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## How do people live life successfully with Parkinson's disease?

Mi-Young Kang and Caroline Ellis-Hill

**Aims and objectives.** The aim of this paper is to explore how people live life successfully with Parkinson's disease and what contributed to the level of success.

**Objectives.** To examine the level of success as defined by people with Parkinson's disease. To find what contributed to the level of success.

**Background.** Self-care support has gained importance for supporting people with their chronic diseases including Parkinson's disease. Although self-care and life adjustments can improve patients' general well-being, it is unclear which approaches best facilitate positive adjustments to illness.

**Design.** Semi-structured interviews with participants with Parkinson's disease.

**Methods.** Eight participants living with Parkinson's disease for 2–16 years were recruited from a Parkinson's disease voluntary group in the UK. Interviews covered their perceived level of success and the factors which they perceived led to that success. Thematic analysis was used to analyse the data.

**Results.** Participants rated a high level of success in living with Parkinson's disease with an average personal rating 75/100 despite facing difficulties. Successful living was perceived to have taken place when people were either (1) able to return to their usual state of health or (2) considered themselves to be stable within a new/readjusted state of health. Aspects which were perceived to support positive psychosocial adjustment included a positive mindset, determination, acceptance of new challenges and family support.

**Conclusion.** Maintaining usual life and physical ability is the major concern among the people with Parkinson's disease. It would be helpful for health care professionals to identify what constitutes a 'usual' life for that person and to support them to develop a positive mindset and acceptance of new challenges, drawing on the determination of the person as well as any available family support.

**Relevance to clinical practice.** In supporting self-care, it is helpful to gain information about the subjective experience of living with Parkinson's disease including their perceived level of success at the time and what led to that perceived success for that person.

**Key words:** assessment, Parkinson's disease, psychosocial adjustment, quality of care, self-management, successful living

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### **What does this paper contribute to the wider global clinical community?**

- The study attempted to provide a definition of successful living with Parkinson's disease which maintains the quality of usual life as much as possible.
- Positive psychosocial assessment by people themselves maximised their physical ability to carry on their normal activities and led to successful living.
- It would be helpful for health care providers to recognise, and for care to be tailored to, the factors which support a sense of success and normality as perceived by each individual with Parkinson's disease.

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### **Introduction**

Improving patients' self-care is one of the key aspects of UK government policy; this is felt to be needed to support the growing population of people living with a chronic illness (Department of Health 2006). Evidence suggested that patients can manage their condition successfully by having adequate knowledge of their illness and treatment, and the ability to control physical condition and psychosocial changes (Barlow et al. 2002). Parkinson's disease (PD) is a chronic, neurodegenerative disorder that generally occurs in older people over the age of 60 years. The physical symptoms of PD include tremor, rigidity, postural instability and bradykinesia (Chenoweth et al. 2013). These physical symptoms affect patients' psychological and social wellbeing. According to the literature, up to 90% of PD patients experience complications such as depression, cognitive problems and anxiety which have a major impact on a person's self-care and quality of life (Ketharanathan et al. 2014). Moreover, patients' loss of physical independence can cause confusion in personal identity, self-worth, social role and family relationships (Bishop 2005, Bramley & Eatough 2005).

Although physical symptoms are different, many of these psychological and social problems are common among the people with later-onset chronic diseases or acquired disabilities (Bisschop et al.

2004). It is felt that psychological problems can influence people's general health and wellbeing more than physical aspects (Bramley & Eatough 2005). However, current treatment and nursing care is still focused on the severity of the symptoms. Many psychosocial problems related to illness may not be recognised or if they are very little is known about how to manage them (Barley et al. 2012). There is little understanding about successful living with an illness. The aim of this research was to explore how people live life successfully with Parkinson's disease. Success was defined by the participants themselves; however, it was felt that success would include experiencing positive psychosocial reactions or responses to their illness and being able to live a life that was not always dominated by PD.

