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The relationship between physical function and psychological symptoms in

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Parkinson's: A Survey of People with Parkinson's and Carers

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22 *York St John University (STHEC0067). Informed consent was obtained electronically at the start of the*

23 *survey, following provision of the participant information sheet.*

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25 Abstract:

26 Background: People with Parkinson's (PwP) can experience both physical and psychological
27 symptoms, and understanding the perspectives of people affected is crucial for improved
28 management, and clinical outcomes.

29 Objectives: This online survey sought to investigate whether individuals perceive a connection
30 between physical and psychological symptoms, while also considering the influence of personal
31 roles and past symptom experiences.

32 Methods: A UK-wide survey of 251 PwP and 61 family/carers was conducted. The survey focused
33 on reported diagnosed and non-diagnosed psychological symptoms experienced, their onset,
34 and the perceived impact of physical and psychological symptoms on one another. Responses
35 were summarised using descriptive statistics.

36 Results: A substantial proportion of respondents reported at least one diagnosed psychological
37 condition (38.5%) or undiagnosed psychological symptoms (44.6%) such as anxiety and
38 depression. Half of respondents reported perceiving a bi-directional interaction between
39 physical and psychological symptoms, with this perception most reported in people with prior
40 experience of psychological symptoms. Our sample shows that while PwP and carers have similar
41 views on the impact of psychological symptoms, carers perceive the impact of physical symptoms
42 to be greater than PwP.

43 Conclusions: PwP and carers appear to perceive an interaction between physical and
44 psychological symptoms in Parkinson's, noting that psychological symptoms frequently precede
45 Parkinson's diagnosis but are often under-recognised. Improved awareness of the potential link
46 between physical and psychological symptoms in PwP may help to improve assessment, and
47 onward referral processes to enhance care. Further research may assist in identifying potential
48 sub-groups and allow the prediction of changes in physical and psychological presentation.

49 Keywords: Parkinson's disease, Movement disorder, Mental health, Physical health,
50 Physiotherapy, Online survey

51 **1. Introduction:**

52 In addition to common physical symptoms, Parkinson's Disease (PD) can affect an individual's mental
53 wellbeing (1). People with Parkinson's (PwP) experience higher rates of mental health issues,
54 including depression, anxiety, schizophrenia, and psychotic symptoms, compared to the general
55 population (1, 2). For example, whilst 17% of the general population will face anxiety and depression
56 (3), this figure rises to 40% among PwP (4, 5). It is believed that this increased likelihood of mental
57 health symptoms is linked to the condition itself or the side effects of medications (6). Despite these
58 concerning statistics, current NICE guidelines (7) do not offer specific recommendations for
59 addressing mental health issues in PwP. Instead, they simply refer to generic guidelines for depression
60 in adults with chronic health conditions and suggest access to allied health professionals (AHP's) such
61 as physiotherapists, and PD nurse specialists. This approach contrasts with guidance for other
62 neurological conditions, including Multiple Sclerosis, which incorporates specific recommendations
63 for regular cognitive, emotional, and mental health screenings (8, 9).

64 While evidence in older populations suggests a link between physical and psychological
65 presentations (10), there is limited research confirming such a relationship in the PD population.
66 Available studies indicate that PwP perceive anxiety as a factor in amplifying their physical symptoms
67 (11), including increased instances of freezing of gait (12). Several studies have suggested a
68 correlation between increased anxiety and greater severity of motor symptoms, as measured by the
69 Unified Parkinson's Disease Rating Scale (UPDRS) (13-16). To our knowledge, this relationship has yet
70 to be confirmed using more specific measures of physical function, such as balance and mobility
71 assessments, or when considering other psychological symptoms associated with PD (17, 18).
72 Confirming this relationship using alternative measures widely used by healthcare professionals is a
73 vital step to progressing clinical practice, particularly given the aforementioned NICE guidelines.
74 Based on the high proportion of individuals with PD affected by psychological symptoms, further
75 research in this area could significantly enhance our understanding of the potential interaction
76 between physical function and psychological symptoms, potentially leading to improved care
77 strategies.

78 Prior to completing this work, our group conducted a systematic review (19) which highlighted
79 that despite many studies routinely collecting data for both physical and psychological outcomes,

80 only one study included in this review has explicitly examined the relationship between these
81 outcomes (20). Furthermore, our exploratory meta-regression analysis of extracted baseline group-
82 level mean data from previous studies suggested a trend for the physical ability of PwP to reduce as
83 symptoms of depression increase. The single study explicitly investigating the relationship between
84 physical and psychological outcomes was completed by Still et al. (20) and completed bivariate
85 correlation analysis for HADS score against performance on the DGI outcome measure. No significant
86 correlation was found between DGI performance and either overall HADS score ($r=0.269$), HADS-A
87 ($r=0.132$), or HADS-D ($r=0.239$). Significant correlations were found between self-reported motor
88 disability (MDS-UPDRS Part 2) and HADS score ($r=0.624$), HADS-A ($r=0.536$), and HADS-D ($r=0.481$).
89 This supports the suggestion of a potential interaction between physical function and psychological
90 symptoms in PD, however, given the lack of an identified significant correlation with clinician-rated
91 measures of physical function, suggests a potential mismatch in this relationship between participant
92 and clinician assessments. This work has provided the foundation for future investigations, including
93 the investigation of the potential mismatch between clinician-rated and participants self-reported
94 measures of physical function.

95 To date, no survey research has explored the perspectives of PwP and carers of PwP regarding
96 the potential interaction between physical and psychological symptoms in PD. This represents a
97 significant gap in our understanding of the lived experiences of those affected by PD. Current
98 evidence lacks direct input from PwP and carers on their perceptions of symptom interactions, offers
99 limited understanding of how these interactions are experienced in daily life, and provides insufficient
100 data on how perspectives might differ between PwP and carers of PwP. Given these under-
101 researched areas, our study aimed to provide a platform for PwP and carers of PwP to share their
102 experiences and insights. Through an online survey, we collected views on potential interactions
103 between physical and psychological symptoms, as well as information on how these interactions are
104 experienced. Understanding these factors is crucial for informing future research directions and
105 improving clinical service delivery in PD care.

106 **2. Materials and Methods:**

107 2.1 Ethics:

108 Ethical approval was given by the School of Science, Technology and Health Research Ethics
109 Committee at York St John University (STHEC0067). Following provision of the participant
110 information sheet, informed consent was obtained. This was completed electronically at the
111 start of the survey with participants confirming “I meet the eligibility criteria and consent to
112 completing the survey”. We confirm that we have read the Journal’s position on issues
113 involved in ethical publication and affirm that this work is consistent with those guidelines.

