Core elements to understand and improve coping with Parkinson’s disease in patients and family carers: a focus group study

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IMPACT STATEMENT

- Coping has recently been established as a key factor which enables the fulfilment of the process of psychosocial adaptation to Parkinson's disease (PD) in patients and family carers.
- The findings of this study highlight that coping with PD for people with the disease and their family members constitute a process of redefinition and search for balance in life, mediated by the dynamics of protection.
- A multifaceted intervention is proposed in this study to improve both coping skills and the quality of life of families who live with PD and other long term conditions.

Title: Core elements to understand and improve coping with Parkinson's disease in patients and family carers: a focus group study

Abstract

Aims. 1) To explore the meaning that coping with Parkinson's disease has for patients and family carers; 2) To suggest the components of an intervention focused on enhancing their coping with the disease.

Background. Adapting to Parkinson's disease involves going through many difficult changes; however, it may improve quality of life in patients and family carers. One of the key aspects for facilitating the psychosocial adjustment to Parkinson's disease is the strengthening of coping skills.

Design. A sequential explanatory mixed-methods study was carried out. Findings from the qualitative phase will be presented.

Methods. Data were collected in May 2014 through 3 focus groups: one of people with Parkinson's disease (n = 9), one of family carers (n = 7) and one of healthcare professionals (n = 5). All focus groups were digitally recorded and transcribed verbatim, and content analysis was independently carried out by two researchers.

Findings. The participants coincided in highlighting that coping with Parkinson's disease helped the patient and the family carer in their search for balance; and it implied a transformation in their lives. To aid the process of coping with Parkinson's disease, a multifaceted intervention is proposed.

Conclusion. Coping with Parkinson's disease is a complex process for both patients and family carers and it should therefore be considered a standard service within healthcare policies aimed at this group. The proposed intervention constitutes a nursing tool which has great potential to improve the quality of life in Parkinson's disease and in other long term conditions.

Keywords: Coping, Family carers, Focus groups, Long term condition, Nursing, Non-pharmacological intervention, Parkinson's disease, Psychosocial adjustment, Quality of life.

SUMMARY STATEMENT

Why is this research needed?

- Psychosocial adaptation to Parkinson's disease implies patients and family carers dealing with multiple physical and social changes.
- Promoting psychosocial adaptation to Parkinson's disease in patients and family carers may influence their quality of life.
- Coping has recently been established as a key factor which enables the fulfilment of the process of psychosocial adaptation to Parkinson's disease.

What are the key findings?

- The redefinition and search for balance in life, mediated by the dynamics of protection, constitute key aspects in the process of coping with Parkinson's disease for patients and family carers.
- Considering previous findings and the Chronic Care Model, the main topics and methodology of an intervention focused on enhancing coping with Parkinson's disease in patients and family carers are suggested.
- The multifaceted intervention proposed in this study could be a tool for nurses to improve both coping skills and the quality of life of families who live with Parkinson's disease.

How should the findings be used to influence policy/practice/research/education?

- Coping with Parkinson's disease is a complex process for both patients and family carers and it should therefore be considered a standard service within healthcare policies aimed at this group.
- The identification of similarities between the coping with Parkinson's disease in patients and family carers confirms that a healthcare approach of dyads patient-carer or the family unit is necessary.
- Nurses need to redirect the process of coping with Parkinson's disease when it is inadequate and is promoting a harmful impact on the life of the person.

INTRODUCTION

In Parkinson's disease (PD), the process of psychosocial adaptation to the illness implies patients withstanding various changes to their social lives and as in their bodies (Fleming *et al*. 2004, Haahr *et al*. 2010, Haahr *et al*. 2011). Family carers, whose lives are influenced by the experience of their family member with PD, also find it difficult to adapt, due to the feeling of uncertainty to which the degenerative nature of PD gives rise, and their lack of preparation for caring for a person with PD (Portillo *et al*. 2012, Tan *et al*. 2012, Haahr *et al*. 2013). However, promoting the development of psychosocial adaptation to a LTC is positive, because this process can help the person adjust their activities and expectations to the new situation (Stanton *et al*. 2007, de Ridder *et al*. 2008, Ambrosio *et al*. 2015).

Background

The experience of living with PD has been a research topic since the beginning of the 21st century. Studies have mainly explored this phenomenon from the perspective of the person with PD; to a lesser extent from the experience of their family carer. The literature highlights psychosocial adaptation to the illness as one of the most relevant processes included in living with PD (Whitney 2004, Stanley-Hermanns & Engebretson 2010, Haahr *et al*. 2011, Portillo *et al*. 2012). According to other authors, adapting oneself to a long term condition (LTC) is a dynamic, complex process, influenced by diverse factors such as social support, coping mechanisms and personality (Stanton *et al*. 2007, de Ridder *et al*. 2008, Ambrosio *et al*. 2015).

The benefits of psychosocial adaptation for PD patients and their family carers were identified recently (Navarta-Sánchez *et al*. 2016a). The authors highlight that psychosocial adaptation significantly influences both the quality of life of the patient with PD and their family carer. Simultaneously, this study emphasises that coping is a key aspect in enabling the realisation of psychosocial adaptation to PD. Nevertheless, the majority of non-pharmacological interventions focus mainly on the self-management of PD and some specific physical impairments, and their benefit remains inconclusive (Hempel *et al*. 2008, Tan *et al*. 2014). Therefore, the aim is to look more closely, within the context of PD and the meaning of coping, at the "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman 1984, p.141). This study is conducted following the assumptions of the Chronic Care Model (Coleman *et al*. 2009) which underlines the importance of providing interventions for fostering motivation, trust and the capacities of both the patient and their relatives, so they can be more responsible in caring for the patient's LTC and health (Coleman *el al*. 2009). In accordance with the philosophy of the Chronic Care Model, this study aims to shed light upon how to promote coping skills in patients with PD and their family carers to improve their adjustment and living with PD.