## **Background**

There has been growing research in the area of changing patients' behaviour, recognising patients' perceptions and psychosocial adaptation to illness to improve self-management (Clark & Hampson 2001, Gatt & Sammut 2008). A previous study has revealed that even people with the most devastating of illnesses can adjust to illness and find positive meaning in their lives without significant psychological problems (Sharpe & Curran 2006). Moreover, people with a sense of high self-efficacy, control and optimism can adjust more successfully to chronic illness (Dennison et al. 2009). Self-worth is gained through active coping in living with chronic illness (Bramley & Eatough 2005). Recent studies have shown that an individual's perception and interpretation of the illness could influence their behaviour leading positive health outcomes (Foxwell et al. 2013, Zoeckler et al. 2014).

There is a growing body of literature related to psychosocial adjustment and self-management following a diagnosis of PD. The majority of the work is quantitative and the researchers have focused on aspects such as neuropsychological outcomes (Dobkin et al. 2014), illness beliefs (Simpson et al. 2013) and coping (Hurt et al. 2012). Despite some useful information, these studies do not give insight into the condition as experienced by people with PD. There are many fewer qualitative studies exploring the perceptions and experience of living with PD. Although these qualitative studies provide insight into life following a diagnosis of PD (Bramley & Eatough 2005, Stanley-Hermanns & Engebretson 2010), they often focus on the difficulties encountered by people rather than specifically exploring the positive aspects of life.

So, although, the literature has claimed that psychosocial problems can be managed effectively by significant psychosocial adjustments (Bramley & Eatough 2005, Stanton et al. 2007), it is unclear which psychosocial approaches best facilitate positive adjustment to Parkinson's disease. Therefore, the aim of this study was to examine the level of success as defined by people with Parkinson's disease and to find out what they perceived to have contributed to the level of success.

## **Methods**

**Design** A qualitative approach was taken incorporating semi-structured interviews and thematic analysis. Qualitative methods are useful to obtain rich narrative data with regard to individuals' experiences, perspectives, feelings and interpretations about their condition (Marks & Yardley 2004). Qualitative methods are also effective in identifying new information (Holloway & Wheeler 2010). The participants were accessed from a voluntary support group in the south of England where people with PD and their informal carers met every month to share experiences and information together. Inclusion criteria included people with PD who attend the voluntary support group and can share some experiences of living successfully with PD. People with severe communication or cognitive problems were excluded. Convenience sampling was used. Semi-structured interviews were conducted by using an interview guide and additional questions related to the research topic (Burns & Grove 2011). The collected data were analysed thematically (Braun & Clarke 2006). The interviews were carried out by MK and data analysis was carried out by MK and reviewed by CEH.

**Data collection** The data were collected between April and June in 2009. Permission was obtained from the organiser to access participants from the Parkinson's support group and ethical approval was given by the University of Southampton. A presentation was given at the regular meeting of the Parkinson's support group and information sheets were given out to those who were interested in taking part of this study. In total, eight participants were recruited. A pilot study was carried out prior to the data collection to assess the feasibility of the methods. The participants' demographical information were obtained including age, duration of diagnosis, living status and daily activities at the start of the interview. The severity of illness was examined by interviewing and observing each participant. Each interview was conducted following the interview guide which covered patients' perceived levels of success on a scale from 1–100 and factors that they thought contributed to this level of successful living. The interviews were carried out by MK and took place in the participants' home, and the interviews were digitally recorded with the participants' consent. The average interview time was 45 minutes for each participant. Field notes were made after the interview to remind the researcher of the context of the interview to inform the later analysis.

**Data analysis** The audio-recordings of each group were transcribed verbatim including both participants and researcher utterances. The transcripts were analysed thematically following five steps (Braun & Clarke 2006). First, the researcher MK transcribed all recorded data and listened to the records against the transcripts repeatedly to familiarise herself with them. She considered the field notes while analysing the transcripts. Second, key points relating to the research question including, frequent languages or phrases were identified in the transcripts to develop initial codes by using line-by-line analysis (Endacott 2008). A subsection of transcripts were also coded by CEH and discussed

with MK to ensure that the focus remained on the research question and that any alternative coding could be considered. Third, the long list of initial codes were categorised into potential themes by using a thematic map (Endacott 2008). Fourth, the accuracy of the each theme was refined by reviewing whole data extracts and data sets repeatedly. Over time, this developing map was shared between MK and CEH and discussed to ensure that alternative interpretations could be taken into account. Finally, the themes were defined in relation to the research questions (Marks & Yardley 2004).