114

115 2.2 Developing the Survey:

116 To ensure that the survey considered priority areas, feedback on questions was sought. A
117 draft survey was produced, and feedback provided by three volunteers recruited through
118 Parkinson’s UK (one carer and two PwP). Volunteers reported that the research purpose was
119 clear and that they supported the completion of research in this area. Language used within
120 the survey and associated documentation was edited based on feedback received.
121 Estimated timescales for completion were adjusted from 20-minutes to 30-minutes to
122 reflect more accurately the time taken for PwP to complete the survey. Following feedback,
123 the topic areas addressed included: Demographics, Physical activity, Mental health,
124 Symptom interactions, and Treatments. A copy of the survey questions and flow is available
125 in the supplementary material.

126

127 2.3 Recruitment and Procedures:

128 The survey was open 24/11/2022-21/03/2024 via Qualtrics, an online survey and
129 questionnaire tool. The survey was promoted via the Parkinson’s UK Research Support
130 Network and associated Parkinson’s research interest groups. The Research Support
131 Network has approximately 7,000 members (May 2022), the vast majority of whom are PwP
132 and partners, family members and carers of those with the condition living in the UK. An
133 email was sent to members of the research support network via a monthly e-newsletter, as
134 well as being promoted via the Parkinson’s UK ‘Take Part Hub’.

135 The survey gathered responses from PwP, and family members or carers who were
136 identified by response to the first survey question. No specific requests were made to
137 identify people with specific physical and/or psychological symptoms. Carers were
138 requested to answer each question based on their perception of the person they provide
139 care for.

140 Whilst some demographic information was collected, the survey did not collect any
141 personally identifiable information. Participants were able to skip any questions they did not
142 wish to answer. A copy of the survey questions and flow is available in the supplementary
143 material.

144

145 2.4 Data Analysis

146 Descriptive statistics were used to characterise the sample and data analysed using
147 Microsoft Excel.

148 **3. Results:**

149 A total of 312 responses were received, of which 251 were from PwP and 61 from family/carers.
150 Responses to questions are detailed in the text and table/figures below. Please note that in some
151 instances participants were able to select more than one response per question.

152

153 3.1 Participant Demographics:

154 Table 1 shows details of participant demographics. Of the 312 respondents, 251 were from PwP,
155 with the remainder from family/carers. PwP completing the survey tended to be aged 60 or over
156 (74.1%), whilst family/carers were generally younger. Overall, 57.4% of respondents were
157 female. For family/carer respondents, 90.2% were female, whilst this was 49.4% in responses
158 from PwP. Responses were overwhelmingly from those identifying as white British (93.6%), with
159 this being evident in both groups (PwP: 93.2%, family/carers: 95.1%). In PwP, time since PD
160 diagnosis ranged from 0.01 years to 22.52 years, with a mean of 5.32 years. Time since PD
161 diagnosis tended to be higher in responses from family/carers, with a mean of 10.56 years.

162

163 3.2 Physical Activity:

164 Table 1 also shows details of the reported physical activity levels, alongside details of the
165 perceived importance of physical activity. The majority of responses from PwP indicate physical
166 activity levels of average or higher (85.7%). Although family/carer responses do not necessarily
167 relate to the same individuals, responses show a difference between the perception of the two
168 groups, with only 41.0% of family members/carers reporting that the individual they care has
169 activity levels of average or higher. Despite this mismatch in reported activity levels, both groups
170 report physical activity to be either very important or extremely important (PwP: 92.8%,
171 family/carers: 85.2%).

172 *Table 1: Participant demographics and physical activity level/importance*

Demographic Item	Group		173	
	PwD		Family/Carer	
	n	%	n	%
Total participants	251	80.4%	61	19.6%
Age				
18-29	0	0.0%	4	6.6%
30-39	2	0.8%	5	8.2%
40-49	15	6.0%	7	11.5%
50-59	48	19.1%	11	18.0%
60-69	100	39.8%	18	29.5%
70-79	71	28.3%	16	26.2%
80-89	13	5.2%	0	0.0%
90 or older	1	0.4%	0	0.0%
Prefer not to say	1	0.4%	0	0.0%
Gender				
Male	123	49.0%	6	9.8%
Female	124	49.4%	55	90.2%
Non-binary	0	0.0%	0	0.0%
Prefer not to say	1	0.4%	0	0.0%
Other	3	1.2%	0	0.0%
Ethnicity				
White: English/Welsh/Scottish/Northern Irish/British	234	93.2%	58	95.1%
White: Irish	4	1.6%	1	1.6%
White: Any other White background	6	2.4%	1	1.6%
Asian or Asian British: Indian	2	0.8%	0	0.0%
Black or Black British: Caribbean	0	0.0%	1	1.6%
Prefer not to say	5	2.0%	0	0.0%
Other	0	0.0%	0	0.0%
Reported Time (years) Since Diagnosis				
Mean (SD)	5.32 (4.36)		10.56 (9.16)	
Range	0.01-22.52		0.13-42.91	
Physical Activity Level				
Very Active	67	26.7%	5	8.2%
Quite Active	75	29.9%	6	9.8%
Average	73	29.1%	14	23.0%
Low	33	13.1%	20	32.8%
Very Low	1	0.4%	15	24.6%
Perceived Importance of Exercise				
Not important at all	1	0.4%	0	0.0%
Slightly important	1	0.4%	4	6.6%
Moderately important	16	6.4%	5	8.2%
Very important	113	45.0%	24	39.3%
Extremely important	120	47.8%	28	45.9%

174 3.3 Psychological Symptoms and Diagnoses:

175 3.3.1 Presence of reported psychological diagnoses/symptoms, and frequency by
176 condition:

177 Figure 1 details reported formal psychological diagnoses received and symptoms reportedly
178 experienced without receiving a formal diagnosis. In the PwP group, 79 (31.5%) reported
179 having received a formal diagnosis of psychological condition(s). Of these, the most
180 commonly reported were anxiety (19.1%) and depression (20.3%). A total of 41 family/carers
181 (67.2%) reported that the individual they provide care for had received a formal diagnosis of
182 psychological condition(s). Of the diagnoses reported by family members/carers, the most
183 common were also anxiety (36.1%) and depression (37.7%).

184 *Figure 1: Details of psychological diagnoses and symptoms reported, and the frequency of reported*
185 *psychological diagnoses and symptoms by condition*

186 A greater proportion of PwP (107, 42.6%) reported having experienced symptoms of
187 psychological condition(s) without receiving a formal diagnosis. The most commonly
188 reported symptoms in this instance were anxiety (35.9%), depression (27.1%), apathy
189 (17.1%) and memory problems (19.1%). A total of 32 family members and carers (52.5%)
190 reported that the individual they provided care for had experienced symptoms of
191 psychological conditions without receiving a formal diagnosis. The most commonly reported
192 symptoms in this instance were also anxiety (27.9%), depression (29.5%), apathy (23.0%)
193 and memory problems (31.1%). Psychological symptoms and diagnoses reported as 'other'
194 included: 'Post-Traumatic Stress Disorder', 'Bipolar Disorder', and 'Stress', however
195 accounted for 1.86% of responses to this question and have therefore not been considered
196 further within data analysis.

