complex needs and will benefit from Specialist Palliative Care (SPC) services, whose core activity is the provision of palliative care to individuals with more complex and demanding care needs. This approach is recommended in current guidelines<sup>6,7</sup>.

However, palliative care needs remain largely unmet<sup>8</sup> and relatively few people are referred to SPC services<sup>9</sup>. For example, a retrospective review in the UK of PwPD who died in hospital found that only 2.7% had a documented care planning discussion with a clinician and just 13.6% were referred to a SPC team<sup>9</sup>. A recent review also noted that palliative services for PD have been slow to develop<sup>10</sup>.

Previous qualitative research, conducted with healthcare workers (HCW), explored palliative care needs in PD from their perspective. Less research has been conducted with carers, and very little with PwPD themselves. This research illustrated the high disease burden in PD and unmet palliative care needs; it was widely found that PwPD and their families have needs and experiences similar to those with metastatic cancer<sup>3</sup>. Other recurring themes were: the emotional impact of diagnosis, including changing social roles, financial difficulties, and

carer strain associated with a family member developing PD<sup>3,11,12</sup>. “Information tension” was another key theme reported<sup>10</sup>, including a lack of information around the time of diagnosis, yet also a seemingly paradoxical fear of knowledge; many reported difficulty requesting information from HCW<sup>3,11,13</sup>.

Hasson et al.<sup>12</sup> examined the end-of-life experiences of bereaved family carers of PwPD: they reported a lack of preparedness for the death of loved ones; many struggled to cope and felt abandoned and unsupported from healthcare services. Most had poor knowledge of SPC, meaning that few accessed these services.

Other qualitative, non-palliative care research has found similar themes, for example the experience of diagnosis as ‘dropping a bomb’<sup>14</sup>, and the lack of support for carers<sup>15</sup>.

It is clear from the literature that there is a high disease-related burden in PD<sup>16</sup> yet PwPD and families are not being fully supported within existing healthcare systems from the perspectives of HCWs and carers; notably this has been described across various countries with different healthcare systems (e.g. Ireland<sup>8,17</sup>, United Kingdom<sup>12,18</sup>, Canada<sup>13,19</sup>).

However, existing qualitative research involves very small sample sizes<sup>13</sup>, and more importantly little previous research has investigated what PwPD identified as their own palliative care and related support needs.

It is important to conduct research *with* a patient group<sup>20</sup> and PwPD are expert on their own lives and condition. Therefore, this research complements our previous research with HCW<sup>8,17</sup> by adding the voice of PwPD and their carers.

The primary aim was to explore the palliative care and related issues affecting PwPD and their families. A secondary aim was to explore participants’ perceptions of palliative care and elicit potential barriers or facilitators to accessing or receiving this care.

121

## 122 **Methods**

### 123 *Participants*

124 This study was granted ethical approval by the Clinical Research Ethics Committee of the  
125 Cork teaching hospitals (reference number ECM4[ee]/ECM3[s]). Participants were recruited  
126 from three movement disorder clinics in Cork, Ireland, between June-September 2014, using  
127 convenience and purposeful sampling. Previous research focused on advanced PD, however  
128 as palliative care is applicable throughout the course of a life-limiting illness, we included  
129 participants from early to advanced stages of illness.

130 Most participants were approached by the primary researcher (S.F.) face-to-face and  
131 informed about the study. Those interested were brought to a private room to read the study  
132 participant information and consent forms. Those choosing to participate could complete the  
133 interview that day, or arrange another suitable time. Other participants were recruited by their  
134 neurologist or geriatrician; those interested had their contact details forwarded to the  
135 researcher.

136 Most participants who were approached agreed to participate. Those who declined reported  
137 feeling tired or unwell, or not having time. Oral and written consent was collected from all  
138 participants prior to the interviews. The demographics of study participants and those who  
139 declined participation were similar for age, sex, and PD duration. We planned to recruit 15  
140 carers and 15 PwPD; however, data saturation was achieved earlier than anticipated in the  
141 carer group (n=12), and later in the PD group (n=19). Where a primary carer was present,  
142 PwPD and carers were given the option to be interviewed as a dyad; six paired interviews

were completed. This made it possible to explore the topics from different perspectives based on the dynamic of dyad or solo interviews.

