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Hunter, Heather

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1 Experiences of people with Parkinson's disease
2 and their views of physical activity interventions: a
3 qualitative systematic review protocol
4

5 Authors:

6 Heather Hunter¹

7 Christopher Lovegrove²

8 Bernhard Haas¹

9 Jennifer Freeman¹

10 Hilary Gunn¹

11 1. School of Health Professions, Plymouth University, UK

12 2. Royal Devon and Exeter NHS Trust, UK

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14 Centre conducting the review:

15 Plymouth University, an affiliated centre of the Joanna Briggs Institute

16 Corresponding Author:

17 Heather Hunter, PAHC Building, Derriford Road, PL6 8BH,

18 University of Plymouth, United Kingdom.

19 Email: heather.hunter@plymouth.ac.uk

20 Tel: + 44 1752 588842

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22 Category of paper: (ii) Systematic Review Protocol

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26 This review aims to explore the experiences of people with Parkinson's diseases' (pwPD) participation
27 in physical activity and their views of interventions designed to engage and sustain engagement.
28 Synthesis of the best available evidence will be used to determine any gaps in the research literature
29 and make recommendations on approaches to increase and maintain engagement in physical activity
30 in pwPD living in a community setting. The specific objectives are to:

31 **Review objectives:**

32 Explore pwPD experiences and preference(s) for physical activity.

33 Explore pwPD perceptions of barriers and enablers to physical activity.

34 Identify, from the perspective of pwPD, the impact of support mechanisms and behavior change
35 interventions in maintaining participation in physical activity.

36

37 **Background**

38 Parkinson's disease (PD) is a neurodegenerative disease which primarily affects the basal ganglia,
39 resulting in progressive movement disorders that over time, become more disabling.¹ The cardinal
40 features of Parkinson's disease include difficulty in initiating movements (akinesia) as well as slowness
41 and difficulty maintaining movement (bradykinesia), tremor and rigidity.² Together, these symptoms
42 contribute to a significant reduction in mobility, loss of function and a reduced quality of life.³ People
43 with Parkinson's disease have been shown to adopt a sedentary lifestyle and reduce levels of physical
44 activity more quickly than their healthy peers.^{3,4} For example, a large study which compared the physical
45 activity data of pwPD (n=699) to controls (n= 1,959) found that pwPD were, on average 29% less active
46 compared to age matched controls.³ Furthermore, Lana et al found increased age, disease severity
47 and inability to perform activities of daily living to be predictors of physical inactivity in pwPD.⁵

48 There is substantial evidence to support the benefits of physical activity in pwPD,⁶⁻¹¹ where physical
49 activity is defined as "any bodily movement produced by skeletal muscles that results in the expenditure
50 of energy".^{12(p127)} Physical activity is an umbrella term for the sum of all activity undertaken throughout
51 the day and can be subdivided into leisure time physical activity (e.g. walking and swimming); non-
52 leisure (occupational and household) and exercise (e.g. aerobic, strengthening, flexibility), which is
53 structured and repetitive and has an objective of the improvement or maintenance of physical fitness.¹²
54 Physical activity can be supervised, unsupervised and performed in a group or individually. People with
55 Parkinson's disease undertaking physical activity, delivered as a supervised exercise program, tend to
56 report better quality of life, improved ambulation, balance, strength, flexibility and cardiovascular fitness
57 compared with those who did not exercise.^{6,7,9} A criticism of much of this research is that follow up is
58 limited to short term (3-6 months) so it is difficult to determine if physical activity is sustained long term.
59 Results from research across a variety of populations¹³⁻¹⁶ suggests that recidivism upon cessation of

60 intervention is a reality. This is likely to be the case for pwPD unless strategies for the maintenance of
61 long-term participation in physical activity are developed.