197 3.3.2 Timepoint of reported diagnoses/symptoms:

198 Figure 2 expands on the reported diagnoses and symptoms to provide details around the
199 timepoint at which the various diagnoses and symptoms were first given or experienced.
200 This data takes into account the number of individuals reaching each timepoint based on the
201 reported date of Parkinson's diagnosis. From all responses received, the greatest likelihood

202 of receiving a formal diagnosis of the following conditions was as follows: Depression – pre-
203 PD diagnosis (63.5%), Anxiety – pre-PD diagnosis (55.7%), Hallucinations – Greater than 10y
204 post-PD diagnosis (35.3%), and Impulsivity or Compulsive behaviours – 2-5y post-PD
205 diagnosis (33.3%).

206 *Figure 2: Timepoint of reported diagnoses/symptoms*

207 From all responses received across both groups, the greatest likelihood of experiencing
208 symptoms yet not receiving a formal diagnosis was as follows: Depression – pre-PD diagnosis
209 (50.0%), Anxiety – pre-PD diagnosis (41.1%), Apathy – Greater than 10y post-PD diagnosis
210 (55.6%), and Memory Problems – Greater than 10y post-PD diagnosis (40.9%). From our
211 data, there appears to be greater variation in the reported timeframe of symptoms
212 experienced without diagnosis in comparison to the timepoints reported for when formal
213 diagnoses were received.

214 3.4 Perceived Symptom Interactions:

215 Figure 3 shows details of reported symptom interactions as perceived by respondents. This data
216 provides additional subgroup analysis for individuals reporting the presence of psychological
217 symptoms and/or diagnosis in comparison to individuals not reporting these.

218 *Figure 3: Perceived Symptom Interactions*

219 3.4.1 Symptoms Experienced First:

220 Graph A shows that despite the high prevalence of psychological diagnoses and symptoms
221 reported pre-PD diagnosis, the majority of PwP and family/carers report experiencing
222 physical symptoms of PD prior to any psychological symptoms (76.5% and 70.5%
223 respectively). This is higher in PwP and family/carers not reporting psychological symptoms
224 (91.3% and 87.5%), dropping to 67.9% and 66.7% when considering only those who reported
225 the presence of psychological symptoms and/or diagnosis.

226 3.4.2 Broad Psychical and Psychological Symptom Interaction:

227 Overall, both PwP and family/carer groups report perceiving physical symptoms to impact
228 on psychological wellbeing (PwP: 78.9%, family/carers: 86.9%). This was again higher when
229 considering PwP and carers who reported the presence of psychological symptoms and/or
230 diagnosis (86.2% and 87.0% respectively) in comparison to those not reporting psychological
231 symptoms and/or diagnosis (66.3% and 75.0%). When considering the inverse relationship,
232 49.4% of PwP and 78.7% of family/carers reported that they perceived psychological
233 symptoms to impact upon physical function. Once again, this was higher in those reporting
234 psychological symptoms/diagnosis (PwP: 61.0%, family/carers: 83.3%) when compared to
235 PwP and family/carers not reporting psychological symptoms and/or diagnosis (29.3% and
236 37.5%). These results are shown in graphs B and C. Overall, 156 individuals (50.0%) reported
237 perceiving that both physical and psychological symptoms impacted on one another. Of
238 these, 127 (81.4%) were individuals with prior experience of psychological symptoms and/or
239 diagnosis.

240 3.4.3 Psychical and Psychological Symptom Interaction (Daily Activities and Quality of

241 Life):

242 Follow-up questions were asked to ascertain the extent of any impact, with questions
243 addressing the impact of both physical and psychological symptoms on daily activities
244 (graphs D and E) and overall quality of life (graphs F and G). Responses indicate that both
245 groups of PwP and family/carers perceive a 'constant' or 'daily' impact of physical symptoms
246 on both daily activities (PwP: 71.7%, family/carers: 91.9%) and quality of life (PwP: 75.3%,
247 family/carers: 91.9%). Based on responses received, a lower impact is perceived on daily
248 activities (PwP: 39.44%, family/carers: 74.2%) and quality of life (PwP: 42.2%,
249 family/carers: 72.6%) as a result of psychological symptoms. These views regarding the
250 impact of psychological symptoms again appear impacted by the presence of reported
251 psychological symptoms/diagnosis, with individuals reporting psychological
252 symptoms/diagnosis perceiving a greater impact of psychological symptoms on daily
253 activities (PwP: 47.2%, family/carers: 83.4%) and quality of life (PwP: 52.2%, family/carers:
254 79.6%) when compared to PwP and family/carers not reporting psychological
255 symptoms/diagnosis (Daily activities: 26.1% and 12.5% and quality of life 25.0% and 25.0%).

256 **4. Discussion:**

257 This online survey sought to investigate whether individuals perceive a connection between
258 physical and psychological symptoms, while also considering the influence of personal roles and
259 past symptom experiences. To our knowledge, this is the first study to explore the perspectives
260 of PwP and family members/carers, which provides a direct account of how these issues are
261 viewed by the recipients of clinical care. This work will help to provide a basis for service
262 development alongside aiding the design of future clinical research projects.

263 Through the analysis of responses, we been able to consider the influence of individuals role
264 and previous symptom experience on their perception of any psycho-physical symptom
265 interactions. This research has helped to improve our understanding of how PwP and
266 family/carers perceive the relationship between physical and psychological symptoms
267 experienced, including at which timepoint various psychological symptoms are most likely to
268 occur and which are most likely to be formally diagnosed.

269

270 **4.1 Physical Activity:**

271 Previous research has shown that PwP generally perceive exercise as highly important in
272 maintaining their level of physical function (21). This perspective is maintained within our study
273 giving reassurance on the representativeness of our sample. When considering group
274 differences, responses highlight a potential mismatch between PwP and carers in the reported
275 levels of physical activity ultimately achieved. This may indicate a possible difference in opinion
276 between PwP and carers in terms of what constitutes a low/high level of physical activity.
277 Alternatively, this could indicate that carers completing our survey represent individuals
278 experiencing a more significant physical and/or psychological impact of PD. This seems to be
279 corroborated by carers reporting a longer time since diagnosis (10.56 years) compared to PwP
280 (5.32 years), which may suggest additional physical decline (22). It is important however to note
281 that the PwP and carer samples are not matched and do not necessarily represent different
282 perspectives of the same individuals.