THE STUDY

Aims

The aims of this study were: 1) To explore the meaning of coping with Parkinson's disease for patients and family carers; 2) Based on findings from the first objective and the assumptions of the Chronic Care Model, to suggest the main components of a non-pharmacological intervention to improve quality of life in people with Parkinson's disease and their family carers through the enhancement of their coping with the disease.

Design

This was a mixed-methods study with an explanatory sequential design (Creswell & Plano Clark 2011). Other results of this research have been published elsewhere (X *et al*. X; X *et al*. X). This study is part of the X research programme to design multidisciplinary education interventions to promote positive living with a LTC in patients and relatives.

Participants

The sample consisted of people with PD, family carers and healthcare professionals. Access to patients with PD and their family carers was gained through a patients' association. Healthcare professionals were recruited through a neurology outpatient clinic and a primary care practice in Navarre (Spain). All participants were recruited using purposive sampling (Miles *et al*. 2014) to include key people who could respond to the objectives of the study. The strategy of maximum variety was followed so that the inclusion of diversity allowed unknown common patterns to be identified (Creswell & Plano Clark 2011). Variables selected to include differences in the composition of the focus groups are presented in Table 1. The consideration of these characteristics in the participants was possible due to collaboration between professionals in participating centres. To ensure homogeneity, people with PD participated in the same focus group and the same for relatives and professionals.

Data collection

Focus groups were formed to obtain an overview of the topic from dialogue between the participants (Miles *et al*. 2014). A moderator and an observer participated in the focus groups and voice recording was used. Open questions were used e.g.:

When we talk about coping with PD, exactly what are we referring to?

What does……mean?

Ethical considerations

This research had ethical approval from the University of Navarre (ref 99/2013 mod 1), and followed the principles of Law 14/2007 of Biomedical Research. Informed consent was obtained. All material gathered through the focus groups was coded to ensure confidentiality.

Data analysis

Data were content analysed (Miles *et al*. 2014) beginning with a thorough reading of the transcripts and the identification of codes. Categories were then created and reflection combined with the reading the literature was conducted throughout the procedure, which allowed the refining of codes and categories.

Rigour

This analysis was done independently by the two researchers (X & X) who participated in the focus groups. The results were later compared and the final codes and categories were agreed. The analysis began after the first focus group so that the results could enrich the data collection and identify the saturation of data (Miles *et al*. 2014). A session with members of the X Programme, who have experience in the clinical care of people with PD but who had not participated in the focus groups, was also held to verify the adequacy and validity of the results (Miles *et al*. 2014).

FINDINGS

Three focus groups were developed with 21 participants (9 people with PD, 7 family carers and 5 healthcare professionals) in May 2014, and each focus group lasted 70, 62 and 80 minutes, respectively. In the focus group of patients, mean age was 71.0 years (SD 7.3); the majority were men (n = 6) and retired (n = 8). Participants were diagnosed with PD on average 6.1 years ago (D.E = 2.8) and in the Hoehn & Yahr Scale mean score was 1.5 (SD 1.0). In the relatives focus group, 4 women and 3 men participated and their average age was 62.1 years (SD 14.1). Their relationship with the person with PD was that of spouse (n = 3) or son or daughter (n = 4). Four participants worked, one was a housewife and two were retired. In the healthcare professionals focus group, the average age was 46.2 years (SD 8.0); the majority were women (n = 4). With regard to profession, two were nurses, one a GP, one a neurologist and one a social worker. Their environment was primary care (n = 3) and specialist care (n = 2). Mean years of professional experience were 23.2 (SD 8.4).

One theme and three categories emerged from analysing the transcripts of three focus groups by comparing the transcripts of the patients, family members and healthcare professionals' dialogues and searching for common issues across the three groups.

Theme: Redefinition and the search for balance

Categories:

- Coping for the person with PD: acceptance and trying to come to terms with the disease and the new situation

- What coping means for the family carer: renouncing and becoming a carer
- Constructing dynamics of protection

The three categories describe the opinions which were shared by most patients, family carers and healthcare professionals in this study about the meaning of coping with PD for a patient and a family carer.

Redefinition and the search for balance

According to the participants, the process of coping with PD implied a transformation of routines and chores in the lives of both patient and family carer. The participants indicated that coping with PD was a process difficult to accomplish for both the patient and the family carer, due to the fact that their priorities assume a new and unwanted direction. Participants thought that, in coping with PD, both the patient and the relative put cognitive and behavioural efforts into operation. As explained below, however, the significance those efforts acquire is different for each person because PD is experienced first-hand by the patient, whereas it is external for the family carer. Nevertheless, the majority of the participants declared that coping with PD is a positive process because it helped the patient and family carer find a new balance in their lives.

Coping for the person with PD: acceptance and trying to come to terms with the disease and the new situation

From a broad perspective, shown in Figure 1, the participants indicated that the meaning of coping with PD for a person with the disease is accepting and trying to come to terms with the disease and the new situation. According to the participants, the process of coping is very difficult for anyone with PD, especially because it means accepting changes that the disease has brought, the majority of which are perceived by the person as losses. However, the participants considered that coping with the illness was a necessary process for the person with PD, because it helped to adapt and live with the disease.