## Results

**Participants** The eight participants ranged in age between 57–78 years and their duration of illness varied from 2–16 years. The participants consisted of five females and three males (Table 1).

**Table 1** Demographical characteristics and level of success in life with PD

Participants*	Sex	Age (Year)	Duration of diagnosis (Year)	Level of success in life (%)
1 Ann	F	67	4	70%
2 Patricia	F	67	2	80%
3 Christine	F	57	6	80%
4 Doris	F	78	3	70%
5 Elizabeth	F	62	4	75%
6 Frank	M	65	15	85%
7 George	M	71	3	60%
8 Harry	M	63	16	80%

\*Pseudonyms have been used

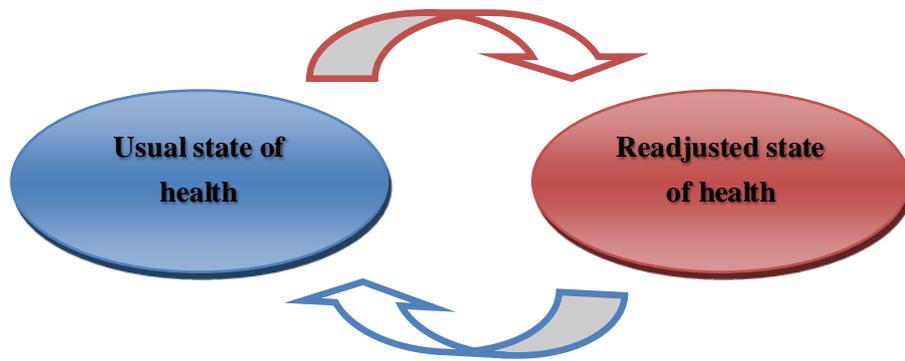
Five participants were totally independent, while the other three people needed minimal assistance in mobility. Physical independence was more likely to be associated with illness duration and age as shown in Tables 1 and 2.

**Table 2** Effect of Parkinson's disease

Participants	Mobility	Physical aspect	Psychological aspect	Social aspect
1 Ann	Independent	Tiredness, shaking, weak right hand, limitation in activity	Depression, tension, stress, blame, worry, shock, deny, relief, panicky, low confidence.	Restriction of socializing,
2 Patricia	Independent	Tiredness, walking, balance, fuzzy, rigidity.	Depression, worry, shock, deny, relief, isolation, silence, scary, nervous, anxious, low confidence	
3 Christine	Independent	Tiredness, walking, balance.	shock, deny, relief, scary, frightened	Stigma, positive in relationship
4 Doris	Independent Use sticks	Tiredness, balance, falls, walking.	stress, frustration, hurt, restricted, low confidence	Stigma, restriction in socializing.
5 Elizabeth	Independent	Tiredness, stiffness, shaking, weak right hand, back pain,	sad, frustration, empty, annoying	Stigma, restriction in socializing, divorce.
6 Frank	Need minimal assistance in walking, able to drive	Slowness, speech and balance problem, lack of co-ordination	depression, blame, sad, fed up, frustration, angry, betrayal	Restriction of socializing, divorce.
7 George	Independent	Shaking, sleeping problem, rigidity, balance, dizziness.	sad, shame	
8 Harry	Mobilize with wife	Slowness, walking, low voice.	fed up	Restriction of socializing

All participants had a certain level of physical difficulty such as shaking, balancing problems, falling and rigidity. These symptoms limited participants' social activities. Participants also expressed that they experienced shock, denial, anger and relief at the diagnosis of PD. Nevertheless, participants rated their level of success of living with Parkinson's disease at a mean of 75/100 (range 60–85/100), despite the differences in duration and severity in illness. This implies that the level of physical

disability does not always determine living successfully with illness. The main contributors to successful living which were identified by **Figure 1**



**Figure 1** Circle of successful living

### **Successful living with PD**

#### **Usual state of health**

Five participants described successful living as being able to live the usual life that they had before having PD. Participants rated their level of success by comparing between their preillness life and current life with PD. They felt that their usual routines and physical appearance had not changed much because of effective medication, personal input or mild symptoms at the time of the study. The five participants were mainly female and diagnosed with PD under five years without severe disability