283

284 4.2 Psychological Symptoms and Diagnoses:

285 4.2.1 Presence of reported psychological diagnoses/symptoms, and frequency by
286 condition:

287 Participants were asked to recall the presence of formal psychological diagnoses and
288 symptoms without formal diagnosis overall, before being asked to select the timepoint at
289 which these diagnoses or symptoms were given/began. These timepoints included pre-
290 Parkinson's diagnosis, diagnosis to 6-months post-diagnosis, 6-months to 2-years post-
291 diagnosis, 2-5 years post-diagnosis, and over 10-years post-diagnosis. These timepoints were
292 chosen in order to capture information relating to significant events such as immediately
293 following Parkinson's diagnosis, but also capture changes potentially relating to disease
294 progression and the impact of elements such as medication. Data analysis for the presence
295 of symptoms/diagnosis was completed by group, whereas timepoint data was combined
296 responses from PwP and family/carers to achieve a more balanced spread across the length
297 of time since formal Parkinson's diagnosis.

298 Since not all symptoms experienced result in or warrant a formal diagnosis, it is to be
299 expected that some individuals will report symptoms without these having been
300 acknowledged formally by clinicians. The reported rates of anxiety and depression in our
301 survey appear to agree with the previously reported prevalence rates (5). Carers reported
302 higher rates of psychological symptoms and diagnoses beyond anxiety and depression. This
303 trend may be attributed to the longer duration since diagnosis in the carer group, allowing
304 more time for various symptoms to manifest and be formally identified.

305 4.2.2 Timepoint of reported diagnoses/symptoms:

306 In our survey, anxiety and depression were most likely to be reported prior to formal
307 diagnosis of Parkinson's. This is of interest given that an increase in symptoms of depression
308 is thought to precede PD diagnosis by a few years (23), with a similar proposal for anxiety
309 (24). It is impossible to say with certainty whether the presence of anxiety and depression
310 prior to formal diagnosis of Parkinson's represents the presence of Parkinson's itself at this
311 stage, however the occurrence of anxiety and depression is higher in PwP than in the general

312 population (25). It is also important to note that it is difficult to fully interpret such findings
313 due to the complexity of any potential interactions, particularly as any relationship between
314 physical and psychological symptoms is likely to be bi-directional in nature.

315 The temporal relationship between the onset of anxiety and depression and the formal
316 diagnosis of PD warrants further investigation. It is possible that the neurodegenerative
317 processes underlying PD contribute to the development of anxiety and depression, or
318 conversely, that these psychological conditions exacerbate the physical symptoms of PD.
319 Additionally, the stress and uncertainty associated with the early, undiagnosed stages of PD
320 could also play a role in the emergence of these symptoms. Future research should aim to
321 disentangle these complex interactions to better understand the relationship between
322 physical and psychological symptoms in PD, and to develop more effective strategies for
323 early diagnosis and comprehensive treatment.

324 Symptoms of apathy and impulsivity were also commonly reported within our sample;
325 however, both were more likely to be experienced as symptoms rather than involving formal
326 recognition. Symptoms of apathy were commonly reported throughout the disease time-
327 course, with symptoms of impulsivity also reported throughout however appeared to peak
328 at 2-5 years post Parkinson's diagnosis, consistent with previous findings (26). In our sample,
329 symptoms of hallucinations were most commonly reported 2-5 years following Parkinson's
330 diagnosis, with formal diagnosis peaking at over 10 years following Parkinson's diagnosis,
331 likely reflecting the side-effects of levodopa treatment and limited treatment for the
332 hallucinations themselves without inducing further side-effects (27).

333 These findings have implications for clinical services with respect to screening for
334 various psychological symptoms and subsequent education provided following diagnosis.
335 For example, given the high reported prevalence of anxiety and depression symptoms prior
336 to formal Parkinson's diagnosis, it may be beneficial for clinical services to screen for these
337 symptoms from the outset to enable optimal signposting to relevant secondary services.
338 Whilst not a conclusive resource for Parkinson's symptoms at each timepoint, this work
339 provides some insight into self-reported symptoms which are not necessarily identified by
340 clinical services. In addition, this work provides a platform for further investigation regarding

341 the presence of various symptoms alongside actions taken on identification within practice.
342 As others have suggested, it may eventually be possible to predict the presence or likelihood
343 of developing Parkinson's based on the identification of non-motor symptoms prior to the
344 development of observable motor symptoms (28-31).

345

346 4.3 Perceived Symptom Interactions:

347 4.3.1 Symptoms Experienced First:

348 As discussed previously, there is evidence to suggest that non-motor symptoms may precede
349 diagnosis of PD, and even the motor symptoms themselves (23). It is therefore somewhat
350 surprising that despite many respondents reporting non-motor symptoms/diagnosis prior to
351 diagnosis of PD, over 75% nevertheless report experiencing motor symptoms first. This may
352 indicate a lengthy process of diagnosis in which both groups of symptoms are experienced
353 before formal diagnosis, a recall bias towards motor symptoms, a lack of recognition that
354 non-motor symptoms may be associated with PD even amongst individuals directly
355 impacted by the condition, or pre-existing non-motor symptoms long before the presence
356 of PD was considered.

357 4.3.2 Broad Psychical and Psychological Symptom Interaction:

358 Individuals who had reported psychological symptoms and/or a formal diagnosis reported
359 an increased recognition of the potential for psychological symptoms to occur prior to
360 physical symptoms. In comparison to individuals without experience of psychological
361 symptoms, this group were more likely to perceive an interaction between physical and
362 psychological symptom on one another. Strikingly, although 50.0% of participants overall
363 reported perceiving that both physical and psychological symptoms impacted on one
364 another, 81.4%) of these were individuals with prior experience of psychological symptoms
365 and/or diagnosis. This may reflect an under-recognition of potential symptom interactions
366 until directly experienced by an individual, and potentially highlight a gap in education from
367 clinicians when preparing people for what to expect as their condition progresses (32, 33).
368 This may be particularly relevant when preparing for the later stages of the condition, or

369 when explaining to individuals that the psychological symptoms they have experienced prior
370 to formal PD diagnosis may be related to the presence of PD itself.

371 This latency in the awareness of the broader impact of physical and psychological
372 symptoms is also reflected in the responses to other questions, suggesting a direct impact
373 of personal experiences (i.e. the presence or absence of psychological symptoms) and an
374 individual's role (PwP or family/carer) on a person's perception. The primary factor involved
375 with this appears to be whether the question is concerned with the impact of physical or
376 psychological symptoms.

377 4.3.3 Psychical and Psychological Symptom Interaction (Daily Activities and Quality of
378 Life):

379 Based on responses to our survey, the presence or absence of psychological symptoms tends
380 to have a greater impact on how individuals perceive psychological symptoms to impact on
381 aspects such as physical function, daily activities, and quality of life. Individuals without
382 experience of psychological symptoms were much less likely to report a perceived impact of
383 psychological symptoms in these areas in comparison to individuals with first-hand
384 experience of psychological symptoms. These responses might reinforce our suggestion that
385 there is an under-recognition of symptom interactions until directly experienced and
386 suggests a role for clinicians in preparing for these scenarios in advance.