- Patients focus group

> "I´ve had this for 8 years and I do the best I can. Now, if I´m allowed to swear, I´ll admit that it´s a bugger of an illness. But you have to face it. You have no options except patience and acceptance. There's the positive part, which is that you don´t have pain but you do have limitations in your movements and everyday there are more of them" (P3, male, 70 years old, retired, Stage I in H&Y, 8 years since the diagnosis of PD)

- Relatives focus group

> "You have to accept the disease, that´s crucial, and if you don´t you´re fooling yourself and making it complicated for the person looking after you" (F5, male, 68 years old, retired, husband of a woman with PD since 8 years ago)

- Professionals focus group

> "A patient with Parkinson´s experiences losses because their life changes and at times, radically. The loss of social relationships, a job, or even the loss of a partner. I don´t know, loss…and inside they feel the loss of the person they were before" (R1, social worker, woman, 53 years old, Primary care, 29 years of professional experience)

Therefore, the majority of participants identified two efforts for the patient in coping with PD (see Figure 1). On the one hand, the cognitive effort of "assuming", which refers to the acceptance of the disease. On the other hand, the behavioural effort of "trying to bear it" which implied searching for solutions to minimise the impact of the symptoms and the changes occurring in the patient's life.

With reference to the behavioural effort of coping, getting activities underway in an attempt to improve symptoms or overcome the difficulties in the activities of daily living, the participants thought this could easily be developed by anyone with PD. Nevertheless, the cognitive effort of accepting the disease was perceived by participants as being more complex and was not always achieved by the patient. In fact, not everyone with PD acknowledged that they had accepted their situation. Some participants expressed that the most difficult aspect to accept was that the disease has a negative progression and that there is no cure.

- Patients focus group

“I try to be as active as they´ve told me to be. I go to the gym twice a week. And well, if you feel like it or if you don´t, I´d say that what you have to do is just get over it, go out and distract yourself as much as possible” (P1, male, 79 years old, retired, Stage II in H&Y, 8 years since the diagnosis of PD)

“I don´t accept and I don´t understand anything that has happened to me. So there it is, I´ve said it” (P2, female, 74 years old, retired, Stage I in H&Y, one year since the diagnosis of PD)

- Relatives focus group

“She thinks that she´s going to get better, that every time we have an appointment with the neurologist she´ll be given some wonderful pill and she´ll be fine the next day. They´ve told her that it isn´t like that, that she will stay the same or get worse, but she isn´t going to improve” (F2, female, 50 years old, working, daughter of a woman with PD since one year ago)

- Professionals focus group

“I believe that what we find most is people saying, I´ve just been diagnosed and I´m starting to live with the illness and if things go well at the beginning, well… great, but if they don´t go well, that´s when they find it more difficult to accept” (R4, physician, male, 38 years old, Specialist care, 14 years of professional experience)

What coping means for the family carer: renouncing and becoming a carer

As is illustrated in Figure 1, the majority of participants in the relatives and professionals focus groups expressed that coping with PD for a family carer meant, in general terms, renouncing things and starting to become a carer. Specifically, participants from these two focus groups said that undertaking the role of carer implied leaving behind social activities or free time, to spend more time with the person with PD. According to most of the healthcare professionals and relatives, the coping process for the family member encourages the person to make various changes in their daily routine, which means that their life essentially centres on the needs and well-being of the patient.

- Relatives focus group

> "When you mentioned "how do you cope with it", one aspect I think is really important is renouncing, because when you have a family member with Parkinson´s you have to give up lots of things" (F1, female, 71 years old, housewife, wife of a man with PD since one year ago)

- Professionals focus group

> "What I do see is that even when the person acts positively towards the illness of the person they´re caring for, the carer´s life is transformed even more. They give up much more of themselves, their activities, their hopes and they focus completely on the person who is ill" (R2, physician, woman, 53 years old, primary care, 30 years of professional experience)

One aspect which the three focus groups found characteristic of coping in family members, was the behavioural effort of looking after a person with PD. According to the participants, regardless of the patient's physical impairment, the relative adopts a continuous role of carer to deal with the new family situation. This can range from physical assistance to do activities that the patient can not longer do alone, to becoming their main emotional support. This is why the participants assure that family carers need to receive information and resources, which will help them to deal with their new situation.

- Relatives focus group

> "You have to be with him all the time….he won´t go out alone and there are days when he´s so exhausted and tired it´s terrible, so you go to your GP and they say that he´s fine, there´s nothing wrong, he has Parkinson´s" (F1, female, 71 years old, housewife, married to a man with PD since one year ago)

> Peter: "I think that what is needed is more tips, because the doctor gives you tablets, right? But you need to know what to do about constipation, for example, and other stuff" (F3, male, 49 years old, working, son of a man with PD since 10 years ago)

> David: "Yes, I believe that all the information professionals can give the relatives is useful" (F5, male, 68 years old, retired, married to a woman with PD since 8 years ago)

- Professionals focus group

> "A carer isn't only the person who's washing and feeding a patient. The simple fact of waiting for when they wake up in the night to go to the bathroom, to make sure they don´t bang into the walls and get back to bed safely, that´s caring too. So that person needs to start having resources because they´re already acting as a carer" (R5, nurse, woman, 50 years old, Primary care, 29 years of professional experience)

