

2019-10-10

A qualitative study on the impact of First Steps- a peer-led, educational intervention for people newly diagnosed with Parkinson's Disease.

Soundy, A

<http://hdl.handle.net/10026.1/14958>

10.3390/bs9100107

Behavioral Sciences

MDPI AG

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.

Title page

Title: A qualitative study on the impact of First Steps- a peer-led, educational intervention for people newly diagnosed with Parkinson's Disease.

Soundy, A*, Collett, J., Lawrie, S., Coe, S. Roberts, HC., Hu, M.T., Bromley, S., Harling, P., Reed, A., Coebergh, J., Carroll, C., Dawes, H.

*Corresponding author

Authors

1. Andy Soundy
Address: School of Sport, Exercise and Rehabilitation, University of Birmingham, Birmingham, B15 2TT. United Kingdom.
Email: A.A.Soundy@bham.ac.uk
2. Johnny Collett
Address: Centre for Movement, Occupational and Rehabilitation Sciences, Faculty of Health and Life Sciences, Oxford Brookes University, OX3 OBP. United Kingdom.
Email: jcollett@brookes.ac.uk
3. Sophie Lawrie
Address: Centre for Movement, Occupational and Rehabilitation Sciences, Faculty of Health and Life Sciences, Oxford Brookes University, OX3 OBP. United Kingdom.
Email: slawrie@brookes.ac.uk
4. Shelly Coe
Centre for Movement, Occupational and Rehabilitation Sciences, Faculty of Health and Life Sciences, Oxford Brookes University, OX3 OBP. United Kingdom.
Email: scoe@brookes.ac.uk
5. Helen Roberts
Address: Academic Geriatric Medicine, University of Southampton. Southampton General Hospital mailpoint 807, Southampton, SO16 6YD. United Kingdom.
Email: H.C.Roberts@soton.ac.uk
6. Michele Hu
Address: Department of Neurology, Nuffield Department of Clinical Neurosciences, Level 3, West Wing, John Radcliffe Hospital, Oxford, OX3 9DU. United Kingdom.
Email: michele.hu@ndcn.ox.ac.uk.
7. Sally Bromley
Address: Parkinson's UK Oxford Branch, Botley Women's Institute Hall, North Hinksey Lane, Oxford, OX2 0LT. United Kingdom.
Email: oxford.sally@gmail.com
8. Peter Harling
Address: Norton Consulting Group
Malthouse, Main Road
Curbridge
OX29 7NT
Email: peter.harling@nortonexecutive.com
9. Alex Reed
Address: European Parkinson's Therapy Centre. Piazzale Delle Terme, 3. 25041 Dafo Boario Terme (Brescia) Italy.
Email: alexreeditaly@gmail.com

10. Jan Coeberg

Address: Department of Neurology, St George's University Hospitals NHS Foundation Trust.

Email: Jan.Coebergh@asph.nhs.uk

11. Camille Carroll

Address: Institute of Translational and Stratified Medicine, University of Plymouth, N14, ITTC Building, Plymouth Science Park, Plymouth Science Park, Plymouth, Devon, PL6 8BX.

Email: camille.carroll@plymouth.ac.uk.

12. Helen Dawes

Address: Centre for Movement, Occupational and Rehabilitation Sciences, Faculty of Health and Life Sciences, Oxford Brookes University, OX3 0BP.

Email: hdawes@brookes.ac.uk

Conflict of interest:

SB, AR and PH were involved in the development of the First Steps program. Sally Bromley is chair of the Parkinson's UK Oxford Branch.

Funding: This project was funded by a Service Improvement Grant awarded to HD, MH and HR in 2016 by Parkinson's UK (<https://www.parkinsons.org.uk>). Grant number: M6002

Individual funding:

MH: Parkinson's UK Monument Discovery Award, Oxford BRC, University of Oxford, National Institute for Health Research, Michael J Fox Foundation, H2020 European Union, GE Healthcare, PSP Association. Consultant for Biogen and Roche Advisory Boards.

HCR is supported by the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Wessex and the NIHR Southampton Biomedical Research Centre.

Acknowledgements:

We would like to acknowledge Valerie Buxton and Katherine McLoughlin from Parkinson's UK for supporting the project.

Abstract

Aim

The dual aim of this research is to consider the impact of providing the First Steps program on the stories of people with Parkinson's Disease (PD) and investigate the psychosocial and emotional mechanisms which may explain this impact.

Methods

A qualitative study using a subtle realist paradigm and hermeneutic phenomenological methodology was undertaken. A single semi-structured interview was used to consider the impact and experiences of people with PD who completed either the intervention (2-day peer-led behavior intervention using storytelling 6-8 weeks apart) or received telephone support calls as part of the active control group. Descriptive statistics and narrative analysis were undertaken on the results.

Results

Forty-two participants were invited to participate of whom forty completed the interview. This included 18 from the intervention group and 22 from the active control group. The intervention group identified the value of the program as worth-while, demonstrating improved exercise behavior and coping mechanisms following the intervention. Three major stories (the affirmed, the validated and the transformed story) identified the impact of the intervention. Three internal mechanisms (perceived control, hope and action, and the individual's mind set) alongside three social mechanisms (social comparison, social control and the first opportunity to share with peers) appeared to explain the impact.

Conclusion

This study provides exciting and novel evidence for the impact of a peer led psycho-educational intervention for people newly diagnosed with PD. Further research is needed to consider the impact of stories-based approaches on participants and consider a critical evaluation of the mechanisms which may explain changes in stories and self-reported behaviour.

1 **Introduction**

2 Parkinson's is the second most prevalence neurodegenerative disease with a prevalence of the
3 disease ranges between 108-250/100,000 (although is higher for individuals over 65 years
4 e.g., up to 950/100000) for westernized countries[1]. In addition to movement impairments
5 and motor symptoms research has highlighted neuropsychiatric symptoms such as mood
6 which subsequently can have a significant and detrimental impact on quality of life[2]. Two
7 major psychosocial challenges exist following the diagnosis of Parkinson's Disease (PD)[3].
8 These include a significant impact on social confidence, self-esteem and social competence
9 as well as becoming self-conscious in social situations[3]. It also includes difficulty in
10 psycho-emotional adaptation to the illness. However, it should be noted that people with PD
11 can adopt psychosocial and behavioural strategies to overcome these factors[4].