387 In addition to the impact of personal experiences, there also appears to be an impact of
388 an individual's role in the response to these questions, with PwP and family/carers
389 responding differently to questions concerning the influence of physical symptoms
390 regardless of their experience's psychological symptoms. In general, responses from
391 family/carers reflect a greater perceived impact of physical symptoms on daily activities and
392 quality of life in comparison to PwP. This was initially surprising however when given further
393 consideration may be because carers are potentially not present at all times and may
394 therefore more likely to overestimate the impact of these symptoms in comparison to PwP,
395 who may themselves have simply become more accustomed to this impact and adapted
396 their lifestyle accordingly. Alternatively, as family/carer responders do not necessarily reflect

397 the same individuals with Parkinson's, and tended to report a longer time since diagnosis,
398 this difference may merely signal an influence of greater symptom progression.

399

400 4.4 Strengths and Limitations of this study:

401 Whilst efforts were made to minimise limitations, this study lacked the ability to objectively
402 assess disease severity and compare this with reported symptoms. Although our survey
403 collected a large number of responses, indicating that many individuals felt strongly enough
404 about the topic to complete it, the sample was non-random. As a result, respondents were
405 potentially more likely to have experienced both physical and psychological symptoms or
406 have an interest in this area, so may not be entirely representative of the Parkinson's
407 population overall. Given the immense variety of potential symptoms that individuals may
408 experience, information was not collected regarding the specific physical symptoms, or the
409 severity of symptoms that were experienced by PwP completing our survey. Due to the
410 subjective nature of survey responses, it is therefore not possible to infer any interactions
411 between specific physical and psychological symptoms, however this is a potential
412 opportunity for further investigation now that an overall perspective has been established.

413 Where possible we have attempted to compare our data to previously published
414 research as a reference point to indicate the representativeness of our sample. For example,
415 our sample reported a high perceived importance of physical activity, and the reported rates
416 of anxiety and depression aligned with the accepted prevalence in PD. Respondents were all
417 from the United Kingdom, which has implications for the availability of clinical services.
418 Despite these limitations, our survey was able to address the aim of this exploratory study,
419 to provide an opportunity for PwP and carers of PwP to share their experiences of any
420 potential interaction between physical and psychological symptoms experienced.

421 A major strength of this study was that it allowed the exploration of the perceived
422 relationship between physical and psychological symptoms of Parkinson's by collecting the
423 views of PwP and carers. PwP and carers themselves were involved in the design of the
424 survey through commenting on draft questions to ensure that the survey focused on areas

425 that were most important to them. The work has helped to provide an overview of how any
426 relationship between these symptom groups is perceived, which will be helpful when
427 combined with ongoing work considering the perspectives of UK-based physiotherapists.
428 The study highlights the need to enhance formal assessment of psychological symptoms and
429 optimising onward referrals to appropriate services to provide comprehensive care for PwP.

430 **5. Conclusions:**

431 From our survey results, PwP and carers appear to appreciate the link between physical
432 function and non-motor symptoms in Parkinson's, however both report an under-recognition of
433 psychological symptoms experienced. Anxiety and depression are most commonly reported as
434 being experienced and formally diagnosed, yet there is large variation in the timepoint of
435 reported diagnosis and symptoms. Psychological symptoms were widely reported to precede
436 formal diagnosis of Parkinson's in many cases. Furthermore, the extent of these reported
437 perceived symptom interactions, and the wider impact of each, appears to be influenced both
438 by role (PwP or family/carer) and by whether an individual has first-hand experience of
439 psychological symptoms.

440 The findings of this study highlight the complex interplay between physical and non-
441 motor symptoms in Parkinson's disease, emphasising the importance of a holistic approach to
442 patient care. The perceived bi-directional relationship between these symptom groups,
443 particularly among those with prior experience of psychological symptoms, underscores the
444 need for comprehensive assessment and management strategies. The discrepancy in symptom
445 impact perception between people with Parkinson's and carers further emphasises the
446 importance of considering multiple perspectives in care planning. By recognising the
447 interconnectedness of symptom groups, healthcare providers can develop more effective,
448 personalised treatment plans that address multiple aspects of the disease, potentially improving
449 overall quality of life for individuals living with Parkinson's.

450 Given the widely reported perceived interaction between physical and psychological
451 symptoms, efforts should be made to improve formal symptom recognition and optimise
452 signposting to appropriate services. Enhancing formal assessment of psychological symptoms
453 and optimising onward referrals to appropriate services is essential to provide comprehensive
454 care for PwP. Further research is needed to identify any potential sub-groups and objectively
455 predict the decline in physical function and psychological symptoms.

456

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458 The authors do not have any financial support or relationships that may pose conflict of interest

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467 **9. Supplementary Material**

468 Supplemental material for this article is available online [DOI: 10.25421/yorks.j.25974733].

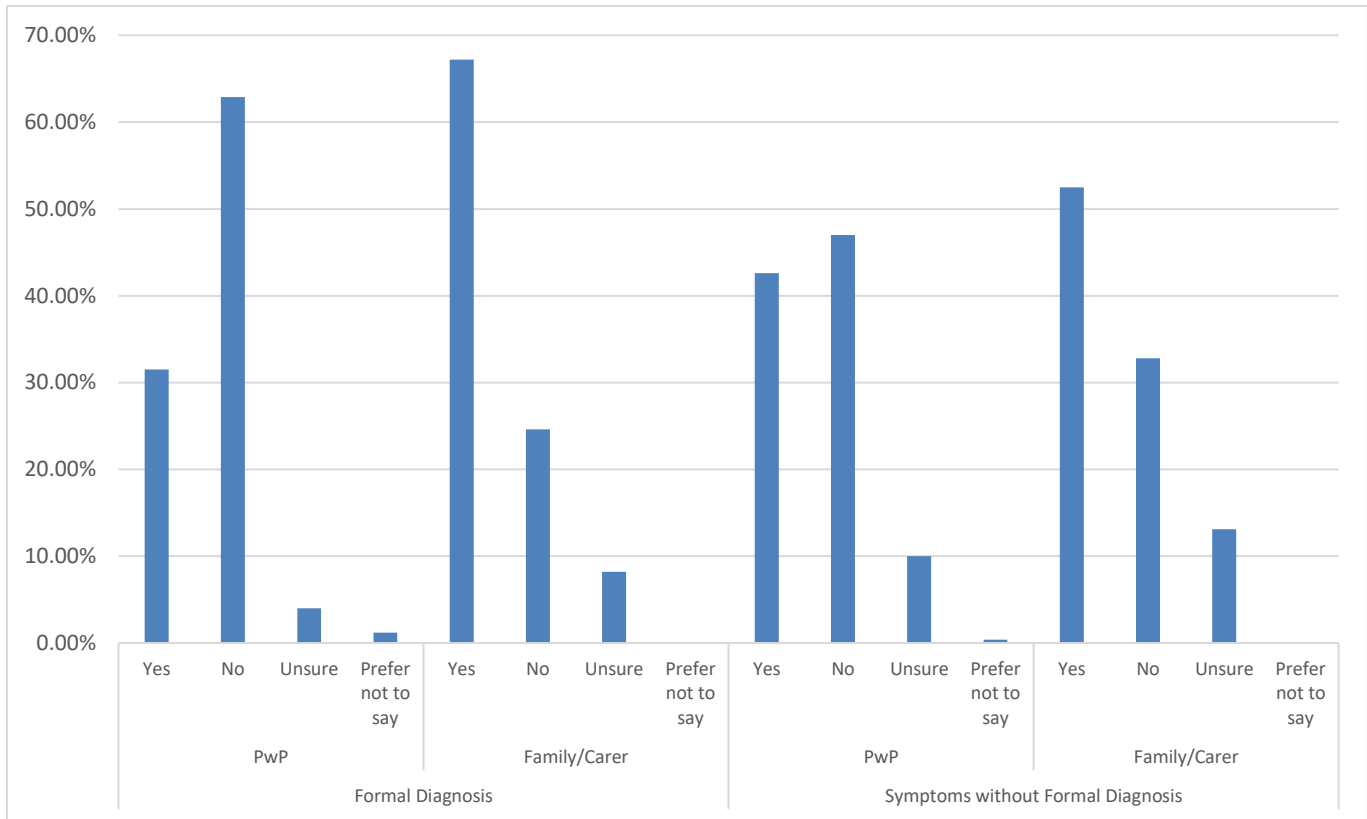
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A. Presence of reported formal psychological diagnosis and/or psychological symptoms without diagnosis by group.