Another theme put forward by the majority of participants was that coping with PD is a hard process for family carers. In fact, some of the participants stated that this process could lead the family carer to a physical and an emotional impairment:

- Patients focus group

> “Relatives already have enough knowing the illness you have, seeing the symptoms and helping you to overcome it. That´s why I try to make sure they suffer as little as possible on my behalf” (P1, male, 79 years old, retired, Stage II in H&Y, 8 years since the diagnosis of PD)

- Relatives focus group

> Peter: “There comes a time when the carers need help, because if not, you either get depressed or you could do anything… I got to the point where I couldn´t take it anymore” (F3, male, 49 years old, working, son of a man with PD since 10 years ago)

> Anne: “The thing is you need time, time for yourself…you need some kind of escape or something worst can happen” (F6, female, 56 years old, working, daughter of a woman with PD since 8 years)

- Professionals focus group

> “Everyone finds physical caring exhausting, but later it completely absorbs you mentally” (R5, Nurse, woman, 50 years old, primary care, 29 years of professional experience)

Constructing dynamics of protection

According to the participants, patients and relatives need to develop coping strategies in order to reduce stress and uncertainty of the disease. These coping strategies were attitudinal, but at the same time they implied a behavioural effort.

Specifically, the participants identified six dynamics of protection: Be positive; Live in the present and enjoy any time; Be patient with issues which could be difficult to change or with no possibility of modification; Look for information about the disease and any benefit aspect for yourself; Partake in activities for promoting a better emotional welfare and physical capacity; and Normalise the symptoms and the new situations that you face due to PD. These coping efforts are illustrated through the fragments of transcript presented in Table 3.

The participants highlighted that in spite of being positive dynamics, the patient or family carer does not always put them into practice innately or from the beginning. They related this to the fact that the background to developing these dynamics is the recognition of the new situation, or at least attempting to look for solutions to improve it. Therefore, the creation of dynamics of protection is a step towards redefinition and the search for balance, as is shown in Figure 1.

The proposed non-pharmacological intervention

As indicated, the components of a non-pharmacological intervention to improve coping with PD in patients and family carers were defined from the results of the study. The proposed intervention consists of a multifaceted intervention with ten topics, which are summarised in Table 2. Due to the complexity of the process of coping with PD, no component can be implemented independently, because all components interact and are necessary and relevant to improve coping with PD.

From the findings described in the theme Redefinition and the search for balance, topics 1, 2, 3, 4, 8 and 10 of the proposed intervention were defined (Table 2). Topic 1 is planned to address the opinion, expressed by people with PD, which relate to the role they have in improving their living with the disease. Topic 2 focuses on covering the lack of knowledge about PD described by the family carers. Topic 3 focuses on promotion of good health, for both patient and family carer. It also addresses the desire expressed by relatives to have tools to prevent or treat basic health problems which the patient, as well as the actual relative, may have; such as constipation, tiredness or difficulty getting to sleep. Topic 4 claims to raise the patient's and family carer's awareness of the existence of the process of psychosocial adaptation and coping with PD. This way cases where the process is not deemed as healthy could be identified and rectified and those where a positive experience of living with PD occurs could be strengthened. Topic 8 is planned to deal with the topic of uncertainty and grieving over losses which the patient and family carers may experience, focusing on their ability to recognise signs of stress in themselves, and put into practice resources which will help them relax. Lastly, topic 10 means to respond to the need for information and resources to cope as a patient and a family carer.

Considering the findings described in the category Constructing dynamics of protection, topics 5, 6, 7 and 9 of the intervention are proposed to strengthen coping with PD in patients and family carers (Table 2). The purpose of these topics is for people with PD and their family carers to reflect upon whether they usually put the six coping mechanisms identified in this study into practice in their daily lives or not. These topics also seek to emphasise the advantages of adopting these coping strategies and discuss how to overcome the barriers that patients and family carers identify when they begin to implement the dynamics of protection.

The methodology proposed for this intervention is described in Table 4 and is worth noting for being based on the six components of the Chronic Care Model. In line with this model, the intervention encourages an approach to support self-care, long-term monitoring and the use of community and technology resources (website and telephone assistance), which can contribute to improving the process of coping with PD, for patients and family carers. In terms of the contextualisation of the intervention, bearing in mind the findings of this study and the assumptions of the Chronic Care Model, it is proposed that the intervention should be developed by primary care nursing professionals.

Discussion

In this paper the significance of coping with PD for people with the disease and their family members has been described (objective 1); and the components and methodology of an intervention to enhance the coping with PD are proposed (objective 2). In this way, the objectives of the study have been fulfilled.

Regarding the first objective, the findings of this study highlight that coping with PD implies a redefinition and a search for balance, which is facilitated by the implementation of different dynamics of protection. This result proves that coping with PD is a dual process, which combines both positive and negative experiences. It is a positive process because coping is conceived as a personal strategy that facilitates difficult situations. However, it can also be experienced as negative because it involves a life transformation, which was not wished for. To date, few studies have been identified that focus on understanding coping in the context of PD from the perspective of patients (Frazier 2002, Whitney 2004, Portillo *et al*. 2012, Zaragoza *et al*. 2014) and family members (Portillo *et al*. 2012, Zaragoza *et al*. 2014). In line with previous research, this study has found that PD patients coped by accepting (Frazier 2002, Whitney 2004, Zaragoza *et al*. 2014), being positive (Frazier 2002, Portillo *et al*. 2012), living in the present (Whitney 2004, Portillo *et al*. 2012), having patience (Frazier 2002), looking for information (Whitney 2004) and partaking in activities (Frazier 2002, Whitney 2004). These findings support that patients and relatives use emotion-focused strategies and problem-focused strategies for coping with PD.