*R: what would successful living mean to you with PD?*

*P: Well. Being able to live my life as normal as possible which is what I try to do, just pretending I haven't got it. (Ann: 100–101)*

*I think I'm very lucky to be exact as I am, very very lucky. You look at me now and you think there is nothing wrong with me but there is some time I can't move but I enjoyed the happy time, so forget about bad. (Christine: 35–37)*

Ann pretended she had not been diagnosed with PD which seemed to be a positive psychological response at the earlier stage of illness, so pretending may not be applicable for patients with severe disability or symptoms. Specially, female participants emphasised maintaining their usual appearance:

*I don't shake normally, no one knows... I'm able to be or appear to be myself, you know um... well that's sort of vain things to say because I fear that people start looking at me shaking and stumbling. (Elizabeth: 65–66)*

Effective medications, various options and personal effort seem to be vital to continue their previous activities:

*I don't know really, it's just I think the tablets got under control and uh I just haven't got very poorly I think it hasn't gone far away enough yet. You just got keep going, haven't I? (Patricia: 6–7)*

*Um I didn't drive about 18 months...my husband encouraged me to have an automatic car... It took quite long time. I did get back to driving. So that is success. (Elizabeth: 9–12)*

Therefore, the usual state of health does not only take account of patients' previous physical health but also their social roles and activities.

### **Readjusted state of health**

Participants felt success when their symptoms seemed not to be getting worse and when they became comfortable and competence with their new adjustment to illness. The new adjustments involved changes in medication, activities and coping skills to control their acquired symptoms and life changes:

*"There are a lot of organizations if I want to go. I seem to cope ok". (22) "I think as time goes, it doesn't get any worse. It seems... sometimes you think back ... little things I got to watch. It doesn't go any worse. I think, in some ways I feel better". (George: 115–117)*

The 'Readjusted state of health' also involved psychosocial stability from the emotional turbulence and social stigma related to physical difficulty. Frank mentioned having peace within himself and his family as success in life:

*R: could you tell me what successful living means to you with PD?*

*P: It means I'm independent. I have peace with myself and with Elizabeth. (Frank: 18–19)*

Frank was living with a 'Readjusted state of health' which was predictable and manageable for him at the time.

### **Capacity in normal activities**

Participants with more advanced PD expressed their sense of success in relation to their physical and psychosocial capacity in activities. For instance, Christine had lived with PD for over 6 years and had a mild walking problem at the interview time. This symptom was not controlled by medication but she still maintained her part-time work:

*“I think I can cope more and also I can do more for myself and I think the future is bright”. (50)*  
*“Yes I’m prepared to do other things. I don’t think about what will happen to cure or something better.” (Christine: 247)*

In comparison, Frank and Harry with over 10 years of living with PD scored their level of success in PD the highest score (80–85). They appreciated being independent and contributing to others’ lives. This seemed to lead participants to believe in their self-worth and the dignity of their lives:

*Because I’m sure I could do more... As I said before, meeting people... Help another people... you can’t stop helping other people. (Harry: 49, 54, 67)*

*“R: could you tell me what successful living means to you with PD?”*

*“P: It means I’m independent.” (19) “I used to be able to do it...I used to do 95% of work around house ...”. (Frank: 40)*

An important aspect linked to feeling successful was a sense of being in control.

### **Strategies to gain sense of control**

#### **Positive mind**

A positive mind was reported as the most effective psychological adjustment in managing negative mood and maintaining a good relationship with others. Participants tried to make most of life by being thankful to be alive and loving self and others:

*Well. It hasn’t been all negative, it’s been quite positive. It made me see myself; it made me see our relationship to others... (10–11) I don’t want to be bitter because bitterness kills you... you have to be positive. I had chance to carry on my life... (55) My husband, he stayed with me and I didn’t think he would... (84) I would think I’m going to be as mobile as I can and keep the job as I can because that’s good thing. (Christine: 170)*

*I think it could be very easy to sort of stay at home and not doing anything, being miserable... um also when you go to a meeting you see so many people much worse than you are. Why am I complaining? (Elizabeth: 115–116)*

The adequate social comparison and family support seemed to create positive feelings that they were not left alone. Elizabeth was relieved because her symptom was not severe as other people with more advanced PD. Christine appreciated her husband remaining beside her.