B. Frequency of reported psychological diagnoses and psychological symptoms without diagnosis by condition

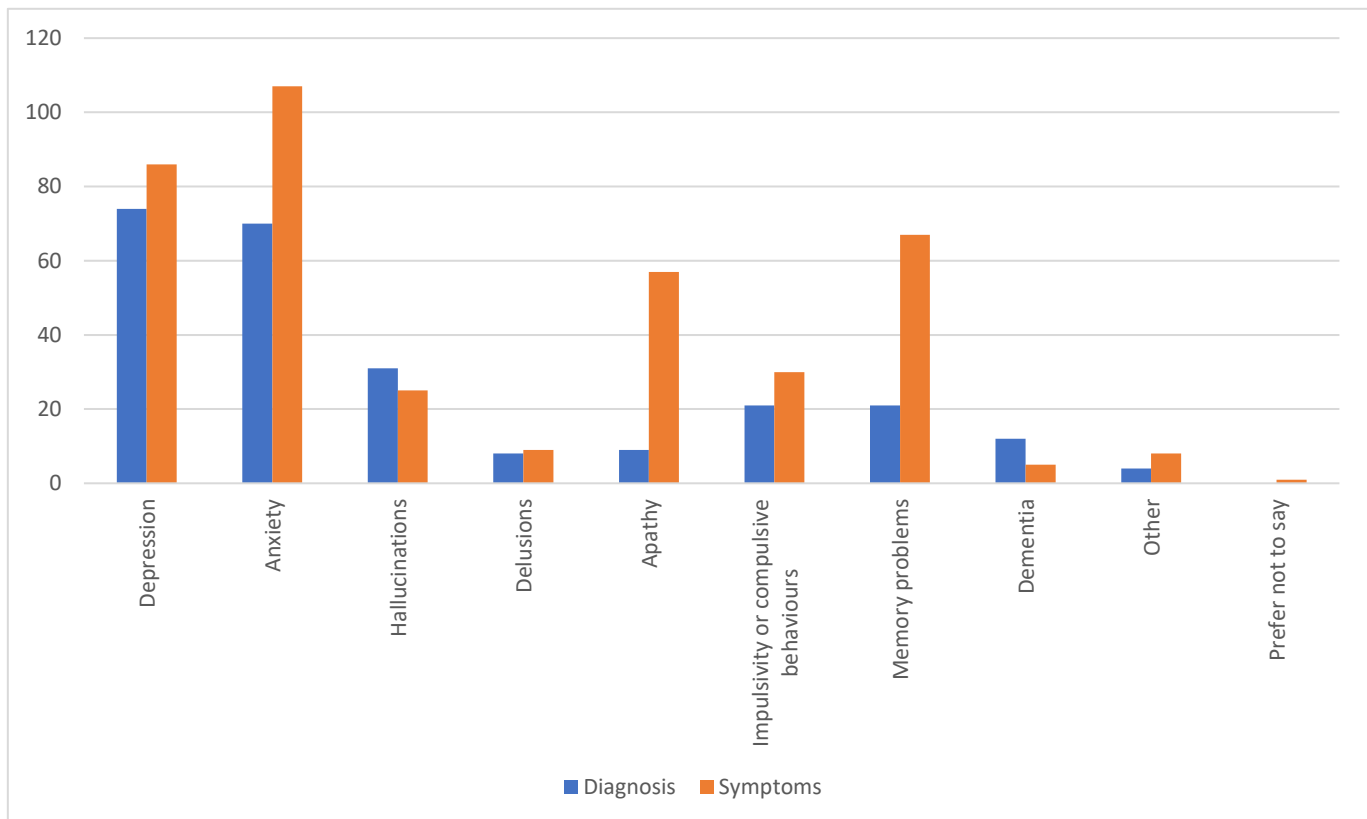
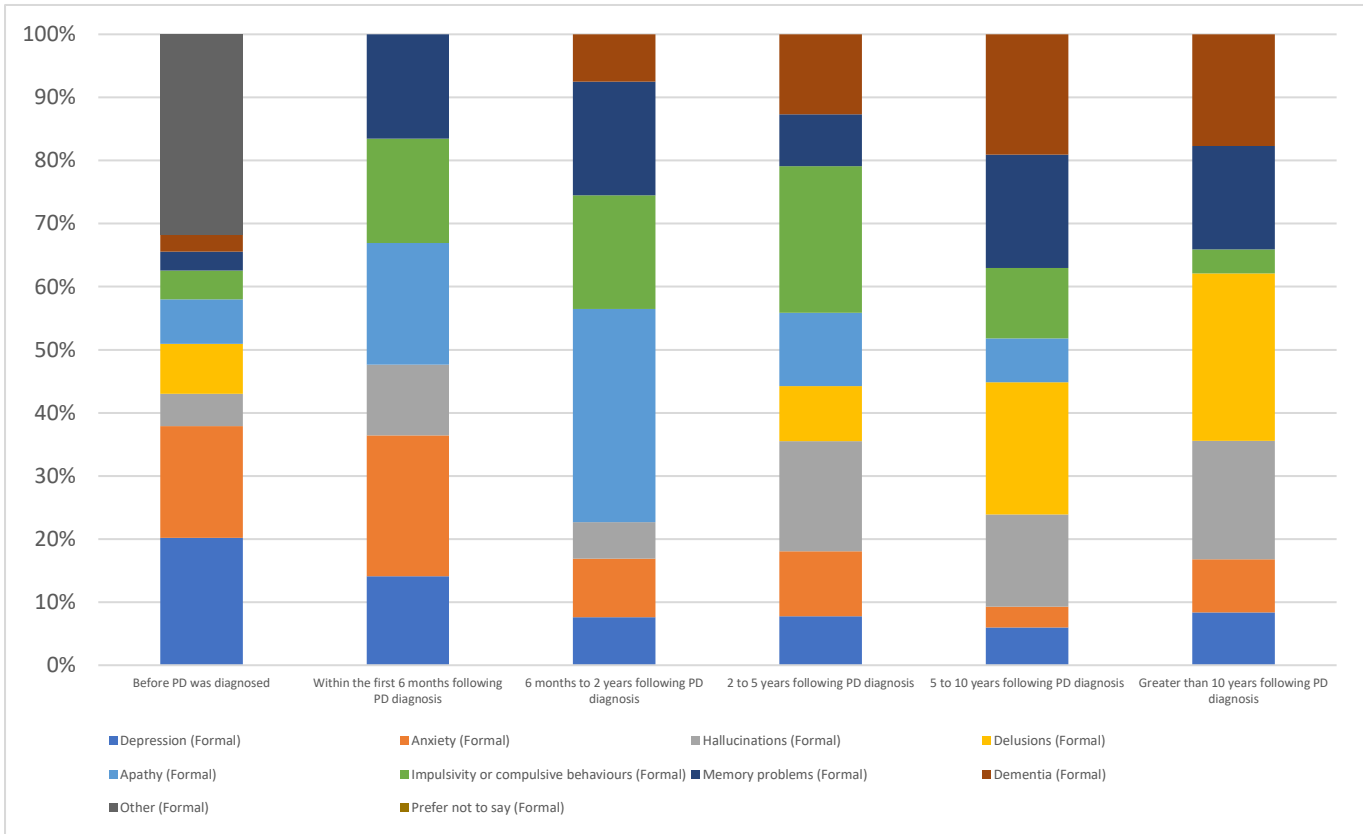