Likewise and of particular interest, is the identification of similarities between the coping with PD in patients and family carers. This finding confirms the need described by different authors (Reinhard *et al*. 2008) about looking after the carers of people with a LTC. In fact, recent research points out that to better respond to the difficulties of a LTC, a healthcare approach of dyads patient-carer (Navarta-Sánchez *et al*. 2016a) or the family unit (Årestedt *et al*. 2014) is necessary. This is why nursing professionals should be responsible for encouraging the process of coping with PD, not only in patients but also in their family carers.

In this sense, one aspect which must be dealt with is accepting the disease. The findings of the study coincide with previous research carried out in patients with PD (Frazier 2002, Whitney 2004, Wressle *et al*. 2007, Haahr *et al*. 2010, McLaughlin *et al*. 2010, Tan *et al*. 2012, Zaragoza *et al*. 2014) and also in patients with other LTCs (Ambrosio *et al*. 2015), where the acceptance of the disease is one of the most important steps, but also one of the most difficult to achieve. When it came to family carers, participants in the current study did not point out the acceptance of the patient's disease or the role of carer as key element in coping with PD. According to the United States National Parkinson Foundation Guidelines (2015), many relatives do not like being identified as carers, because, amongst other reasons, they associate this term with performing physical caring tasks. Nevertheless, as the guide highlights, relatives should accept their role as carer as another aspect of their lives, which does not replace but broadens other aspects of their identity (National Parkinson Foundation, 2015). Along these lines, Tan *et al* (2012) indicated that accepting the role of carer, together with maintaining one's social life, were strategies used by family carers to cope with their situation. Therefore, it could be said that a failure to mention accepting the patient's disease or the role of carer is related to giving up daily activities which the relatives used to do to cope with PD. In accordance with these findings, it is crucial that nurses value and reinforce the acceptance in people with PD and in their family carers. In addition, nurses should be in charge of redirecting the process of coping with PD when it is inadequate and is promoting a harmful impact on the life of the person, as occurred in this study with relatives who mentioned that they had given up activities or that they had reached a point of worrying about their emotional health.

Different studies have reported that many people do not change their coping skills although their stress does not decrease (Frazier 2002, Folkman 2011, Cheng *et al*. 2014). Thus, nurses need to identify the coping skills used by patients with PD and relatives, and how these skills influence the patients' and carers' well-being. This assessment is necessary so that patients and relatives learn to redirect their coping skills for improving their wellbeing and quality of life (Folkman 2011, Rice 2012).

Therefore, this research proposes a multifaceted intervention to promote positive coping skills in people with PD and their family carers. Some topics included in the proposed intervention such as health promotion, information about PD and management of stress have been researched in previous studies (Lindskov *et al*. 2007, A'Campo *et al*. 2010, Tickle-Degnen *et al*. 2010, Nelson *et al*. 2011, Van der Marck *et al*. 2013, Ory Magne *et al*. 2014). However, most interventions (Lindskov *et al*. 2007, A'Campo *et al*. 2010, Nelson *et al*. 2011, Van der Marck *et al*. 2013) did not find significant improvements in the quality of life or health of participants. Taking into account findings from the present qualitative study, it is suggested that the combination of the 10 topics of this intervention is essential to address the complex process of coping with PD. Also, the proposed methodology based on the Chronic Care Model is necessary due to the chronic nature of PD.

Limitations

The sample size prevents the findings being generalised to other communities. However, it is a suitable size for the development of an exploratory qualitative study, which has allowed an in-depth understanding of the meaning of coping with PD for patients and family carers. In addition, the authors are aware that the findings of this study could be influenced by their own experiences and beliefs. Nevertheless, to reduce this limitation, the analysis was carried out independently by two researchers, member checks were performed, as were the criteria of accuracy proposed by Guba and Lincoln (1981) (credibility, transferability, dependability, confirmability).

Conclusions

This study has contributed to the understanding of the meaning of coping with PD and to the identification of a multifaceted intervention, which could encourage its promotion in clinical nursing practice. Coping with PD is envisaged as a complex process with a positive connotation associated with the search for balance; but also with a negative sense because it entails a redefinition of life that was not chosen. This whole process is mediated by the development of dynamics of protection that seek to protect the person's well-being. Due to the individualistic nature of the process of coping with PD, the nursing role is paramount to encourage holistic evaluation and the building of a relationship of trust. This intervention is proposed to support coping with PD and constitutes a nursing tool with great potential to improve the quality of life of patients with PD and their family carers, as well as that of families who live with other LTCs.

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Table 1 Variables selected in order to assure diversity in each focus group.

Patients focus group	Relatives focus group	Healthcare professionals focus group
• Age • Sex • Occupation(Working/Retired) • Stage of Hoehn & Yahr • Number of years since diagnosis	• Age • Sex • Occupation(Working/Retired) • Relationship to patient (Spouse/Son/Daughter)	• Disciplines (Nursing, Medicine, Social work) • Healthcare context(Primary or Specialist Care) • Years of professional experience.

Table 2 Main content of the proposed intervention.