62 Because physical activity is a complex and dynamic process involving an intricate series of behaviors,
63 identification of the variables affecting uptake and sustained participation is often difficult.¹⁷ This should
64 begin with an appreciation of the perspectives of pwPD in terms of understanding their preferences for
65 physical activity as well as barriers and enablers to participation. Pentecost & Taket undertook a large
66 study, interviewing 130 people with chronic conditions from diverse socio-demographic backgrounds;
67 including those, who did and those who did not attend exercise services, as well as supporters of those
68 who attended. Results identified three factors that were particularly important in influencing engagement
69 and sustained participation in physical activity: 'exercise identity', 'support' and 'perceived benefits of
70 attending'. Having at least one person providing different types of support was associated with higher
71 levels of attendance.¹⁸ Those people who valued the social and psychological benefits of attending
72 were more likely to attend.¹⁸ Research in pwPD by Ellis et al. identified the importance of self-efficacy,
73 education and age as significant factors associated with increased physical activity. Respondents with
74 high self-efficacy were more than twice as likely to engage in physical activity as those with low self-
75 efficacy (adjusted OR=2.34, 95% CI=1.3-4.23).¹⁹ Ellis et al identified a number of barriers to
76 participation in physical activity, such as low outcome expectations, a lack of time and fear of falling.²⁰
77 Enabling factors which have been identified in the PD literature include provision of support via
78 instrumental, (e.g., provision of transport and mutual participation), emotional (e.g., provision of
79 encouragement through a variety of face-to-face and remote means), and informational mechanisms,
80 (e.g., type of exercise that would be beneficial to their condition by health professional or fitness
81 instructor).

82 Changing health behavior in terms of moving from a sedentary lifestyle to one that is physically active
83 is both a complex and challenging process, particularly as the success of many rehabilitation programs
84 requires both attendance at structured sessions and adherence to exercises that are to be completed
85 un-supervised at home^{21,22}. A range of behavior change interventions have been developed and studied
86 to support this process. Whilst a variety of approaches have been used, for the purposes of this
87 systematic review, behavior change interventions are defined as any psychology-based interventions
88 (used alone or in combination with other interventions, such as exercise therapy) aimed directly or
89 indirectly at behavior change with regard to level of physical activity participation or change in perceived
90 physical function.²³

91 The National Institute of Health and Clinical Care Excellence (NICE) Public Health Guidance has
92 identified a number of elements for inclusion in an effective behavior change intervention, which
93 includes the use of goal setting, feedback and monitoring, fostering of self-efficacy, and social support.²¹

94 While NICE does not recommend one specific behavior change approach, it does recommend that

95 it should match the service users' needs and be evaluated.^{21,24} Behavior change interventions in people
96 with long-term conditions such as Multiple Sclerosis (MS) and Rheumatoid Arthritis (RA) have been
97 evaluated in two systematic reviews with equivocal results. Sangelaji et al concluded that after
98 completion of a short term behavioral intervention there was a positive effect on the amount of physical
99 activity undertaken by people with MS.²³ In contrast, Cramp et al determined that due to methodological
100 flaws and a lack of comparison with usual care, it was not possible to conclude whether health behavior
101 change interventions could increase physical activity in people with RA, although the number of included
102 studies was low.¹⁴ The effect of the addition of behavior change interventions to physical activity
103 programs in pwPD was studied by Speelman et al who identified increased physical activity in all sub
104 groups of pwPD (grouped by gender, activity level and disease severity). Given the varied results of the
105 use of behavior change interventions in long term conditions, it is particularly important to develop an
106 understanding of service users' experiences and perceptions of these interventions in order to inform
107 which specific aspects should be incorporated into the program.²¹

108 Summary

109 Research in physical activity in PD to date has tended to focus on supervised exercise programs. The
110 views and preferences of pwPD towards physical activity is an important aspect to consider to support
111 long-term participation, while an appreciation of barriers and enablers to physical activity would help
112 healthcare practitioners design physical activity programs which best meet the needs of pwPD.
113 Behavior change interventions have been used with pwPD to promote uptake and long-term
114 participation in physical activity. However, when designing behavior change interventions, the needs
115 and preferences of the target audience need to be addressed to ensure that the most appropriate
116 approach is utilized.

117 This systematic review will aim to identify and synthesize the best available evidence for interventions
118 that foster pwPD's uptake and long-term participation in physical activity, and identify any gaps in the
119 existing evidence for further investigation. A preliminary search of PROSPERO, The JBI Database of
120 Systematic Reviews and Implementation Reports and Cochrane databases has been performed to
121 ensure the originality of this proposed review.