### *Data collection*

Two semi-structured interview schedules were developed based on our previous research<sup>8</sup> and existing literature<sup>12</sup>. These were pilot-tested with one PwPD and one carer, and minor changes to wording and question order were made. These interviews were included in the final analysis. The topic areas are listed in table 2. As the literature indicated that many people are unfamiliar with palliative care, a definition was read to all (see Table 2).

Most interviews lasted 20-40 minutes, and were audio-recorded. All interviews took place in a private clinic room. Written reflections were recorded detailing participants' non-verbal interactions. Participants completed a basic demographics questionnaire.

### *Analysis*

The first author (S.F.) conducted all interviews and analysis, ensuring familiarisation with the data. S.F. is a female researcher with a PhD in psychology and experience of conducting quantitative and qualitative research in PD. S.F. wasn't known to any of the participants, limiting a personal influence in recruitment. S.F. introduced herself as a local University researcher interested in exploring the experiences of PwPD and their carers, and their support service and related needs. To identify and minimise potential bias a reflexivity diary was logged throughout data collection and analysis. Interviews were transcribed verbatim and analysed using NVivo software, which assisted in storage, searching and managing the coding.

Data were analysed and reported according to Consolidated Criteria for Reporting Qualitative Research guidelines<sup>21</sup>, wherever possible.

166

## 167 **Results**

### 168 *Demographics.*

169 Thirty-one people participated in 25 interviews: 19 PwPD and 12 carers. The sample  
170 characteristics are shown in table 3. Interviews were conducted across Clinic A (n=5), Clinic  
171 B (n=10), and Clinic C (n=10).

172

### 173 *Themes.*

174 Seven themes were identified in the analysis. The theme names and the relationships between  
175 the themes are represented visually in figure 1. This diagram highlights the key issues faced  
176 by PwPD and their carers, and how sometimes the needs of the PwPD and carer overlap and  
177 at other times they experience unique needs. The diagram also highlights that palliative care  
178 (general or specialist) can have a role in addressing all of these needs, at every stage of  
179 illness.

180

### 181 *High disease-burden.*

182 This theme refers to the significant challenges of managing the physical and psychological  
183 effects of PD on both the person and their carer.

184 *Patient burden.* PD clearly affected people physically. Declining physical health with  
185 increased fatigue interfered with people's ability to complete activities of daily living. One  
186 PwPD reported "*feel[ing] a lot older than what I am*".

187 Decreased physical health was one factor directly affecting mental health. One carer  
188 identified depression as ‘*part-and-parcel*’ of PD. Motivation loss was common throughout  
189 the illness. Participants spoke about the impact of non-motor symptoms: “*I get up in the*  
190 *morning and just kinda say to myself ‘God almighty, the start of another day’ ... I feel tired, I*  
191 *feel kinda tired the whole the time, and I feel ‘how am I going to get through the day [sic.]’”*  
192 (*PwPD 2*)

193 and how this may go unnoticed:

194 “*you might look ok from the outside but on the inside we are suffering away in our own way*”  
195 (*PwPD 18*).

196 Advancing illness impacted participants’ social lives. Some were embarrassed by their  
197 tremor, or worried that it would worsen with people watching them. PwPD withdrew from  
198 social engagements: “*I don’t go out as much because I get tired way earlier in the night and I*  
199 *might be spoiling other people nights, so I just come home early*” (*PwPD 19*). Some felt that  
200 they couldn’t complain to friends as they might ‘*bore*’ them and ‘*drive them away*’.

201 Overall, loss of independence and mobility were cited as the biggest impacting factors on  
202 quality-of-life.

203 ***Carer burden.*** Carers, themselves often elderly and/or ill, experienced significant financial,  
204 physical and emotional caregiving burden. Some carers felt guilt acknowledging this burden:

205 “*I know that is selfish but [I would like] some time off, not every weekend but maybe the*  
206 *odd weekend just to have time and not feel guilty.*” (*Carer 8*).