	Topic	Aim of the session
1	Individual presentation and evaluation	To carry out an individual study of the difficulties which both the patient and the family member have with psychosocial adaptation and find out their abilities to cope. Explain the aim of the sessions to the participants; that only they can improve their experience with the illness. The responsibility is theirs.
2	Getting to know PD	Present the main characteristics of PD and refute any false beliefs related to it.
3	Healthy life habits	Encourage the patient and relative to adopt a healthy lifestyle (diet, physical exercise, sleep/rest). Show them behavioural strategies in order to prevent or treat possible health problems.
4	Adapting to and coping with PD.	Raise awareness of the process of psychosocial adaptation to PD and coping with the illness, to promote the sharing of opinions about their meanings.
5	Positive self-esteem	Boost the participants´ self-esteem through dialogue. Discuss how much they tend to use the coping strategy of "being positive" and what its benefits are.
6	Empathy and patience	Promote empathy towards the corresponding family member through dialogue. Talk about situations where patience has played an important role and the advantages of this.
7	Normalise the situation and partake in activities	Talk about the meaning and the advantages of the coping mechanisms, "Normalising the situation" and "Engaging in activities".
8	Management of stress and complicated situations	Discuss the topic of uncertainty, the evolution of PD and the possible losses they have experienced. Recognise symptoms of stress and learn how to relax.
9	Look for information and live in the present	Talk about the advantages of the coping strategies, "looking for information" and "living in the present". Discuss personal barriers in order to use these strategies.
10	Resources	Give information about existing resources for people with disabilities and their families and how to apply for them.
11	Conclusions	Obtain a global vision of the topics dealt with.

Table 3 Fragments of transcript to illustrate the six dynamics of protection in coping with PD.

	Fragments of transcript
Be positive	*"We have to be a bit positive, just a little, or very positive. We have to be positive because it´s the only thing which will help us to face the ups and downs that life brings us"(P4, Person with PD, Male, 85 years old, retired, Stage I in H&Y, 1 year since the diagnosis of PD)*
	"There are so many differences in the way people cope. There are those who, even when they are feeling very ill, make an effort to be positive. On the other hand, some see everything in life so negatively that they just end up making everyone bitter; themselves and everyone around them" (R5, Nurse, woman, 50 years old, Primary care, 29 years of professional experience)
	Alison*: "In the case of my husband, what helps is the fact that he´s so positive, he always sees the glass half-full" (F7, Female, 74 years old, housewife, married to a man with PD since 8 years ago)*
	Anne*: "Sure, but that depends on each person" (F6, female, 56 years old, working, daughter of a woman with PD since 8 years ago)*
Live in the present	*"My strong point is to live day to day, not to think about the future but to ignore it. I don´t mean I ignore the future….I just don´t live in the future; I don´t think about it and live in the present" (P8, Person with PD, Male, 73 year old, retired, Stage II in H&Y, 6 years since the diagnosis of PD)*
	"I think that if they lose the fear of what´s going to happen and can live day to day, they would cope better" (R2, Physician, woman, 53 years old, Primary care, 30 years of professional experience)
	"My mother still doesn´t accept that she has Parkinson´s and I tell her that she has to, but she can´t just yet. So we try to live for the moment" (F2, female, 50 years old, working, Daughter of a woman with PD since one year ago)
Be patient	"*It´s hard, but if you repeat it to yourself a few times and you´re patient, it´s easier to bear.*" *(P3, Male, 70 years old, retired, Stage I in H&Y, 8 years since the diagnosis of PD)*
	"*For me, the most difficult thing for families is to know how to have patience, to be able to manage the changes which are coming" (R1, Social worker, woman, 53 years old, Primary care, 29 years of professional experience)*
	"I believe that helping as much as you can and patience, a lot of patience" (F4, male 41 years old, working, son of a man with PD since 8 years ago)
	Anne*: "My mother has come into my room at three in the morning more than once, saying I don´t know what I have to do now. What can I say to her! And these things happen!" (F6, female, 56 years old, working, daughter of a woman with PD since 8 years)*
	Claire*: "That´s why I say that you have to know that it´s like that and just have patience"(F1, female, 71 years old, housewife, married to a man with PD since one year ago)*