12 A core treatment for PD following diagnosis is supportive therapies [5] which include the
13 delivery of health care professional led treatment like physiotherapy[6]. However, the
14 experience of diagnosis has consistently identified a lack of social support (e.g., perceived
15 lack of value of information provided or ability to ask questions) in the care of people with
16 PD at the time of their diagnosis [7-9]. As a response to this, education based programs have
17 been developed [10-14]. The benefits of these programs include self-reported mood and
18 psychosocial improvements [13,14] as well as quality of life [1]. In contrast to this two
19 studies identified no improvement in quality of life [12,13]. More recently research has used
20 peer led approaches and identified positive findings. For instance, peer based interventions
21 have been identified as improving behaviors like physical activity [15] and psychological
22 well-being [16]. Further investigation into peer led approaches would provide needed
23 evidence on the benefits of rehabilitation programs for people with PD which is at presence

24 scarce [3]. Further to this, review evidence [3] has highlighted that peer social support can
25 positively impact psychosocial and behavioural well-being.

26 The First Steps program is a peer led program for people newly diagnosed with PD. The
27 program is led by presenters who themselves have PD. Further information can be found at
28 ([https://www.parkinsons.org.uk/professionals/first-steps-people-newly-diagnosed-](https://www.parkinsons.org.uk/professionals/first-steps-people-newly-diagnosed-parkinsons)
29 [parkinsons](https://www.parkinsons.org.uk/professionals/first-steps-people-newly-diagnosed-parkinsons)). The First Steps program was derived from the European Parkinson's Therapy
30 Centre (<https://www.terapiaparkinson.it/en/> with input from members of the Parkinson's UK
31 [Oxford Branch \(https://oxfordparkinsons.org.uk/branch\)](https://oxfordparkinsons.org.uk/branch)). An important element of this
32 program is the provision of storytelling by presenters with a focus on specific topics and
33 through meeting peers. There is evidence of the value of using story based educational
34 interventions to; (a) enhance research through patient participation [17] and (b) improve
35 knowledge of health care professionals [18].

36 The First Steps program was able to consider if a peer-led Parkinson's education group could
37 change attitudes and behaviours through stories. This would be facilitated in two ways within
38 the program: (1) Being able to explore and express one's own story. For instance, past
39 research has shown just the ability to explore one's own story can help people with PD
40 renegotiate their social identity and cope [19]. (2) Research has also identified that telling and
41 sharing stories can be used to influence attitudes and behaviours by 'transporting' the listener
42 into the world of the teller [20;21]. One factor which may aid the effectiveness of the First
43 Steps program could be the level of similarity the listener feels towards the story being shared
44 by their peer [22]. The level of similarity and impact of the First Steps program can be
45 documented by considering the master plot of the stories told by individuals following the
46 intervention. The master plot illustrates how an individual psychologically adapts and copes

47 when living with the illness. Research has identified 13 common plots¹ told by people with
48 neurological illnesses [23]. The First Steps program allowed people with PD to listen to
49 stories that illustrate adaptive behaviours and coping and contrast these stories with their
50 own. This process provides access to and understanding of positive psycho-emotional
51 adaptation [24,25]. It is important that research documents the impact hearing such stories by
52 documenting the reactions and master plots of the listeners. It is also important that the
53 mechanisms behind this process may also warrant further consideration. It is likely that
54 particular psychosocial mechanisms are involved given the importance of perceived
55 similarity with others when stories are used to persuade others [22]. The mechanisms most
56 likely behind any impact would include social comparison and/or social control as well as
57 self-esteem [26]. Qualitative based approaches would be well suited to understanding the
58 'how' and 'why' perceived changes occur. To the best of the authors knowledge this would
59 be the first attempt to understand this.

60 Given the above there is a need to understand if a peer led psycho-educational intervention
61 for people newly diagnosed with PD could impact their own story and how this was possible.
62 Thus, the dual aim of this research is to consider the impact of providing the First Steps
63 program on the stories of people with PD and investigate the psychosocial and emotional
64 mechanisms which may explain the impact.

65

¹ For instance, the heroic master plot can illustrate how it is possible to overcome challenges, the Quest master plot can illustrate how living with an illness can be viewed differently.

66 **Material and Methods**

67 *Study design*

68 A qualitative study based on hermeneutic phenomenology (study focusing on the interpretation
69 of experience by participants) and situated within a subtle realist paradigmatic world view (a
70 view which seeks to focus on common realities for participants and a view that a-priori
71 knowledge can be used to enhance understanding of such realities) was undertaken. This
72 qualitative study was assessed using a final interview to examine participant experiences of a
73 feasibility study that used a step wedge pragmatic design.

74 *The qualitative researcher*

75 All semi-structured interviews were undertaken by researcher AS. He was a white male, aged
76 39 at the time of the interviews. He had 13 years of post-doctoral experience with qualitative
77 research. No relationship with AS was gained prior to the phone interview. He was identified
78 to participants by author (SL). Author SL informed participants of the aim of the process and
79 identified a suitable time to call. Both authors were blind to the allocation of the participant
80 until the time of the interview.

81 *Setting and context*

82 *Control group*

83 The non-active control group received three phone calls from researcher (SL) and were based
84 in Surrey (as the First Steps program was not yet available in this area). Each phone call
85 contained standardised questionnaires assessing health and wellbeing, clinical service use,
86 activities of daily living, physical activity and diet (as listed below).

87 *Intervention group*

88 This section is presented according to TIDeR checklist²².

89 *Name:* The First Steps program, UK.

90 *Why:* The program was co-designed by people with PD to enable support in coming to terms
91 with a diagnosis of PD. A key element of the program is the opportunity to provide information
92 around specific topics. This information is given by presenters who have PD and use
93 experiences and stories to inform those who attend. Time is also allocated for participants to
94 discuss and share stories.