122

123 Inclusion criteria

124 *Types of participants*

125 The review will consider studies that include people with a confirmed diagnosis of Parkinson's disease.

126 Phenomena of interest

127 The review will consider studies that explore experiences, preferences, barriers and enablers to
128 physical activity in pwPD, including the use of behavioral interventions and support strategies. Behavior
129 interventions could include goal setting, cognitive re-structuring, and motivational interviewing, while
130 support strategies could include, facilitation of peer/ family support.

131 **Context**

132 The context for this review is a community setting

133 ***Types of studies***

134 This review will consider studies that focus on qualitative data including, but not limited to, designs such
135 as phenomenology, grounded theory, ethnography, and action research and the qualitative component
136 of mixed methods studies.

137 **Search strategy**

138 The search strategy aims to find both published and unpublished studies. A three-step search strategy
139 will be utilized in this review. An initial limited search of MEDLINE will be undertaken, followed by an
140 analysis of the text words contained in the title and abstract, and of the index terms used to describe
141 the article. A second search using all identified keywords and index terms will then be undertaken
142 across all included databases. Thirdly, the reference list of all identified reports and articles will be
143 searched for additional studies. Studies published in English since the inception of the database will be
144 considered for inclusion in this review. Two independent reviewers will screen abstracts and full text
145 articles for eligibility for inclusion, and any duplicates will be removed

146 **The databases to be searched include:**

147 MEDLINE (Ovid), EMBASE (Ovid), CINAHL (EBSCO), AMED (EBSCO), Web of Sciences, SCOPUS,

148 The search for unpublished studies will include hand searches of reference lists of all identified article
149 and searches using Google, CRO database, PQDT open, Open Grey, MEDNAR, Conference Papers
150 Index. Authors will then be contacted directly to request the full papers for inclusions, where these are
151 available.

152 **Initial keywords to be used will be:**

153 Parkinson's Disease; Parkinson's; PD; Physical activity; exercise; motor activity; exercise program*;
154 leisure activity; walking; tai chi; swimming; yoga; experiences; preferences; views; attitudes; beliefs;
155 participation; engagement; adherence; compliance; concordance; enablers; motivators; facilitators;
156 barriers.

157 See appendix I for search strategy

158

159 **Assessment of methodological quality**

160 Qualitative papers selected for retrieval will be assessed by two independent reviewers for
161 methodological validity prior to inclusion in the review. The JBI Qualitative Assessment and Review
162 Instrument (JBI-QARI) (Appendix II) will be used. JBI-QARI is a standardized critical appraisal
163 instrument from the JBI System for the Unified Management, Assessment and Review of Information
164 (JBI-SUMARI) software. Any disagreements that arise between the reviewers will be resolved through
165 discussion, or with a third reviewer.

166 **Data extraction**

167 Qualitative data will be extracted from papers included in the review, by two people independently,
168 using the standardized data extraction tool from JBI-QARI (Appendix III). The data extracted will include
169 specific details about the interventions, populations, study methods and outcomes of significance to the
170 review question and specific objectives. Authors of primary studies will be contacted as required for
171 missing information or to clarify unclear data

172 **Data synthesis**

173 Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the
174 aggregation or synthesis of findings to generate a set of statements that represent that aggregation,
175 through assembling the findings rated according to their quality, and categorizing these findings on the
176 basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to
177 produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-
178 based practice. Where textual pooling is not possible, the findings will be presented in narrative form.

179 **Conflicts of interest**

180 There are no conflicts of interest for any of the authors.

181 **Acknowledgements**

182

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241

242

243 **Appendix I**

244 Search Strategy

245 Parkinson's Disease OR Parkinson's OR PD

246 AND

247 Physical activity OR exercise, OR motor activity OR exercise program*, OR leisure activity, OR walking
248 OR tai chi OR swimming OR yoga

249 AND

250 Experiences, OR preferences, OR views, OR attitudes, OR beliefs OR participation OR engagement
251 OR adherence OR compliance OR concordance OR enablers, OR motivators, OR facilitators, OR
252 barriers

253

254

255 **Appendix II: appraisal instruments**

256 **QARI appraisal instrument**

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer Date

Author Year Record Number

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info.

Comments (Including reason for exclusion)

257
258
259

260 Appendix III: Data extraction instruments

261 **QARI data extraction instrument**

**JBI QARI Data Extraction Form for Interpretive
& Critical Research**

Reviewer Date

Author Year

Journal Record Number

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete

Yes

No

262

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete

Yes

No

263

264

265