#### **Facing up to it and determination**

Another common psychological reaction towards the physical fluctuations was determination in which participants often used words such as 'fighting', 'forcing' and 'facing up to it'. Physical disability can discourage people in taking up and participating in activities. Frank and Harry often felt fed up by taking a long time to do certain works, but they forced themselves to complete it with determination. Harry suggested trying different things whether he likes it or not because it sometimes turns out to be interesting:

*Having peace myself means fighting myself rather than getting depressed. Everybody fought with my depression so as my wife, with my wife but she was hurt by that time, she encourages me now on. .... (Frank 26–28)*

*R: In relation to mental attitudes, could you tell me more about what kind of mental attitudes mean by?*

*P: I mean not giving in, I mean fighting all the way... um forcing myself to do things or at least not sitting there but accepting. (Christina: 99–101)*

*Well I can do nothing. It's not the sort of I really want to do, things I can so, I do them, then the things are what I want to do. (Harry: 21–22)*

However, this involves individuals' emotional strength to change their behaviour which may require patience and much encouragement.

### **Social disclosure**

The second common adjustment made by patients was the openness that was used to deal with social stigma and isolation. Participants found that sharing information about their illness helped other people to understand their situation:

*Um well I think because I met a lot of people and the fact that I was quite open, I said I have PD because people think I might be drinking because I was shaking, you know. Um people have been so kind and helpful, um not in a patronising way um but in a helpful way and I think half of the battle is not being embarrassed over own of the fact that you have it. (Ann: 188–191)*

*I think that helps. Yeah I think it does with people on the same boat and you talk to the other people who have husband or wife, partners. That's helps. (Patricia: 286–287)*

Therefore, positive family support helped participants to manage their illness by being always beside them, being cooperative, accepting their illness and treating them as normal rather than treat them differently:

*We don't really talk about it, do we? No within the family they just accepted it. That's it you know. I mean we just love family. (Patricia: 156–157)*

### **Medical support and new challenges**

Medication and backup were obviously helpful factors contributing to successful living because the medication was a key in controlling their symptoms, and the health care professionals provided helpful resources and consultation through regular calls and visits:

*Yeah, I didn't want to meet people, but it just gets better over the time. You know, the medication as took whole I think everything has sort itself really. (Patricia: 16)*

*I'm lucky because I have very good care from doctor Sharon and I used to have another Parkinson's nurse because I was in Ramsey called Teresa and I knew her very well. (Elizabeth: 70–71)*

Participants tried new challenges to maintain their usual state of health. Most of the participants were engaged with more than two social activities such as exercise classes (physiotherapy), walking, poetry and painting. These activities were beneficial for both physical and emotional distress:

*Before I have PD? Oh yes. I did so much more, I just kept going from time I get up till I go to bed but I can't do it anymore... so um, yes I decided that I wasn't going to let this beating me that I started new challenges. (Ann: 10, 15)*

*I mean hospital didn't give us information. It was six weeks course. Yeah we found from there. Occupation therapist they are all there every week somebody doing different things. It was very helpful it certainly give better ideas. (Patricia: 86–89)*

Participants suggested trying different things to find suitable activities without prejudging them:

*I had something call Reiki. I don't know how it works but believe me it works for me... Well Reiki, my husband sneer that and most people think well that's not good. How do you know something got any good until you try? (Christine: 198–199)*

### **Discussion**

This study explored the perception of successful living in people with PD. The eight participants demonstrated their success in life with PD by rating the level of success as an average of 74/100 (range 60–80/100) in relation to their perception of successful living and sense of control. The meaning of successful living was described as maintaining either their usual state of health or a readjusted state of health. Having capacity in daily activities was also linked with success in living with late-stage PD. Usual state of health meant closeness to the participants' pre-illness life while

readjusted state of health involved a period of being stable in health and life following new adjustments. Participants who were diagnosed with PD less than five years previously and whose symptoms were not severe felt successful because their physical appearance and social role remained almost the same as their pre-illness life. Another group of participants with similar duration also felt success because their symptoms are steady and they were confident in their coping skills. These two stages may occur in sequence throughout the illness progression as shown in Fig. 1. People may always either try to get back to their previous state of health or shape another life patterns based on their physical ability.