Figure 1: Details of psychological diagnoses and symptoms reported, and the frequency of reported psychological diagnoses and symptoms by condition

A. Timepoint of reported formal diagnosis



B. Timepoint of reported symptom onset without formal diagnosis

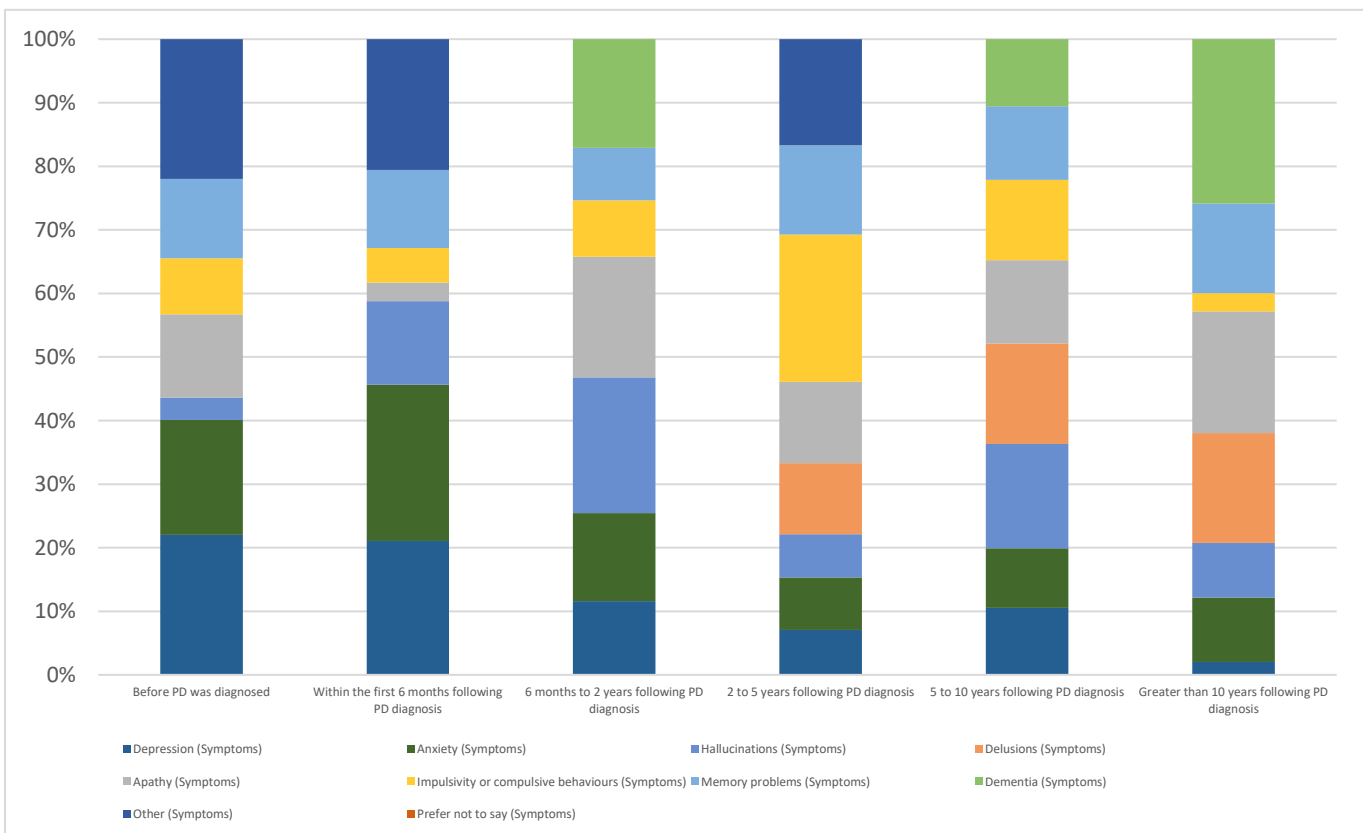
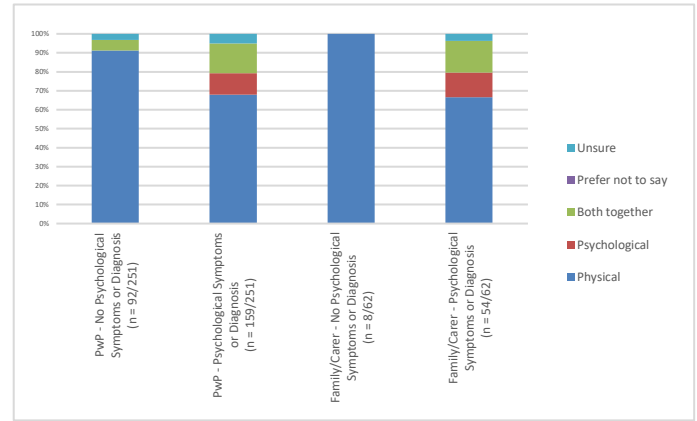