207 Carers experienced social isolation as the PwPD became more dependant and required full-  
208 time care. Carers faced complex psychosocial issues. For example, the bereavement process  
209 may start before the PwPD’s death as carers grieve the loss to a nursing home or loss of their

210 loved one's personality. *'What I miss would be his personality; he was a very chatty man,*  
211 *now he's quiet' (Carer 1).*

212

### 213 *Information and Support needs: no 'one-size-fits-all'*

214 There was an overall lack of information at diagnosis. Some participants were missing basic  
215 information about PD, even to know that it is incurable. Some participants would have liked  
216 all of the information up front to prepare for advanced illness...

217 *"I wanted to know, what I wanted to ask ... is there a progression, is there a time scale ...*  
218 *some people mightn't want to know about that at all, but I would prefer to know, so you can*  
219 *deal with it then, and you can be prepared for it" (PwPD 10).*

220 ...while others preferred to *'live day-to-day'*. Participants suggested that information should  
221 be: tailored to individuals, depending on their illness stage and mind-set; available in many  
222 formats, including printed, online, phone support, DVD, seminar, leaflets, etc. People who  
223 had used the phone support service of the Parkinson's Association of Ireland to speak with a  
224 PD nurse found it helpful for general information, or clarifying information that they heard  
225 elsewhere.

226 PwPD and carers were sometimes unsure of what services or supports were available, and/or  
227 didn't know how to access these. Most who were experiencing advanced disease highlighted  
228 the importance of having sufficient and timely information to adapt homes, contact relevant  
229 services, prepare emotionally.

230 Support needs were very individual. For example, many people greatly valued patient and/or  
231 carer support groups; for others attending such groups caused anxiety when seeing others  
232 with more advanced illness.

233 “We met some very nice people, they are all in the same boat, and [by comparison with  
234 other’s in the support group] I seem to be coping fairly well.” (PwPD 15)

235 “Witnessing people who had more advanced Parkinson’s than myself, I find that quite  
236 disturbing.” (PwPD 14)

237 Informal family support was viewed as very important. Participants agreed that PwPD living  
238 alone would need greater formal supports, such as regular nurse visits. PwPD living alone  
239 admitted more vulnerability to depression as they have ‘too much time to think’ (PwPD 1).

240 Overall PwPD and their carers wanted to have different information and support options to  
241 suit individual preference and illness stage, as no ‘one-size-fits-all’.

242

#### 243 *Crisis times needing extra support*

244 *Crisis at diagnosis.* This theme related to the feelings of grief, depression, uncertainty, and  
245 hopelessness at the time of diagnosis. For many, the diagnosis was a prolonged, stressful  
246 process. A lack of previous knowledge about PD meant that many thought they had been  
247 given a ‘death sentence’: “I immediately classified Parkinson’s as ‘Parkinson’s, multiple  
248 sclerosis, cancer’, they were all the same, they all wiped you out.” (PwPD 15). Carers with  
249 experience of PD were aware of the serious implications of the diagnosis, ‘we never in our  
250 darkest days thought X would get it. Never, ever, ever.’ (Carer 3).

251 Some PwPD coped initially by ‘living in hope’ for a cure however many also admitted that  
252 they were ‘burying their head in the sand’ (PwPD 14). Carers more often considered the  
253 reality of the incurable disease: ‘do you think he will need more care in the years to come?’

254

255 *Crisis at advancing illness.* This theme related to the many challenges faced by both carers  
256 and PwPD as the illness progresses. PwPD faced the reality of their illness at this stage:

257 ‘[you get] a realisation that Parkinson’s is a serious thing and there is no cure and you  
258 see yourself going downhill every day, that’s sometimes difficult to take.’ (PwPD 7).

259 Many carers were unprepared for advanced illness and their partner’s high support needs, as  
260 they had often been told ‘you don’t die from Parkinson’s’. Carers found it difficult making  
261 tough decisions about the care of their loved one, and would value support:

262 “I found it difficult making the right call, whether to call the doctor or to take him in [to  
263 hospital], judging whether he was going to be ok, things like that. When you have no  
264 experience, when you are going through it for the first time and you are trying to find  
265 your feet, I found that very stressful.” (Carer 8)

266 Most carers wanted to care for the person at home, and felt guilt and despair when that was  
267 no longer possible or preferential.