Similar responses have seen elsewhere, for example in a study into experience of late-stage Parkinson's disease described the readjusted state of health as 'bridging' between the continuity with the past and stability with present routines (Williams & Keady 2008). Other researchers have explained transition in chronic illness as 'extraordinariness' and 'ordinariness' (Kralik 2002). These are periodic episodes between the time people being diagnosed and the time people reconstructing life with illness. 'Extraordinariness' involved the initial stage of illness when people feel disruption, loss and frustration by illness. The concept of 'ordinariness' is similar to readjusted state of health in this study in which patients accept their illness and make progress in their lives with illness. Patients learn how to maintain their illness from their everyday experience. Kralik (2002) found that people with chronic illness feel different from others and not normal, whereas patients with early stage PD expressed that successful living with illness is maintaining their normal life (preillness life) as much as possible in this study. A great deal of the literature focuses on keeping normality is a natural response of people with chronic illness to maintain their quality of life (Bury 1997, Whitney 2004). Such a response as 'pretending' appears to be an effective psychological adjustment to illness to deal with emotional distress and social stigma. Although the literature has described pretending as denial or false reconciliation (Johansson et al. 2009), this can be useful for female patients and early stage of PD patients as women appear to care about their physical appearance more than men (Kralik 2002).

However, the perception of successful living among the participants with over 10 years of PD was different from earlier stage of PD. They tended to focus on the physical ability to take care of their daily activities of living as much as possible. Their expression of 'I am independent' or 'I can do more' implies that their measurement of success can be based on the level of independence and capacity against the worst case such as physical immobility. If they scored their level of success in living with PD against their preillness life, it may not be as high as their current scoring over 80. Thus, the duration of illness and severity did not seem to have a major influence on the level of successful living but it changed the perception of successful living.

All participants had gone through typical psychosocial difficulties since their diagnosis in Table 2. The most effective psychological adjustments to illness were shown in this study to be a positive mindset and determination. The positive mindset was helpful to control patients' negative mood against the physical fluctuation and to maintain their relationship with others. A strong determination enabled people to face up their illness and accept in reality what was possible for them, and do as much as they could to maximise their ability and enjoy their life (Phinney et al. 2007). The same responses such as fighting and forcing have been seen among disabled people with chronic illness to maintain a normal life and its quality (Bury 1997). For the social aspects, openness and family support were central to overcoming the social stigma and restriction in social activities. A lack of understanding between relatives and friends can cause problems in relationship and socialising (Wressle et al. 2007). Participants in this study appreciated family for just being beside them and accepting them as they were. It is important to involve patients and partners in care and acknowledge their experiences and, further, allow them to make meaningful changes in their relationships through illness (Paterson 2001).

The effectiveness of medications seemed to be the main contributor to the success among the people with early stage of PD because it helped participants to maintain their usual appearance as well as diminish the period of discomfort and loss caused by illness (Johansson et al. 2009). However, the availability of various options can be more important as the illness progress because medications may no longer be very effective for motor fluctuations after 6 years from the onset (Fahn et al. 2007). Being able to engage in activities means a lot to ill people; it makes them feel they belong to this world, being connected with family or friends, being a useful person, retaining identity and providing enjoyment (Whitney 2004, Phinney et al. 2007). It can help patients to either recover previous routines or shaping the transition to a new life smoothly. Such decision-making and personal adjustment is required in this stage.

Although chronic illnesses are unpredictable, the common goals of patients are to improve or maintain functional abilities, independence, safety and confidence. So, the care plan should take account individuals' functional and psychological capabilities and social support (Kralik 2002). Such individualised care plan can help patients to shape a dynamic and continuous self-regulation while they manage their illness (Detweiler-Bedell et al. 2008). Thus, it is important for health care professionals to identify changes and plan adequate self-management support. Furthermore, encouragement of both social and physical activities is needed to fill the loss and to build self-esteem and identity. Health care professionals may give patients certain activities as a task to maximise independence and well-being after assessing patients' changes in usual state of health and their desired goals. Therefore, the activities should be agreed and doable for patients.