95 *What:* A two-day period is used to provide the following sessions. On day 1; (a) welcome (b)
96 information regarding PD and medication, (c) how to face the future positively, (d) addressing
97 fears and misconception, (e) accessing the right services, getting the right information and
98 support, and (f) the importance of exercise and lifestyle in managing the condition. On day 2
99 (6-8 weeks later); (a) re-cap of day 1, (b) rights in relationship to PD including employment,
100 driving, prescription, changing doctors, and further practical facts.

101 Discussion activities; (a) review of participant's physical activity and how participants have
102 been getting on since day one, and (b) group discussions for loved ones on how they can best
103 support their partner or relative.

104 A single taster exercise session; the exercise sessions is provided in a group setting and is
105 followed by the provision of information on local exercise classes for people affected by PD.

106 *Who provided:* A Parkinson's UK facilitator registered all people and scheduled all sessions.
107 Two people with PD led all sessions, except the exercise session which was provided by a

108 neurological physiotherapist (day 2 only). Other support staff were available to provide lunch
109 and information.

110 *How:* The delivery was face to face and arranged in groups. Group size of the intervention was
111 aimed at around 5 people with PD and they could bring a partner, family member, friend, or
112 carer each day of the intervention.

113 *Where:* The intervention took place in three locations (Oxfordshire, Hampshire or Devon)
114 within non-clinical environments. Free parking, easy access to the location, a free lunch and
115 access to exercise equipment was provided at each location. The intervention was not yet
116 available in Surrey.

117 *When and how much:* The two-day program included specific information topics across both
118 days (as outlined above). Both days had breaks for sustenance. Day 2 had a single group
119 exercise session delivered within a hall setting.

120 *Tailoring:* People with PD could ask questions on both days.

121 *Modification:* No modification was made.

122 *Intervention Assessments*

123 Both the intervention and control groups completed the standardised questionnaires over the
124 telephone. The same questionnaires were completed at a 3 month and 6 months post baseline
125 follow-up (after the first telephone assessment was completed). The participant's spouse,
126 partner, family member or friend (if consented) were also assessed for carer strain at each
127 follow-up assessment. For the purpose of this study only baseline data is reported to give an
128 overview of participant demographics.

129 ***Procedures for the qualitative interview***

130 All participants were contacted using a single telephone interview conducted by author AS
131 (following their 3 assessment calls conducted by SL).

132 Participants were assessed for the feasibility study at baseline on enrolment into the trial. The
133 first participant was enrolled onto the trial on 5 February 2018. For full details of the trial
134 processes see Trial registration number: ISRCTN14760402. Participants were reassessed at 3
135 and 6 months and as such the trial is currently ongoing. This research contains a sub-sample of
136 participants selected from the trial until data saturation had been reached.

137 The following baseline demographics of the trial group as of 10 June 2019 were: 53 participants
138 (34 male, 19 female), with a mean age of 67.8 ± 7.8 years and time since diagnosis of 5.1 ± 3.2
139 months. The EQ5D mean was 79.9 ± 13.6 . Full details of demographics will be available in a
140 subsequent publication.

141 As of 10 June 2019, 53 people had been recruited, of which 39 had reached the 6-month
142 assessment point. Out of the 39 participants, 1 had withdrawn from the study prior to their 3
143 month assessment, leaving 38 participants with completed 6 month assessments. The reason
144 for the withdrawal was due to not having enough time to complete the telephone calls. No
145 participants were lost to follow-up. Out of these 38, two participants opted to complete the
146 interview in paper-based forms by post due to difficulties hearing over the telephone. 36
147 participants were therefore available to interview over the telephone by researcher AS.

148 ***Sampling Strategy***

149 Purposive sampling of individuals who had taken part in the program were identified. This was
150 to represent a range of ages and to be split across the intervention and control group. Individuals

151 were included if: (a) they had been given a recent (within 12 months) diagnosis of PD, (b) were
152 above the age of 18 years. Individuals were excluded if: (a) they had a clinical diagnosis of
153 severe depression or psychosis, (b) they had reduced cognition that would preclude active
154 involvement and capacity to consent to participate, or (c) they were unable to understand
155 English.

156 *Sample Size*

157 The sample size was directed by the ability to critically consider the main themes and
158 determined by data saturation [28]. Initially, 22 interviews were conducted and analysed. This
159 generated a focus on the importance and impact of stories and storytelling and the psychosocial
160 mechanism behind them. The final 18 interviews were focused on the content that followed to
161 allow confidence in saturation of sub-themes.

162 *Outcome Measures:*

163 Demographics: Demographics were recorded including; age, gender, and time since diagnosis.

164 Primary outcome measure: A semi-structured interview to assess the experiences of the
165 intervention, the feasibility and acceptability of the intervention as well as the impact of the
166 intervention in relationship to stories that were heard and shared. The interview schedule was
167 pilot tested. No changes were made to the original design. The interview schedule contained 2
168 closed questions and 16 open questions with several additional prompt questions. The
169 supplementary file contains the interview schedule.

170 *Ethical approval*

171 Ethical approval was gained for the study from South Central - Hampshire A Research Ethics
172 Committee on 23rd August 2017 (17/SC/0346). Health Research Authority (HRA) approval
173 was gained on 8 September 2017.

174 ***Analysis***

175 Descriptive statistics were used to analyse age, time undertaken since start of trial and time
176 since diagnosis. Narrative analysis focusing on master-plots [24] (common stories plots told
177 by participants) was used to explore and explain the impact of the program on individuals with
178 PD. A thematic analysis using a-priori concepts was used to consider the established
179 psychosocial mechanisms of impact [26] on the stories of individuals. Two general stages of
180 analysis were undertaken: Stage 1 included open coding and immersion in interviews and
181 multiple reading of scripts. Stage 2 identified a mind map of the most common comments or
182 themes relating to psychosocial mechanisms of physical activity or behavioral impact and or
183 change. Stage 3 to 6 looked to identify common story plots that illustrated impact from the
184 First Steps program and identify the likely psychosocial mechanisms behind the impact. The
185 final stage is available in the Supplementary file with verbatim quotes. An audit trail is
186 available on request from the AS. No computer program assisted the analysis.