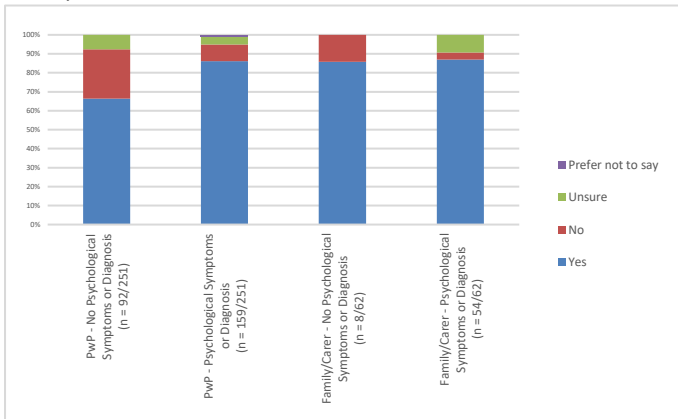
Figure 2: Timepoint of reported diagnoses/symptoms

- A. Symptom group experienced first
- B. Impact of physical symptoms on psychological wellbeing
- C. Impact of psychological symptoms on physical function
- D. Impact of physical symptoms on daily activities
- E. Impact of psychological symptoms on daily activities
- F. Impact of physical symptoms on quality of life
- G. Impact of psychological symptoms on quality of life

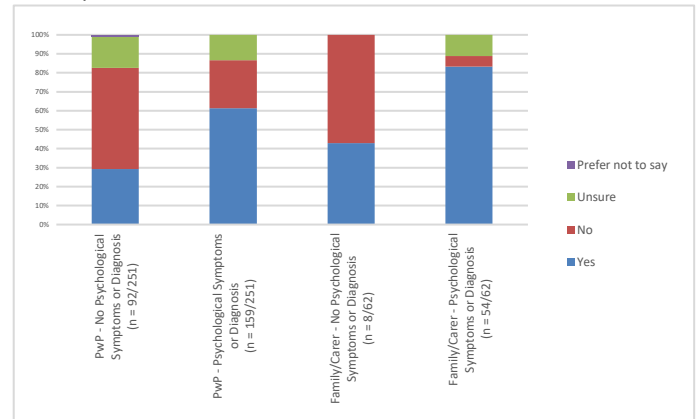
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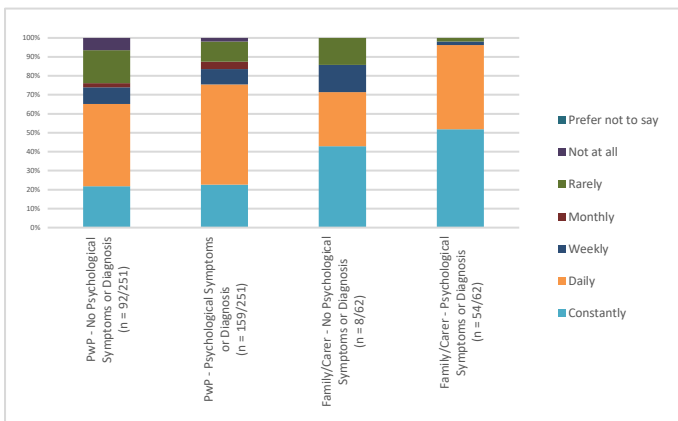
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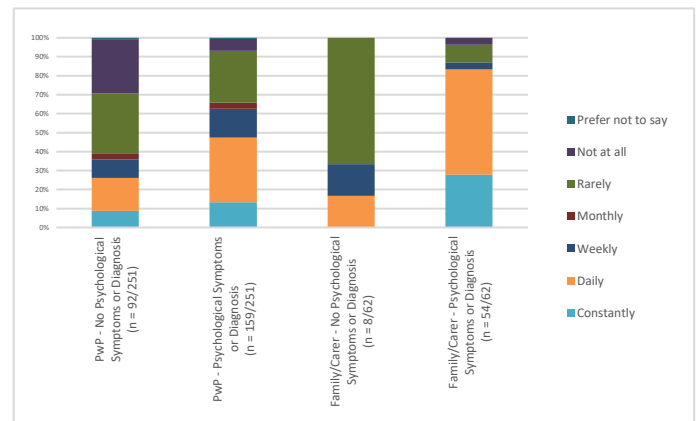
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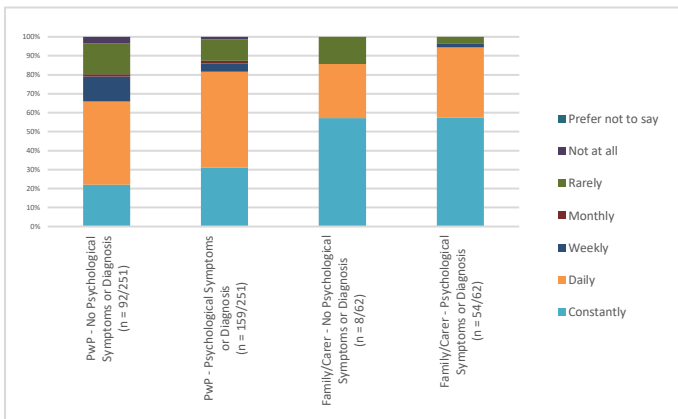
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E)



F)



G)

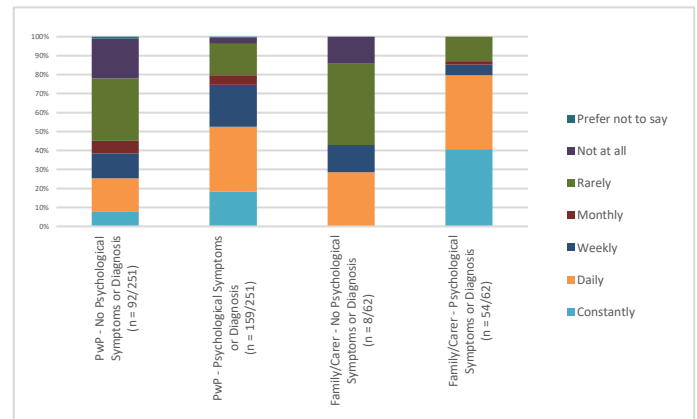


Figure 3: Perceived Symptom Interactions