These findings should be seen within a certain framework and they have certain limitations. This is a small study with only eight participants; however, even with this small number the findings were surprising to the authors, people were more positive about their lives than was expected. The findings can only be generalised to people living with Parkinson's disease living in the South of England; however, they may be useful for others if it is felt their clinical groups are in a similar situation. It should be remembered that all of the participants were already attending a voluntary group and so they may have a more positive sense of success compared to those who do not attend groups. They were around 70 years of age and so these findings may not be relevant to younger people living with Parkinson's disease. Also, the participants were not severely disabled by their illness.

This paper highlights that it is possible to live successfully with Parkinson's disease and has described the perceived factors which need to be taken into account when supporting people to live successfully. A great deal of research has focused on the problems of living with Parkinson's disease and this work contributes to a developing approach in health care which has been influenced by the rise of positive psychology (Seligman et al. 2005) and which focuses on the possibilities and positive aspects of life. This is a small initial study and further research work is needed to explore success with larger numbers of people, over a wider age range, who have more severe Parkinson's disease and with people who do not attend groups. It will also be important to understand how people transition between their different states for what is 'usual, for them' and more about the relationships that bring these changes about'.

## **Conclusion**

The study showed how much people are concerned about keeping their normal life and ability to carry on personal activities while still being able to contribute to others despite aging and illness. This study helps us to gain knowledge about the patients' world and make a realistic care plan for individual patients. Health care professionals should examine any changes in patients' routines and health. Their desired goals and practical options should be discussed together with them according to their ability. Most importantly, patients should be reminded about their own values, emotional and physical strength to carry on a meaningful life.

## **Relevance to clinical practice**

This study suggests various ideas for health care providers on how to approach individuals with chronic illness. These ideas could involve: (1) gauging individual's perceived level of success in living with PD at the time, to identify what led to that perceived success for that person; (2) examining patient's physical and psychosocial changes by comparing between their preillness life and current life. Identifying what are the important aspects of individuals life and what are the possible options to keep them or replace them. This should be updated in a timely manner; (3)

working partnerships with patients and their family to find suitable coping skills and providing various social as well as physical options with encouragement and (4) educating health care professionals about the importance of psychosocial adjustments and helping professionals to draw on positive potentialities in life.

### **Disclosure**

The authors have confirmed that all authors meet the ICMJE criteria for authorship credit ([www.icmje.org/ethics\\_l1author.html](http://www.icmje.org/ethics_l1author.html)), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content and (3) final approval of the version to be published.

### **Conflict of interest**

None.

### **References**

- Barley EA, Walters P, Tylee A & Murray J (2012) General practitioners' and practice nurses' views and experience of managing depression in coronary heart disease: a qualitative interview study. *BioMed Central Family Practice* 13, 1471–2296.
- Barlow J, Wright C, Sheasby J, Turner AP & Hainsworth J (2002) Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling* 48, 177–187.
- Bishop M (2005) Quality of life and psychosocial adaptation to chronic illness and acquired disability: a conceptual and theoretical synthesis. *Journal of Rehabilitation* 48, 219–231.
- Bisschop MI, Kriegsman DMW, Beekman ATF & Deeg DJH (2004) Chronic diseases and depression: the modifying role of psychosocial resources. 733.
- Bramley N & Eatough V (2005) The experience of living with Parkinson's disease: an interpretative phenomenological analysis case study. *Psychology and Health* 20, 223–235.
- Braun V & Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 77–101.
- Burns N & Grove SK (2011) *Understanding Nursing Research: Building an Evidence-Based Practice*, 5th edn. Elsevier/Saunders, Maryland Heights, MO.
- Bury M (1997) *Health and Illness in a Changing Society*. Routledge, London and New York, NY.
- Chenoweth L, Sheriff J, McAnally L & Tait F (2013) Impact of the Parkinson's disease medication protocol program on nurses' knowledge and management of Parkinson's disease medicines in acute and aged care settings. *Nurse Education Today* 33, 458–464.