187 ***Trustworthiness***

188 Trustworthiness was considered by the use of reflexivity by the researcher, by adhering to the
189 COREQ guideline [29], and by documenting the follow strategies to enhance rigor [30]; (a)
190 an audit trail, (b) attention to negative cases (searching for instances when participants
191 directly contrasted or contradicted the themes and content identified) within the analysis, (c)
192 peer debriefing (AS presented a defensible case to other authors HD, SL, JC) for critical
193 comment after the first 22 interviews, and (d) theoretical triangulation as themes were fitted

194 with existing knowledge of psychosocial mechanisms which impact physical and mental
195 health [26]. These steps are in-line with studies that situate themselves within a subtle-realist
196 paradigm [3]. Further to this AS was required to provide a defensible case to the research
197 group about the findings. The presentation of the findings to the group was made after
198 interview 24. Following this, interviews were focused towards exploring the themes and
199 saturating content identified. Quotes are presented verbatim and identified by a participant
200 number e.g., P1M52 (Participant number; P1, gender; male, age; 52 years old).

201 **Results**

202 *Demographics*

203 Forty-two individuals (16 female, 26 male) were phoned. One male (P31M74) did not
204 respond to phone calls or follow up postal questionnaires. One male (P28M74) declined
205 participation at the point of the phone call with AS. He identified that the data collection
206 process had taken up too much time and he could not give any further time to the study.
207 Across the remaining 40 participants the average age was 66.7 ± 9.0 years (control 68.4 ± 10.7
208 years; intervention 66.2 ± 7.5 years). The average time since diagnosis at the end of the
209 interviewing process was 13.5 ± 4.6 months (control 13.2 ± 4.7 months; intervention 14.7 ± 4.8
210 months). The average time since diagnosis at point of enrollment on to the study was 5.4 ± 3.3
211 months (control 5.2 ± 3.4 months; intervention 5.8 ± 3.4 months). Eighteen individuals (18/40,
212 45.0%) received the intervention, 22 (22/40, 55%) received the active control condition.
213 Table 1 in the Supplementary file provides full break down of the demographics.

214 *Non-active Control Group Responses*

215 All individuals in the active control group perceived that the intervention had no impact or
216 resulted in no change. No individual in the control group had contact with the intervention
217 group. When asked about the value of participating in the active control group the following
218 statements were made: (a) that there was no value (P47M60) or that it was difficult to
219 determine (5/20; 25.0%; P9M47; P23F54, P21M73; P51F60; P74M70), (b) that talking to
220 someone had value (8/20; 40.0%; P9M47; P10M63; P20M72; P34F74; P43M60; P48M80;
221 P54F56; P64M71). For instance, P48M80 stated “*it is interesting to know that people are*
222 *interested in how things are going. But umm, I wasn't expecting it to make any difference to*
223 *my actual condition*”. This could be seen in a more critical way for participant FS20 who

224 stated: “*outside of talking to you [AS] and the GP, if I ever get to see them, I don’t talk to*
225 *anybody.*”, and (c) it was identified that there was some impact in thinking about aspects
226 related to behaviour. One individual (P5M75) said it got them “*thinking about aspects like*
227 *sitting*”.

228 ***Intervention Group Responses - Closed answer questions***

229 All individuals identified the program as; (a) very worthwhile to be a part of, (b) being
230 undertaken at a good and appropriate location and (c) having staff that were competent. Six
231 individuals (6/18, 33%, P5M75, P14M69, P18F57, P19M55, P24M76, P26M83, P35F59,
232 P36F58, P38M63) identified that they were ‘feeling better’ or ‘more positive’. The most
233 consistent impact was identified as changes in attitudes or behaviours of participants.

234 ***Intervention Group Responses - Synthesis of qualitative responses about the course***

235 *Theme 1: The response and impact on the stories of participants*

236 The first theme considers the impact of the First Steps Program according to the stories
237 shared during the interview. This theme had 3 sub-themes; (a) the affirmed story (no
238 behaviour change), (b) the validated story (where individuals were affirmed and understood
239 how to engage in physical activity) and (c) the transformed story (where behaviour change
240 was created as a direct result of the First Steps program).

241 *Sub-theme 1a: the affirmed story*

242 The affirmed story was told by individuals who identified that the program provided no extra
243 knowledge for them. It was defined by an acknowledgement that their past choices and
244 behaviours were affirmed by the First Steps program and that this knowledge remained
245 unchanged. This implied that physical activity levels were unchanged. Five individuals (5/18;

246 28%; P5M75, P6M64, P16M69, P17F70, P26M83) identified that the First Steps program
247 affirmed their choice but lead to no change in behaviour. For instance, P5M75 stated: “*I*
248 *mean it [physical activity] is not something that you need to stop doing.*” For P16M69 and
249 P17F70 the Parkinson’s had not progressed so no lifestyle changes were needed. Related to
250 this P26M83 stated: “*as much as possible I forget about Parkinson’s Disease [and carry on*
251 *as before]*”. For P6M64 the same barriers to exercises existed after the course and no changes
252 were perceived possible.

253 *Sub-theme 1b: the validated story*

254 The validated story identified that First Steps program had helped them understand and
255 validate the importance of using information gained. The individuals had received the stories
256 and experiences of others and planned to adopt similar behaviors. It was evidence of the
257 presenter’s stories becoming their own story. They appeared more motivated to continue
258 physical activity or exercise. The course had provided a reinforcement of the message that
259 physical activity had to be part of their lives with Parkinson’s. Terms used by the presented
260 were remembered and repeated during the interview for instance, the need to undertake
261 ‘strong’ exercise or increase what they were doing. The validated story was identified in 7
262 individuals (7/18; 39%; P2M68, P16M69, P8F70, P24M76, P26M83, P32M60, P36F58). For
263 instance, for P36F58 it validated the choices made; “*I think it validated what I felt I should be*
264 *doing...For instance, if I don’t do that [exercise], I won’t be able to do the other stuff*
265 *anyway. It is about knowing you’re not being selfish when you look after yourself*”.

