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

3 **Authors:** Siobhan Fox^{1*}, Alison Cashell², W George Kernohan³, Marie Lynch⁴, Ciara
4 McGlade¹, Tony O’Brien⁵, Sean S O’Sullivan⁶, Mary J Foley⁷ and Suzanne Timmons¹

5 ¹Centre for Gerontology and Rehabilitation, University College Cork, Ireland

6 ²Parkinson’s Association of Ireland, Ireland

7 ³Institute of Nursing and Health Research, University of Ulster, United Kingdom

8 ⁴Irish Hospice Foundation, Ireland

9 ⁵Marymount University Hospital and Hospice, Ireland

10 ⁶Cork University Hospital, Ireland

11 ⁷St Finbarr’s Hospital, Ireland

12 ***Corresponding author:** Siobhan Fox, Centre for Gerontology and Rehabilitation, St. Finbarr’s Hospital,
13 Douglas Road, Cork City, Ireland. Email: s.fox@ucc.ie

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18 care.

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

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22 related to this manuscript.

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24

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

51 **Abstract**

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

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

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

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

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

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

74 **Introduction**

75 Parkinson's disease (PD; see abbreviations table 1) is the second most common
76 neurodegenerative disorder after Alzheimer's disease¹. PD is life-limiting, with complex and
77 progressive symptomatology; thus a palliative care approach is appropriate. People with
78 advanced PD share some symptoms and have an equivalent overall disease burden to people
79 with metastatic cancer^{2,3}. There has recently been increasing recognition of the palliative care
80 needs of people with neurological illnesses, nationally⁴ and internationally⁵.

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

87 However, palliative care needs remain largely unmet⁸ and relatively few people are referred
88 to SPC services⁹. For example, a retrospective review in the UK of PwPD who died in
89 hospital found that only 2.7% had a documented care planning discussion with a clinician and
90 just 13.6% were referred to a SPC team⁹. A recent review also noted that palliative services
91 for PD have been slow to develop¹⁰.

92 Previous qualitative research, conducted with healthcare workers (HCW), explored palliative
93 care needs in PD from their perspective. Less research has been conducted with carers, and
94 very little with PwPD themselves. This research illustrated the high disease burden in PD and
95 unmet palliative care needs; it was widely found that PwPD and their families have needs and
96 experiences similar to those with metastatic cancer³. Other recurring themes were: the
97 emotional impact of diagnosis, including changing social roles, financial difficulties, and

98 carer strain associated with a family member developing PD^{3,11,12}. “Information tension” was
99 another key theme reported¹⁰, including a lack of information around the time of diagnosis,
100 yet also a seemingly paradoxical fear of knowledge; many reported difficulty requesting
101 information from HCW^{3,11,13}.

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

106 Other qualitative, non-palliative care research has found similar themes, for example the
107 experience of diagnosis as ‘dropping a bomb’¹⁴, and the lack of support for carers¹⁵.

108 It is clear from the literature that there is a high disease-related burden in PD¹⁶ yet PwPD and
109 families are not being fully supported within existing healthcare systems from the
110 perspectives of HCWs and carers; notably this has been described across various countries
111 with different healthcare systems (e.g. Ireland^{8,17}, United Kingdom^{12,18}, Canada^{13,19}).

112 However, existing qualitative research involves very small sample sizes¹³, and more
113 importantly little previous research has investigated what PwPD identified as their own
114 palliative care and related support needs.

115 It is important to conduct research *with* a patient group²⁰ and PwPD are expert on their own
116 lives and condition. Therefore, this research complements our previous research with
117 HCW^{8,17} by adding the voice of PwPD and their carers.

118 The primary aim was to explore the palliative care and related issues affecting PwPD and
119 their families. A secondary aim was to explore participants’ perceptions of palliative care and
120 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

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

145 *Data collection*

146 Two semi-structured interview schedules were developed based on our previous research⁸
147 and existing literature¹². These were pilot-tested with one PwPD and one carer, and minor
148 changes to wording and question order were made. These interviews were included in the
149 final analysis. The topic areas are listed in table 2. As the literature indicated that many
150 people are unfamiliar with palliative care, a definition was read to all (see Table 2).

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

154 *Analysis*

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

164 Data were analysed and reported according to Consolidated Criteria for Reporting Qualitative
165 Research guidelines²¹, 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 PD¹⁶. 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.³ 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^{12,17}, 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 needs¹⁷. 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

345 survey research which showed that 21% of PwPD would like early discussion about end-of-
346 life planning and 27% about end-of-life care options such as hospice²².

347 As in past research^{3,11,13}, a lack of information was highlighted; many participants had limited
348 information about PD. This was problematic for many reasons, for example many didn't
349 realise that their non-motor symptoms may be attributable to their PD, and didn't seek help
350 from their specialist, even when in great distress. This study also uniquely adds to the
351 previous discussion by using both solo and dyad interview structures which highlighted the
352 differences in what information PwPD and carers want, how they want this to be delivered,
353 and by whom. Notably, carers were lacking information about coping with advanced disease
354 and were unprepared for this burden. Goy¹⁹ also noted unpreparedness for their loved ones'
355 death in PD. Information given to the carer must be balanced however with the PwPD's
356 readiness to accept information, and they may prefer to receive this information more slowly.

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

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

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

371

372 *Recommendations.*

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

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

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

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

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

392 Conclusion.

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

400

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