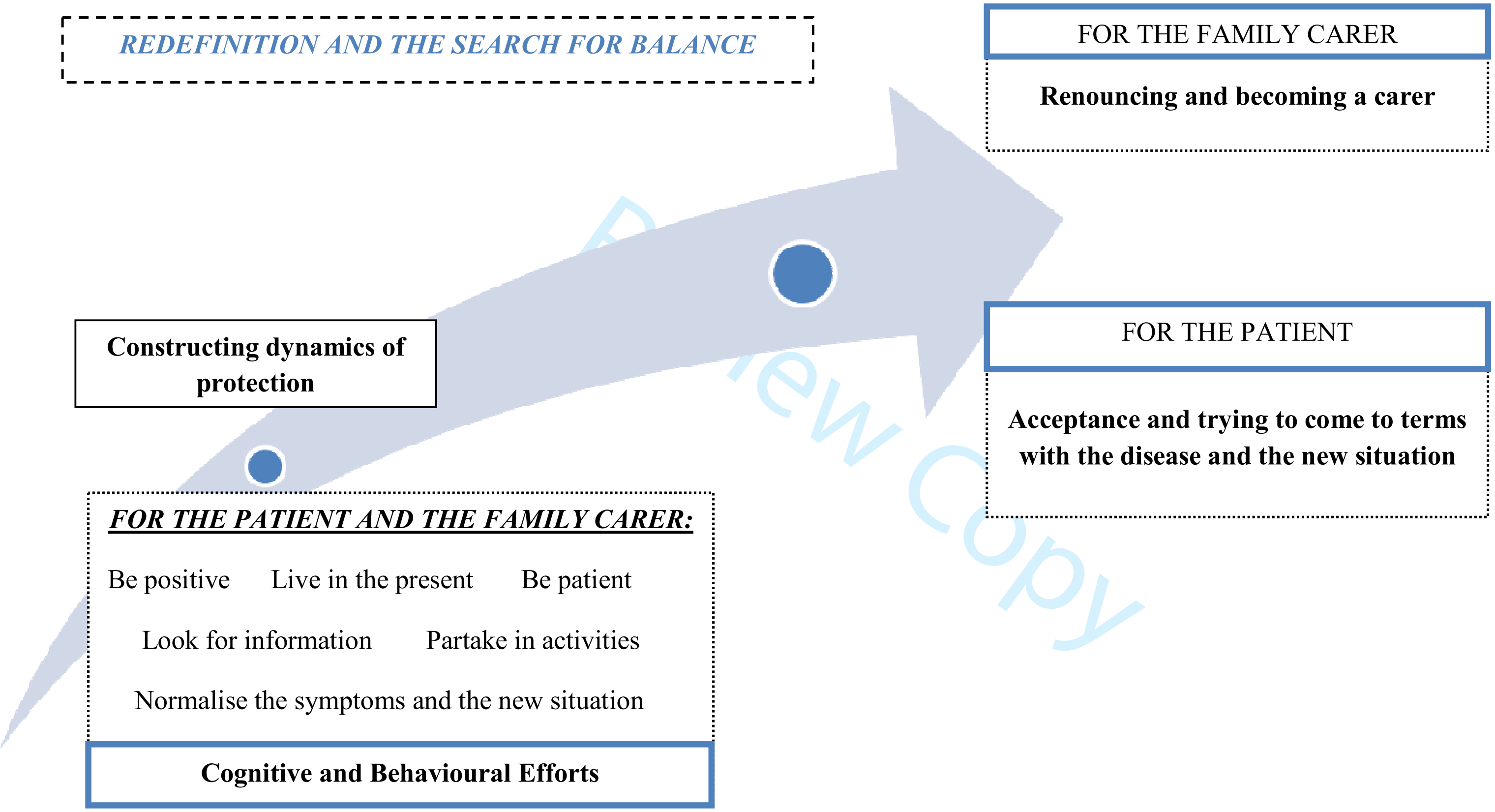
Table 3 Fragments of transcript to illustrate the Dynamics of protection in coping with PD (*continued*).

	Fragments of transcript
Look for information	*"When I was diagnosed with the first symptoms, my priority was information. What is this? What future do I have? That was my main worry" (P7, Person with PD, Male, 62 years old, Retired, Stage I in H&Y, 9 years since the diagnosis of PD)*
	"I think that the patient has to have a lot of information, early on, because that´s going to influence how he and the people around him react "(R1, Social worker, woman, 53 years old, primary care, 29 years of professional experience)
	"I feel that the most important thing for carers is to have information about tips on how to react when things arise" (*F3, male, 49 years old, working, son of a man with PD since 10 years ago)*
	Claire*: "I think it's important that they know the illness. I´ve found out a lot; some people like to read, others don´t, because really I think that you need to know how much they can tolerate" (F1, female, 71 years old, housewife, married to a man with PD since one year ago)*
	Andrew*: "Decide what to tell them and what not to, because they can get nervous" (F2, female, 50 years old, working, daughter of a woman with PD since one year ago)*
Partake in activities	*"I go to a keep fit class twice a week and to a speech therapist, to the swimming pool and for walks. Other times I look after my grandchildren and I always keep myself busy, within my limits"(P3, Male, 70 years old, retired, Stage I in H&Y, 8 years since the diagnosis of PD)*
	"I tell the carers that they have to try and get out; go to the hairdresser´s or to the gym" (R5, Nurse, woman, 50 years old, primary care, 29 years of professional experience)
	"For me a key point is that the patient is disciplined and has an occupation; well today I have to do this, do that, I mean that their time is taken up with an activity" (F5, male, 68 years old, retired, husband of a woman with PD since 8 years ago)
Normalise the situation	*"I try to live in the present, to enjoy the time I have and then to normalise the bad moments. I mean, there are times when the illness gives you a slap in the face, it reminds you that you´re still there and the way things are going. It serves to lower the pressure a bit and normalise the situation" (P8, Person with PD, Male, 73 year old, retired, Stage II in H&Y, 6 years since the diagnosis of PD)*
	"The relative who is doing alright usually tries to make the patient lead a normal life, so they feel as if they can continue taking care of him/herself as much as possible" (R3, Nurse, woman, 37 years old, specialist care, 10 years of professional experience)
	"We used to go to the cinema but now we don´t because there are no good films, they´re all really bad. What I mean, I suppose, is that in the end you turn the situation around so that it doesn´t seem so hard. My husband gets desperate when he can´t remember stuff; but it isn´t down to him, it´s "Mr Parkinson´s" making him slip up. He realises this and it isn´t a big deal" (F1, female, 71 years old, housewife, married to a man with PD since one year ago)

Table 4 Methodology of the proposed intervention based on the CCM Model.