268

#### 269 *Experience of healthcare services: feeling unsupported*

270 Limited and sporadic contact with healthcare teams left some PwPD and carers feeling  
271 ‘alone’ facing their illness; PD is “a one-man show, and anything I got I got it myself”  
272 (PwPD 7). Participants felt unsupported when meeting different HCWs at every clinic or  
273 hospital visit, and felt that support ‘dropped off’ when they returned home following a  
274 hospital or respite stay. Many participants perceived that their doctor was only interested in  
275 their medication needs, overlooking social and psychological needs which were often more  
276 distressing.

277 Poor cohesion between services, and uncertainty about the available support services caused  
278 frustration for participants, impinging on carers' ability to care for the PwPD:

279 *"The doctor, he promised us everything, he promised us loads of home help, it isn't*  
280 *available, it just isn't available, we were actually very very lucky to even get the one*  
281 *hour five days a week, that's what we were told and there was never a question of*  
282 *coming in again during the day, that was never going to happen."* (Carer 8)

283

#### 284 *Experience and perceptions of palliative care*

285 *Advance care planning.* This theme relates to planning for the future, an emotive topic for  
286 all participants. All participants worried about the future to some extent. However, some with  
287 early stage illness didn't want to think about the future, hoping that a cure would come in  
288 time for them: *you just have to wait and hope they get a cure in time (PwPD 18).* These  
289 people felt that advance care planning may be too depressing.

290 However, those living with more advanced illness, when medications were becoming less  
291 effective, were more open to discussions about the future. Some PwPD living with advanced  
292 illness had already given a lot of private thought to care directives: *'I don't want to be kept*  
293 *alive because I am alive; I want to be kept alive because I want to be alive'* (PwPD 14).

294 Another man who had lived with PD for 24 years was very comfortable discussing death and  
295 dying: *"I have a few friends who died ... and again they are not different because they are*  
296 *dying, it is a natural thing, and then hopefully they are not in pain, and quality of life is a big*  
297 *thing"* (PwPD 7).

298 Similar to the "no 'one-size-fits-all' theme", discussions around advanced care planning need  
299 to be delivered at a time when the individual person/couple is ready; participants felt that this

300 would change depending on age, personality, disease stage.

301

302 *Perceptions of palliative care.* Many participants were unfamiliar with the term palliative  
303 care, others misunderstood it as ‘home help’ or ‘counselling’, or thought that it was only  
304 available to people with a cancer diagnosis:

305 “I have [heard of palliative care], they are attached to X Hospital but I don’t know about  
306 them, but they are for cancer patients I know that, but whether they apply to [PD], I suppose  
307 they probably do I don’t know.” (Carer 5).

308 Those who had previous experience of SPC nurses, often during the death of a relative, all  
309 reported positive experiences: ‘*they are fantastic people*’ (PwPD 14)

310 When the role of SPC in symptom control was explained, most people felt that they would  
311 benefit from this support. Carers were interested in a service which would include them in the  
312 unit of care. Participants experiencing advanced illness welcomed any specialised support,  
313 including help with anxiety, breathlessness, fatigue, or other issues affecting quality-of-life.  
314 Participants experiencing advanced illness stages were pragmatic about their needs and  
315 welcomed any supports that would decrease burden.

316

## 317 **Discussion**

318 Increasing attention is being paid to the need for palliative care for neurological illnesses,  
319 including Parkinson’s disease (PD). This study adds to the literature by directly asking people  
320 with PD (PwPD) and their carers about their support needs, and eliciting their perceptions of

321 palliative care. Past research has largely relied on the experiences of healthcare workers  
322 (HCW) or carers only, omitting the PwPD's voice.

323 It was evident in these interviews that the holistic and person-centred approach of palliative  
324 care could potentially help to alleviate the complex burden experienced by PwPD and their  
325 carers. In the opinion of these participants, their care focused on the management of motor  
326 symptoms and medication, with little or no psychological support. Past research has  
327 highlighted the importance of non-motor symptoms to quality-of-life and health status in  
328 PD<sup>16</sup>. Thus, a palliative care approach which considers the holistic or bio-psycho-social  
329 model of illness is needed, in contrast to the dated 'medical-model'. As Hudson et al.<sup>3</sup> noted,  
330 the psychological support offered to PwPD and families in response to feelings of loss and  
331 fear of the future, a common part of palliative care practice, would help in supporting the  
332 PwPD and their carer, and the complex grieving processes reported in this study.