- Clark M & Hampson SE (2001) Implementing a psychological intervention to improve lifestyle self-management in patients with Type 2 diabetes. *Patient Education and Counseling* 42, 247–256.
- Dennison L, Moss-Morris R & Chalder T (2009) A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clinical Psychology Review* 29, 141–153.
- Department of Health (2006) *Self Care for People with Long Term Condition*. Department of Health, London.
- Detweiler-Bedell JB, Friedman MA, Leventhal H, Miller IW & Leventhal EA (2008) Integrating comorbid depression and chronic physical disease management: Identifying and resolving failures in self-regulation. *Clinical Psychology Review* 28, 1426–1446.
- Dobkin RD, Tröster AI, Rubino JT, Allen LA, Gara MA, Mark MH & Menza M (2014) Neuropsychological outcomes after psychosocial intervention for depression in Parkinson's disease. *Clinical Neurosciences* 26, 57–63.
- Endacott R (2008) Clinical research 4: qualitative data collection and analysis. *International Emergency Nursing* 16, 48–52.
- Fahn S, Jankovic J, Hallett M & Jenner P (2007) Chapter 6 – Medical Treatment of Parkinson Disease. In *Principles and Practice of Movement Disorders*. (From SFJC & Jenner MH eds). Churchill Livingstone, Philadelphia, PA, pp. 129–165.
- Foxwell R, Morley C & Frizelle D (2013) Illness perceptions, mood and quality of life: a systematic review of coronary heart disease patients. *Journal of Psychosomatic Research* 75, 211–222.
- Gatt S & Sammut R (2008) An exploratory study of predictors of self-care behaviour in persons with type 2 diabetes. *International Journal of Nursing Studies* 45, 1525–1533.
- Holloway I & Wheeler S (2010) *Qualitative Research in Nursing and Healthcare*, 3rd edn. Wiley-Blackwell, Oxford, UK.
- Hurt CS, Landau S, Burn DJ, Hindle JV, Samuel M, Wilson K & Brown RG (2012) Cognition, coping, and outcome in Parkinson's disease. *International Psychogeriatrics* 24, 1656–1663.
- Johansson K, Ekebergh M & Dahlberg K (2009) A lifeworld phenomenological study of the experience of falling ill with diabetes. *International Journal of Nursing Studies* 46, 197–203.
- Ketharanathan T, Hanwella R, Weerasundera R & de Silva VA (2014) Major depressive disorder in Parkinson's disease: a cross-sectional study from Sri Lanka. *BioMed Central Psychiatry* 14, 1–7.
- Kralik D (2002) The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing* 39, 146–154.
- Marks DF & Yardley L (2004) *Research Methods for Clinical and Health Psychology*. SAGE, London.
- Paterson B (2001) The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship* 33, 22–26.

- Phinney A, Chaudhury H & O' Connor DL (2007) Doing as much as I can do: the meaning of activity for people with dementia. *Aging and Mental Health* 11, 384–393.
- Seligman ME, Steen TA, Park N & Peterson C (2005) Positive psychology progress: empirical validation of interventions. *American Psychologist* 60, 410–421.
- Sharpe L & Curran L (2006) Understanding the process of adjustment to illness. *Social Science & Medicine* 62, 1153–1166.
- Simpson J, Lekwuwa G & Crawford T (2013) Illness beliefs and psychological outcome in people with Parkinson's disease. *Chronic Illness* 9, 165–176.
- Stanley-Hermanns M & Engebretson J (2010) Sailing the stormy seas: the illness experience of persons with parkinson's disease. *The Qualitative Report* 15, 340–369.
- Stanton AL, Revenson TA & Tennen H (2007) Health psychology: psychological adjustment to chronic disease. *Annual Review of Psychology* 58, 565–592.
- Whitney CM (2004) Maintaining the square: how older adults with Parkinson's disease sustain quality in their lives. *Journal of Gerontological Nursing* 30, 28–35.
- Williams S & Keady J (2008) 'A stony road. . . a 19 year journey': 'Bridging' though late-stage Parkinson's disease. *Journal of Research in Nursing* 13, 389–390.
- Wressle E, Engstrand C & Gran\_erus AK (2007) Living with Parkinson's disease: elderly patients' and relatives' perspective on daily living. *Australian Occupational Therapy Journal* 54, 131–139.
- Zoeckler N, Kenn K, Kuehl K, Stenzel N & RiefW(2014) Illness perceptions predict exercise capacity and psychological wellbeing after pulmonary rehabilitation in COPD patients. *Journal of Psychosomatic Research* 76, 146–151.