266 Alternatively, P8F70 identified the reinforcement of the positive benefits that physical
267 activity could bring by stating “*I think I have always felt better when I have done exercise*
268 *classes*”. This story could also include statements that enabled greater engagement with
269 physical activity. Individuals identified small changes learnt from the course that allowed

270 this. For instance, knowing limits regarding physical activity participation (P2M68), having a
271 better understanding of the choice and technique of specific exercises (P26M83).

272 *Sub-theme 1c: the transformed story*

273 The final story, the transformed story, identified transformation of behaviour and a
274 subsequent change of physical activity or exercise. The change was attributed to the course
275 and related to an increase in the level, intensity or type of physical activity or exercise
276 engaged in. This was directly attributed to the First Steps Course. This was identified by 8
277 participants (8/18; 44%; P1F61, P2M83, P5M75, P8F70, P14M69, P18F57, P19M55,
278 P35F59). The changes identified included beginning a new class like Zumba Gold or Pilates
279 (P1F61, P2M68, P5M75, P19M55), joining a gym (P18F57), doing more walking or walking
280 better (3/18; 17%; P1F61, P14M69, P19M55) and changing a fitness regime or doing more in
281 general (4/18; 22%; P8F70, P18F57, P26M83, P35F59).

282 *Theme 2; Psychosocial Mechanisms explaining the benefits from receiving stories*

283 Many participants identified psychological and social reasons or mechanisms which
284 explained the impact of the First Steps program. These were identified with 7 sub-themes.
285 This included 3 internal sub-themes; (a) perceived control, hope and action, (b) the
286 individual's mind-set, and (c) perceived confidence. It also included 3 social sub-themes; (d)
287 social comparison, (e) social control, and (f) the first opportunity to share with peers.

288 *Sub-theme a; Perceived control, hope and action*

289 This sub-theme was generated as a result of participants seeing that a future was possible by
290 listening to the stories of the presenters and others. Individuals perceived that action could be
291 taken as illustrated by others who are sharing their own experience. This theme was

292 supported by 9 participants (9/18; 50%; P1F61, P2M68, P8F70, P14M69, P32M60, P35F59,
293 P36F58 and P38M63). The theme was illustrated by the recognition of the importance of
294 physical activity and exercise in maintaining physical well-being. For instance, P32M60
295 stated; *“if you as a Parkinson’s patient want to keep active, want to keep your mobility,
296 balance and things of that nature, you have to put in the effort and do the exercise.”* P14M69
297 summarises the theme and the importance of taking control and action to enable living with
298 PD: *“AS: in terms of getting on with your life? What impact would it [the First Steps
299 programme] have had on that? Any change? P14M69: well, I, I think, what was important
300 for me at that stage was that you could actually, fight back to some degree. Take the future in
301 your own hand to some degree and that is quite important.”* This theme was a key
302 illustration of the perceived impact of the stories shared by participants and outcome of social
303 comparisons and the ability to relate to others and take onboard the message to utilize it in
304 their own life situation.

305 *Sub-theme b; The individual’s mind-set*

306 Many individuals talked about the impact on mood and mindset from the program,
307 identifying that the First Steps program provided a protective mind-set against the
308 experiences of the symptoms and an acceptance of the feelings or emotions about having PD.
309 For instance, P18F57 stated *“I don’t want to just stagnate. Whereas before I was sort of like,
310 feeling sorry for myself I suppose. I have a positive attitude.[now]”* This theme was
311 identified by 11 individuals (11/18; 61%; P1F61, P2M68, P6M64, P13M84, P14M69,
312 P18F57, P19M55, P24M76, P32M60, P36F58; P38M63). The impact on an individual’s
313 mind-set had several influences. This included thoughts about the program before attending
314 because of the opportunity to give and share with others (P2M68), the value of meeting
315 varied people with different outlook (P38M63). Further individuals highlighted a positive

316 atmosphere within the group (2/18; 11%; P1F61, P18F57). This was identified as important
317 because of the worry (P24M76), difficulty (P19M55) and sadness (P14M69) that was
318 associated following the diagnosis of PD. P13M84 noted that the content of the session could
319 be depressing. P13M84 only attended the first session and it was noted by another participant
320 that the experience of the second session could be more positive; “*people [who were]*
321 *negative on first sessions [were] more positive on next session*” (P6M64). This theme linked
322 to hope because it related the impact the course had on psychological adaptation and
323 emotions.

324 *Sub-theme c; Perceived confidence*

325 An increase in self-efficacy and being confidence about living with PD and illustrated by
326 how others achieve that. This was identified by 6 individuals (6/18; 33%; P1F61, P2M68,
327 P14M69, P18F57, P36F58, P37M71). It was identified through stories of how to engage in
328 living with PD. For instance, this could include the confidence to identify you have PD in
329 social situations. P2M68 stated: “*one of the presenters made it quite clear that whatever*
330 *stage you are at, you should never be afraid to put your hand up and say I can't do this*
331 *because I have Parkinson's*”. Second to this participants' identified the confidence to do
332 more activities and interaction. Example of this included the confidence to enroll on a course
333 and join the gym (FS18), the confidence to attend a dinner party without worry about
334 wrecking other people's night (FS14). This theme could have been related to the successful
335 engagement in physical activity following the program which had a direct influence on an
336 individual self-efficacy.

337

338 *Sub-theme d; social comparison*

339 An essential mechanism explaining the impact identified above was through social
340 comparison. Most frequently this was identified as being able to relate to another individual
341 who has had a similar experience. Relatedness was identified through listening and sharing
342 stories that demonstrated a positive and possible way to live with PD. Within each day there
343 was also an opportunity to talk with others, listen and understand others stories. This theme
344 was supported by 14 individuals (14/18/ 78%; P1F61, P2M68, P5M75, P7F63, P13M84,
345 P14M69, P18F57, P19M55, P24M76, P26M83, P32M60, P35F59, P36F58, P38M63). Most
346 comments related to the benefit of understanding others experience and broadening one's
347 own knowledge of PD. For instance, P17F70 stated: "*it is interesting for me to see other*
348 *people, you know how different we all are*". This process primarily allowed individuals an
349 insight to how others coped and managed the condition and a chance understanding how
350 others viewed or let the PD affect them. This theme was captured by P2M68 who
351 summarised the value by stating:

352 "*it was from listening to the presenters who have had Parkinson's for such a long*
353 *time, umm, and how, how severe they have got it and how well they have coped with it*
354 *and their coping mechanisms, made me realise, I am at the beginning of the journey*
355 *that they are already on, umm, and they are obviously very wise because they have*
356 *learnt a lot about their disease and management and umm, you know all sorts of*
357 *coping strategies, both psychological and physical and I need to listen and take them*
358 *on-board."*

359 There were two instances (2/18; 11%; P26M83, P18F57) where this was identified as not so
360 beneficial; P26M83 identified that the group appeared "*concerned about giving away their*
361 *own position*". These concerns illustrate the benefits of sharing were not always occurring.

362 Alternatively, another participant (P18F57) noted that one lady was reluctant to embrace
363 ideas from the group.

364 *Sub-theme e; social control*

365 Social control was identified within the mechanisms as participants could identify direct
366 instances of when advice was given to them and taken on-board and embraced. This was
367 identified by 9 individuals (9/18; 50%; P1F61, P2M68, P5M75, P7F63, P8F70, P16M69,
368 P26M83, P35F59, P36F58). It was reflected by general statements regarding physical activity
369 and exercise and undertaken more intense exercise and devoting more time to it. It also was
370 reflected in specific comments that illustrated a change in physical activity or exercise like
371 participating in a new Pilates or yoga class. For instance, P2M68 stated: “*one lady suggested*
372 *I went out and tried Zumba gold which was very helpful*”. This then went further than just
373 including physical activity as advice was also given about living with PD and having access
374 to aspects which improve life like a radar key, or when to take medication. Some of this was
375 summed up generally, for instance P7F63 stated that the benefit was through “*meeting people*
376 *with the same condition and comparing notes, it is interesting*”. The benefit of this
377 understanding was identified for people’s partners also. This was mentioned by three
378 individuals (3/18; P16M69; P18F57; P19M55).

379 *Sub-theme f; the first opportunity to share with peers*

380 The First Steps program was identified as an essential opportunity to meet with others and
381 share stories and experienced. Six people (6/18; 33%; P1F61, P2M68, P5M75, P32M60,
382 P35F59, P38M63) identified that they had not met others with PD before the course. This
383 group identified that they would not have known the valuable information if it wasn’t for the
384 course. P6M64 stated it would be beneficial to receive this information closer to diagnosis

385 (he was enrolled on to First Steps 6 months after diagnosis). Importantly one individual
386 (P2M68) identified that she would not do anything like the course again. Further P8F70 was
387 very complimentary of the First Steps program and valued listening to peers, but didn't want
388 to share with others. She stated:

389 *“well, I made a conscious decision not to talk [about PD], other than sharing it with*
390 *some immediate family members. I made a conscious decision not to say anything, on*
391 *the wider side of things, because I know, of two or three people who had diagnosis of*
392 *Parkinson's and also the reactions that people have given and my feeling, for me*
393 *personally, was that, until the time comes when it is obvious enough that people need*
394 *to know, I don't need to share that”*

395 **Discussion**

396 This study illustrates the behavioral impact of the First Steps program and the importance and
397 impact of peer stories. Our results are able to further the scarce evidence and show that
398 people can value, remember and act to change their lifestyle and that this change was likely
399 due to the relatedness they felt towards the stories from peers. This study supports past
400 psycho-educational interventions regarding the positive benefits experienced by people with
401 PD and extends these findings to people who are newly diagnosed. The identified benefits
402 included perceived change in attitude and behaviours following the intervention as well as
403 benefits related to psycho-emotional adaptation and coping.

404 The critical mechanisms that appeared to influenced participants stories included; social
405 comparison and relatedness and motivation to adopt the view of the presenters and others in
406 the group. Enhancement of the individual's physical activity and exercise social identity was
407 likely across participants as they were often able to relate to the presenters and peers within

408 the First Steps program. This process could be similar to a process described as reframing the
409 social identity following participation within an exercise programs [31]. This process likely
410 leads on to positive psycho-emotional changes as the impact of peer stories impacts their
411 own. This supports previous theoretical evidence regarding this process [24].

412 Storytelling is regarded as an effective way to enhance education and learning for individuals
413 with chronic disease [32]. Review evidence has identified a lack of studies that use story
414 telling for people with PD [33]. In other populations storytelling interventions have been
415 associated with encouraging positive attitudes and behaviors such as physical activity and
416 dietary changes [25,34]. This current study supports these findings for people with PD. The
417 adoption of similar stories meant that following the First Steps intervention, participants past
418 experiences and stories can change and evolve from potentially negative stories to more
419 positive ones.

420 Exercise has been recognized as a possible adjunct therapy for individuals newly diagnosed
421 with PD which has the potential to reduce disease progression and aid motor symptoms
422 [4,35] as well as promote global cognitive function [36]. Within the current study it is
423 possible that physical activity and exercise behaviors are enhanced by sharing information
424 about one's individual ability to cope and live with the disease [37]. The current results
425 provide an illustration that the poor experience of communication of disease and its impact at
426 diagnosis [7] can be buffered and supported by a peer educational storytelling intervention.

427 The perceived impact on positive behaviours supports past work on the value of peers within
428 psychoeducational interventions [38] and illustrates the importance of people with PD
429 knowing how to engage in activities and behaviors [39]. It is likely that the findings
430 identified here are in part a result of individuals adopting positive coping strategies to
431 manage PD [40]. The reasons for this likely include an impact of the program on the

432 individual's mind-set, confidence, and acceptance of condition through relatedness with
433 others. These findings support the findings by Hellqvist et al [16]. It is also important to note
434 that the participants who reported no change in attitude still identified the event as being
435 worth it. The main reason for this was due to the being with peers which likely had value
436 including e.g., reduced fear, feeling accepted, considering the possibility of different attitudes
437 and behaviours and affirming past choices. This is important, because in the absence of
438 reporting behaviour change participants still valued the program. Where no behavior change
439 was reported the benefit appeared to be on a participant's psycho-emotional well-being. This
440 has been identified in other studies e.g., [25].

441 The shared experience of the presenters likely represented a positive psycho-emotional
442 response to adapting to the diagnosis. This may occur through key mechanisms [24]: (a) an
443 ability to aid acknowledgement of present constraints and impact of PD and (b) an ability to
444 enforce an idea of possibility about what changes may occur in the future, how these changes
445 can be managed, and an understanding of the emotional impact of PD through the observation
446 of positive outcomes and encouraging stories from peers.

447 ***Limitations***

448 Several limitations are acknowledged: (a) The analysis focuses on the impact considering
449 attitudes and behaviours most frequently related to physical activity and exercise. This may
450 limit the focus of the current article. (b) The approach may be limited to a self-selected
451 sample. (c) The culture, environment, level of education of participants and setting may be, to
452 some extent unique. (d) The geographical location of the First Steps program may prevent
453 some people attending. This could limit the representativeness of the sample. (e) This study
454 should not be considered as an exact documentation of behaviour change. The results must be
455 viewed as common realities experienced by participants.

456 ***Implications***

457 Specific implications were identified: (a) The First Steps program could represent a very
458 good supplement to support individuals newly diagnosed with PD. It is likely that the
459 program can support or enhance their attitude and behaviour towards physical activity and
460 exercise. (b) Sharing experiences related to physical activity and coping behaviour likely
461 impacts the bio-psycho-emotional and social well-being of newly diagnosed individuals with
462 PD. (c) Social comparison and social control are evident as two mechanisms which appeared
463 to aid changes in perceptions of behaviour and physical activity as a direct result of hearing,
464 sharing and comparing stories. However, benefits often existed even if change did not occur
465 as participants valued the connection and relatedness of experiences to peers. This finding
466 should be considered more widely within rehabilitation programs. (d) Psycho-emotional
467 adaptation and hope likely play a central role in allowing perceived changes in attitude and
468 physical activity behaviour to occur. A patient co-delivered work shop appeared to allow this
469 by being immersed in a positive group environment associated with positive views,
470 perceptions and experiences about managing PD. This exchange and sharing could allow
471 seeing possibilities and could help others move past a simple acknowledgement of limitations
472 caused by symptoms to embrace limitations. Considering the change in psycho-emotional
473 adaptation is essential to establish this in further research.

474 **Conclusion**

475 This study provides novel evidence for the impact of a peer led psycho-educational
476 intervention for people newly diagnosed with PD. In particular, the study supports the notion
477 that positive stories from peers can support and encourage positive attitudes towards
478 behavioural change. The storytelling element of the First Steps program could be used as an
479 intervention strategy that can be explored in other illness conditions and other geographical

480 locations. However, further research is needed to consider the impact of stories-based
481 approaches on participants and consider a critical evaluation of the mechanisms which may
482 explain changes in stories and self-reported behaviour.

483

References

1. Abbas, M. M., Xu, Z., Tan, L. C. S. Epidemiology of Parkinson's disease- East Versus West. *Movement Disorders*. 2017; 5: 14-28.
2. Dobkin, R. D., Interian, A. Improved understanding, detection, and management of neuropsychiatric complications: essential components to the optimal treatment of Parkinson's disease. *International Psychogeriatrics*. 2019; 31; 1-4.
3. Soundy, A., Stubbs, B., Roskell, C. The experience of Parkinson's disease: A systematic review and meta-ethnography. *The Scientific World Journal*. 2014; 613592: 1-19.
4. Vescovelli, F., Sarti, D., Ruini, C. Subjective and psychological well-being in Parkinson's disease; a systematic review. *Acta Neurologica Scandinavica*. 2018; 138: 12-23.
5. National Health Service (2019). Treatment Parkinson's disease. National Health Service. Retrieved from the world wide web on 4 June 2019 from <https://www.nhs.uk/conditions/parkinsons-disease/treatment/>.
6. National Institute for Health and Care Excellence (2017). NICE Guideline [GN71]. Parkinson's disease in adults. National Institute for Health and Care Excellence, UK. Accessed from the world wide web on 4 June 2019 from <https://www.nice.org.uk/guidance/ng71/ifp/chapter/What-else-might-help>.
7. Edwards, R. H., Barlow, J. H., Turner, A. P. Experiences of diagnosis and treatment among people with multiple sclerosis. *Journal of Evaluation in Clinical Practice*. 2008; 14: 460-464.
8. Schrag, A., Modi, S., hotham, S., Merritt, R., Khan, K., Graham, L. (2018). Patients experiences of receiving a diagnosis of Parkinson's disease. *Journal of Neurology*. 2018; 265: 1151-1157.
9. Udow, S. J., Hobson, D. E., Kleiner, G., Masellis, M., Fox, S. H., Lang, A. E., Marras, C. Educational needs and considerations for a visual educational tool to discuss Parkinson's disease. *Movement Disorders Clinical Practice*. 2018; 5: 66-74.
10. A'Campo, L. E. I., Wekking, E. M., Spliethoff-Kamminga, N. G. A., Le Cessie, S., Roos, R. A. C. The benefits of a standardised patient education program for patients with parkinson's disease and their caregivers. *Parkinsonism and Related Disorders*. 2010; 16: 89-95.
11. A'Campo, L. E., Spliethoff-Kamminga, N. G., Roos, A. An evaluation of the patient education program for Parkinson's disease in clinical practice. *International Journal of Clinical Practice*. 2011; 65: 1173-1179.
12. Macht, M., Gerlich, C., Heiner, E., Schradi, M., Rusinol, A. B., Crespo, M et al. (2007). Patient education in Parkinson's disease: formative evaluation of a standardised programme in seven European countries. *Patient Education and Counselling*. 2007; 65: 245-252.
13. Simons, G., Thompson, S. B. N., Pasqualini, M. C. S., and Members of the EduPark Consortium. An innovative education programme for people with Parkinson's disease and their carers. *Parkinsonism and Related Disorders*. 2006; 12: 478-485.
14. Sunvisson, H., Ekman, S. L., Hagberg, H., Lokki, J. An education programme for individuals with Parkinson's disease. *Scandinavia Journal of Caring Sciences*. 2001; 15: 311-317.
15. Colón-Semenza, C., Latham, N. K., Quintiliani, L. M., Ellis, T. D. Peer coaching through mHealth targeting physical activity in people with Parkinson's disease: Feasibility study. *JMR MHealth and UHealth*. 2018; 6: 1-13.
16. Hellqvist, C., Dizdar, N., Hagell, P., Berterö, C., Sund-Levander, M. Improving self-management for persons with Parkinson's disease through education focusing on

- management of daily life: Patients' and relatives experience off the Swedish National Parkinson School. *Journal of Clinical Nursing*. 2018;27: 3719-3728.
17. Novak, L. L., George, S., Wallston, K., Vaughn, Y., Isreal, T., Joosten, Y., et al. The value of storytelling in community stakeholder feedback for clinical and translational research. *Journal of Clinical and Translational Science*. 2018; 2: 75.
 18. Bhimani, R., Palluck, H., Mathiason Moore, M. A., Anderson, L. C. A continuing education conference about patients with Parkinson's disease and their caregivers. *The Journal of Continuing Education in Nursing*. 2017; 48: 270-275.
 19. Lutz, S. G., Holmes, J. D., Laliberte Rudman, D., Johnson, A. M., LaDDonna, K. A., Jenkins, M. E. (2017). Understanding Parkinson's through visual narratives: "I'm not Mrs. Parkinson's. *British Journal of Occupational Therapy*. 2018, 81: 90-100.
 20. Green, M. C. Narratives and Cancer Communication. *Journal of Communication*. 2006, 56:163-183.
 21. Shen, F., Sheer, V. C., Li, R. Impact of narratives on persuasion in health communication: A meta-analysis. *Journal of Advertising*. 2015, 44; 105-113.
 22. Ooms, J., Hoeks, J., Jansen, C. "Hey, that could be me": The role of similarity in narrative persuasion. *Plos One*, 2019, 14; e0215359.
 23. Soundy, A., Smith, B., Dawes, H., Pall, H., Gimbrere, K., Ramsay, J. *Health Psychology Review*. 2013, 7: 177-201.
 24. Soundy, A. Psycho-emotional content of illness narrative master plots for people with chronic illness: Implications for assessment. *World Journal of Psychiatry*. 2018; 20: 1-11.
 25. Soundy, A., Reid, K. The psychosocial impact and value of participating in storytelling intervention for patients diagnosed with cancer: an integrative review. *Open Journal of therapy and Rehabilitation*. 2019; 7: 35-77.
 26. Thoits, P. A. Mechanisms linking social ties and support to physical and mental health. *Journal of Health and Social Behaviour*. 2011; 52: 145-161.
 27. Hoffmann, T. C., Glasziou, P. P., Boutron, I., Milne, R., Perera, R., Moher, D., et al., Better reporting of interventions: template for intervention description and replication (TIDER) checklist and guide. *British Medical Journal*. 2014; 7: 1-12.
 28. Saunders, B., Sim, J., Kingstone T., Baker, S., Waterfield J, Bartlam, B., Burroughs, H and Jinks, C. Saturation in qualitative research: exploring its conceptualisation and operationalisation. *Quality and Quantity*. 2018; 52: 1893-1907.
 29. Tong, A., Sainsbury, P., Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item check list for interviews and focus groups. *International Journal for Quality in Health Care*, 19; 349-357.
 30. Morse, J. M. Critical analysis of strategies for determining rigor in qualitative research. *Qualitative Health Research*. 2015; 25: 1212-1222.
 31. O'Brien, C., Clemson, L., Canning, C. G. (2016). Multiple factors, including non-motor impairments, influence decision making with regard to exercise participation in Parkinson's disease: a qualitative study. *Disability and Rehabilitation*. 2016; 38: 472-481.
 32. Cangelosi, P. R., Sorrell, J. M. Storytelling as an educational strategy for older adults with chronic illness. *Journal of Psychosocial Nursing in Mental Health Services*, 2008; 46: 19-22.
 33. Gucciardi, E., Jean-Pierre, N., Karam, G., Sidani, S. Designing and delivering facilitated storytelling interventions for chronic disease self-management; a scoping review. *BMC Health Services Research*. 2016; 16: 249.
 34. Perrier, M. J., Martin Ginis, K. A. Narrative interventions for health screening behaviours: A systematic review. *Journal of Health Psychology*. 2017; 22: 375-393.

35. Fox, S. H., Katzenschlager, R., Lim, S-Y., Barton, B., De Bie, R. M., Seppi, K et al. International Parkinson and movement disorder society evidence-based medicine review: Update on treatments for motor symptoms of Parkinson's disease. *Movement Disorders*. 2018; 33: 1248-1266.
36. Da Silva, F. C., Da Rosa Lop, R., de Oliveria, L. C., Boll, A. M., de Alvarenga, J. G. S., Filho, P. J. C. G et al. Effects of physical exercise programs on cognitive function in Parkinson's disease patients: A Systematic review of randomised controlled trials of the last 10 years. *PLOS One*. 2018; 13: e0193113.
37. Claesson, I. M., Ståhle, A., Johansson, S. Being limited by Parkinson's disease and struggling to keep up exercising; is the group the glue? *Disability and Rehabilitation*. 2019; e-pub: 1-8.
38. Colón-Semenza, C., Latham, N K., Quintiliani, L. M., Ellis, T. D. Peer coaching through mhealth targeting physical activity in people with Parkinson's Disease: Feasibility study. *JMIR MHealth UHealth*. 2018; 6: e42
39. Hitchcott, P. K., Fastame, M. C., Corona, F., Piloni, G., Porta, M., Pau, M., Conti, R., Penna, M. P. Self-reported physical and mental health and movement functioning in elders with and without Parkinson's. *Psychology, Health and Medicine*. 2019; 24: 788-798.
40. Ethlen, F., Schindlbeck, K., Nobis, L., Maier, A., Klostermann, F. Relationship between activity and well-being in people with Parkinson's disease. *Brain and Behavior*. 2018; 8: e00976.