333 Similar to previous international research with carers which reported 'fragmented and patchy'  
334 access to social and health care services<sup>12,17</sup>, PwPD, as well as carers in this study, often  
335 experienced disjointed support from the healthcare system. PwPD without a formal carer may  
336 be particularly vulnerable; they may be less likely to seek formal supports (often difficult and  
337 frustrating to access), a task often carried out by carers.

338 Past research with HCW highlighted their uncertainty about the appropriateness and timing of  
339 palliative care interventions, resulting in unmet needs<sup>17</sup>. Key 'crisis times' for extra support  
340 and/or SPC involvement were identified, namely at diagnosis and at advancing illness. PwPD  
341 and carers would further benefit from all HCW adopting a palliative approach to their care at  
342 all stages, focusing on psychological and other non-motor issues. Regarding advance care  
343 planning, PwPD and carers differed in preparedness for this discussion, but notably a sizeable  
344 portion would like to have these discussions soon after diagnosis. This is in line with past

survey research which showed that 21% of PwPD would like early discussion about end-of-life planning and 27% about end-of-life care options such as hospice<sup>22</sup>.

As in past research<sup>3,11,13</sup>, a lack of information was highlighted; many participants had limited information about PD. This was problematic for many reasons, for example many didn't realise that their non-motor symptoms may be attributable to their PD, and didn't seek help from their specialist, even when in great distress. This study also uniquely adds to the previous discussion by using both solo and dyad interview structures which highlighted the differences in what information PwPD and carers want, how they want this to be delivered, and by whom. Notably, carers were lacking information about coping with advanced disease and were unprepared for this burden. Goy<sup>19</sup> also noted unpreparedness for their loved ones' death in PD. Information given to the carer must be balanced however with the PwPD's readiness to accept information, and they may prefer to receive this information more slowly.

A common theme in previous research with HCW was their perception of the fear and stigma associated with palliative care in the minds of PwPD and carers, which inhibited HCW in discussing these issues with their patients with PD<sup>8,17,18</sup>. However, the current results revealed few participants who exhibited this 'fear' of palliative care. Many were simply unfamiliar with the term, and most PwPD in later disease stages were open to any supports that may improve their quality-of-life.

*Limitations.* The authors acknowledge that this research is based on a limited qualitative sample. While effort was made to reach a varied sample of participants in urban and rural settings, attending three different clinics, and at different stages of illness, no claim to generalisability of the findings is made. However, the current results add to the literature the experiences and perceptions of PwPD, and their current carers, about palliative care. A single author completed the data analysis, however the analyst is experienced in methods of

qualitative analysis, and we ensured a robust research process through establishment of a project steering group which oversaw all stages of the research.

### *Recommendations.*

The following recommendations are made based on the current results, and in light of previous literature:

*Clinical.* HCW should be mindful of cues from patients that they want to discuss palliative or end-of-life issues; HCW may underestimate PwPD and family's need for frank discussion and overestimate the stigma associated with palliative care. The delivery of information should however be tailored to the individual PwPD and/or carer.

Participants in this study experienced fragmented support from the healthcare system. The provision of palliative care to PwPD requires a multi-professional and integrated approach, with effective communication between HCW.

*Research.* It is becoming widely accepted that PwPD and their families would benefit from a palliative care approach supplemented by SPC, and the specific areas in which they most require support have been outlined. Future research should focus on developing, implementing, and evaluating palliative care supportive interventions. Research looking at cost-effectiveness will be important. The public/patients should be involved in all stages of research.

*Policy.* SPC should be offered on a needs basis; currently there are some PwPD and their carers who need these services, yet are not accessing them. The introduction of evidence-based guidelines for palliative care in PD would improve HCW confidence in supporting PwPD, and improve referral to SPC where needed.

## Conclusion.

PwPD and their carers experienced complex physical and psychosocial symptoms, and could benefit from their HCW adopting a holistic palliative care approach to their care. Most PwPD's 'palliative care' needs are addressable within existing disease management programmes. Accurate and responsive needs assessments are important to involve SPC when needs become complicated and outside the scope of the primary care team. As many PwPD and carers are unfamiliar with palliative care, further education is essential so that they can access these services as needed.

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