	ACTIONS AIMED AT PATIENTS AND RELATIVES	**ACTIONS AIMED AT PROFESSIONALS**
Self-management support	• Encourage an active role in health management with education in PD, healthy life habits and coping skills. • Offer peer group sessions to patients and carers led by a nurse in order to promote discussion about their progress in self-care. Provide training support for those coping skills difficult to incorporate in daily life.	• Supply professionals with training which can help patients and relatives with self-help, such as motivational interviewing techniques or techniques to develop mindfulness.
Delivery system design	• Ensure regular monitoring through face to face or telephone interviews. • Offer care which is appropriate to the cultural context and background.	• Define roles and distribute tasks of nurses in all levels of healthcare. • Enable teamwork and collaboration for improving prevention, diagnosis and the evaluation of health problems.
Decision support	• Write a diary describing stressful events and the coping skills they use to face them. Write personal conclusions of their progression in the use of the different coping skills reinforced in the intervention.	• Use evidence-based instruments to evaluate coping with PD, psychosocial adjustment and quality of life. Consider findings to tailor the intervention goals and actions. • Develop interviews with patients and carers to discuss their progress, outcomes and future actions.
Clinical information systems	• Promote the use of websites to share and update information about the topics covered in the intervention in an attractive way. Websites can be an efficient tool to promote psychosocial issues in people with LTCs (Paul et al., 2013). Patients who do not have access to Internet could receive brochures.	• Ease efficient communication between primary and specialist health care through the information registration. All information about patient and carer has to be registered in the electronic health record, if available. This information should be accessible for healthcare professionals in all healthcare levels.
Community resources	• Encourage the use of voluntary organisations and community groups, which promote social integration, self-help and a healthy lifestyle. These voluntary organisations and groups create a friendly environment around patients and carers, and provide social and emotional support in LTCs (Portillo et al., 2015).	• Identify useful voluntary organisations and groups in the community, which could be of continuous support and help to patients and relatives. Cooperation with these voluntary organisations and groups help to sustain the support in the long term (Portillo et al., 2015).
Health care organization	• Set up a telephone helpline system to clear up doubts and solve specific problems, as well as for the monitoring of patients and relatives' health in primary care.	• Coordination of the voluntary organisations and community groups, to provide support for all patients and relatives in need.

Figure 1. The meaning of Coping with Parkinson's disease from the patients', family carers' and healthcare professionals' perspective.



Supplementary information

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No Item	Guide questions/description	Explanation
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Navarta-Sánchez MV & Caparrós N
2. Credentials	What were the researcher's credentials?	Navarta-Sánchez MV: PhD, MSc, BSc, RN Caparrós N: PhD, MSW, SW
3. Ocuppation	What was their occupation at the time of the study?	Navarta-Sánchez: Lecturer Caparrós N: Associate Professor
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	Navarta-Sánchez MV: Basic experience in focus groups and content analysis. Caparrós N: Extensive experience in focus groups and qualitative research.
6. Relationship established	Was a relationship established prior to study commencement?	Navarta-Sánchez MV: had previously met some participants, because they participated in a previous study. Caparrós N: had not previously met the participants.
7. Participant knowledge of the interviewer	What did the participants know about the researcher?	Participants knew the aim of our research program called ReNACE and received all the informative documents about the study and their participation
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	The occupation and credentials.

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist (continuation).

No Item	Guide questions/description	Explanation
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study?	Content analysis in the qualitative phase which is presented in this publication, but the design of the study is a mixed-methods research
10. Sampling	How were participants selected?	Purposive sampling
11. Method of approach	How were participants approached?	Health professionals working in the participant centres recruited participants to protect their privacy.
12. Sample size	How many participants were in the study?	21 participants
13. Non-participation Setting	How many people refused to participate or dropped out? Reasons?	One patient with PD and one family carer refused to participate, although their partners participated. They explained they prefer not to tell their experience.
14. Setting of data collection	Where was the data collected?	In a room of each participant centres.
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	No.
16. Description of sample	What are the important characteristics of the sample?	Demographic and clinical characteristics

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist (continuation).

No Item	Guide questions/description	Explanation
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Before to start the focus group, participants knew the topic and objectives of the focus group, but not the exact open questions. The open questions were reviewed by a team of professionals with experience in the healthcare of Parkinson's disease.
18. Repeat interviews	Were repeat interviews carried out?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	We used voice recording to collect the dialogue.
20. Field notes	Were field notes made during and/or after the interview or focus group?	One researcher wrote notes during the focus groups. After each focus group, both researchers discussed the achievements of the objectives and the development of the session.
21. Duration	What was the duration of the interviews or focus group?	The duration of the focus groups was 70, 62 and 80 minutes.
22. Data saturation	Was data saturation discussed?	Yes, two researchers analysed the data and they agreed that the saturation of data was obtained after ending the analysis of the third focus group. A session with other members of the ReNACE Programme was also held as part of the analysis validation.
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No.
24. Number of data coders	How many data coders coded the data?	Two researchers.
25. Description of the coding tree	Did authors provide a description of the coding tree?	No.

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist (continuation).

No Item	Guide questions/description	Explanation
26. Derivation of themes	Were themes identified in advance or derived from the data?	The theme and categories were derived from the data
27. Software	What software, if applicable, was used to manage the data?	No software was used.
28. Participant checking	Did participants provide feedback on the findings?	No
29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified?	Yes. The results are illustrated with verbatim transcripts from participants. The names used in quotes are pseudonyms to ensure confidentiality of participants. The quotations are identified with a number and a letter (P for patients, F for family carers, and R for Professionals). Also, demographic and clinical characteristics are included in each quotation.
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes.
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes.
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes.