




Parkinson's disease: coping and coexistence


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Abstract

Objective: To know the ways of coping when living with Parkinson's disease. *Method:* The methodological framework used was the Grounded Theory. Thirty people diagnosed with Parkinson's disease registered at the Parkinson Santa Catarina Association, SC, Brazil, participated in the in-depth interview. After the data coding process, five people with the disease validated the findings. Data collection took place between September 2013 to April 2014. *Results:* The categories that emerged were: Share activities with people with Parkinson's disease; Have family support; Seek healthy living: activities for self-esteem and quality of life. *Discussion:* The study highlights the importance of family company in promoting patient stability and self-esteem, where family support helps in coping with the health condition. *Conclusion:* It was possible to know the ways of coping to live with the disease, especially in sharing experiences with peers; family support, leisure activities, and lifestyle changes; Such characteristics are pertinent to the health care of people with neurodegenerative diseases.

Keywords: Parkinson Disease. Social Support. Nursing. Family. Qualitative Research.

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INTRODUCTION

Chronic diseases can cause disabilities and physical, cognitive and social dependence, resulting in a significant impact on society. These diseases can produce limitations in activities of daily living, difficulties in self-care and dependence on others, such as caregivers/family members¹.

Health policies should be aimed at promoting the autonomy and functionality of those living with chronic illness. This approach is essential to reduce costs through early retirements, social security and sick leave due to illness and, for the individual and their family, who can foresee a better quality of life, greater social participation and autonomy to exercise their citizenship².

One important non-transmissible chronic disease (CNCD) is Parkinson's disease (PD), considered a neurological disorder, which is progressive in nature, characterized by "degeneration of the cells of the ventral layer of the compact part of the *substantia nigra* and the *locus ceruleus*"³, with impairment in the motor and non-motor areas, influencing the quality of life of sufferers. Thus, holistic assistance through the use of prevention tools, health education, support and treatment for people with PD, their family members and caregivers could allow them to live healthier.

As well as the physical aspects of the disease, non-motor dimensions should be considered, as they can affect quality of life as much as motor impairments, ensuring that individuals have a better quality of life, supporting their social lives for a longer period⁴.

Literature describes a variety of non-pharmacological interventions that can affect the quality of life of people with PD, such as: dance, yoga, acupuncture, reflexology, music therapy, Nordic walking, physiotherapy and group cognitive-behavioral therapy. Such activities have a positive impact in improving neuropsychiatric symptoms, in addition to reducing the severity of the motor and non-motor symptoms of PD, improving the adaptive response of individuals in coping with the disease⁵.

It is important to note that none of the therapeutic interventions currently available, whether used alone or in combination, offers an entirely satisfactory

strategy for caring for people with PD⁶. However, it is up to health professionals to understand the meaning of living with the disease, providing the individual with information and helping them to live a healthy life.

The guiding question of the present study was therefore: what are the ways of coping with living with Parkinson's disease? The objective was: to identify ways of coping with living with Parkinson's disease.

METHOD

A qualitative study was performed, using the Grounded Theory (GT) methodological framework. In this method, the researcher evaluates the data to understand an established situation, and "how" and "why" the informants behave in a certain way in relation to a phenomenon or situation⁷.

The study respected the precepts of theoretical data saturation, conducting an in-depth interview with three sample groups, according to time since diagnosis of PD: Sample group 1 - people diagnosed up to 5 years ago; Sample group 2 - those diagnosed from 5 years to 10 years ago; Sample group 3 - people diagnosed over 10 years ago.

In this context, 30 people with PD, registered with the Santa Catarina Parkinson's Association (or APASC) participated in the study. This association is a private, non-profit civil organization, founded in March 2004 with the aim of incorporating, supporting and guaranteeing the rights of its 139 members. To achieve this goal, it works with educational, health and community institutions in general to offer activities that promote health, treatment, self-care and healthy coexistence with PD. The multidisciplinary activities offered in partnership with higher education institutions in the region are: meetings of the Mutual Help Group (MHG) mediated by nurses; group speech therapy; ballroom dancing; physiotherapy and bocce ball.

In addition to APASC registration, the inclusion criteria for the study were: preserved cognitive condition, according to Mini Mental State Examination score⁸ (score of 30 to 27 - preserved

cognitive function. Score of 26 to 24 - alteration not suggestive of deficit. Score of 23 points or less - suggestive of cognitive deficit); and the ability to communicate verbally with the researcher. Non-older people with PD were included, to consider how the disease, as well as other neurodegenerative diseases, accelerates the aging process, and coping with aging with the disease.

The interviews were conducted by the researcher from September 2013 to April 2014. For data collection, an in-depth interview was used, guided by the following questions: - *Tell me how the disease was diagnosed; Tell me about your experience with Parkinson's disease; After the diagnosis of the disease, did you have any changes in your daily activities?; Have there been changes in your family?; What about other relationships?; How do you cope with this chronic condition?; How do you feel about living with other people who also have the disease?* Other questions emerged from the dialogue established by the initial questions, and in order to expand upon the findings of previous interviews. The interviews lasted between 30 minutes and two hours, and were recorded in mp3 and then transcribed. Afterwards, they were returned to the participants so that they could make corrections or insert other necessary information.

People with PD were invited to participate in the study by telephone or in person, and interviews were arranged at their homes or at the Center for the Study of Older Adults (NETI), where MHG meetings take place. During data collection and analysis, memos and diagrams were used to record information and perceptions and to better visualize data and concepts.

For the analysis and codification of the data, the techniques established by the GT were used (open coding - allows the data to be separated, examined and related in order to visualize similarities and differences, which allows effective discrimination and differentiation between categories; axial coding - the categories are related to and defined by their subcategories to elicit more precise and complete clarifications, and selective coding - refers to the process of integrating and refining categories)⁷. In

the present study, Word documents, rather than data analysis software was used to manage the data coding process.

The study was approved by the Human Research Ethics Committee of the Universidade Federal de Santa Catarina (the Federal University of Santa Catarina), under Opinion number 329,662. Authorization was obtained from the APASC management committee, to invite those registered with the Association to participate. Participants signed an Informed Consent Form (ICF) before the interview. All phases of this research were based on the international and national ethical standards of Resolution 466/12 of the National Health Council⁹. In relation to confidentiality, participants were identified with the letter "P" followed by a number corresponding to data collection, for example: participant with interview number 1 = P1, and so on.

The validation of the theoretical model used is the criterion of bringing scientific rigor to the study. In this way, after the theory has been elaborated, it is essential that the researcher validates the categories and their relationship with the central theme⁷. During validation, the participants must recognize themselves in the story being told. Therefore, the model was validated through the assessment of the findings by another group of people with PD who did not participate in the previous stage.

Five people participated in the validation process, four men and one woman, with ages varying from 41 to 75 years, and a time since diagnosis of PD of between two and 18 years. The validation took place through dynamics, in which the validators were asked to look at the model presented in order to concentrate and reflect on it, to allow comparison with their experiences, and the consideration of whether they did or did not recognize themselves in the experience of PD described.

RESULTS

Table 1 represents their characterization of the study participants in terms of sex, age and time since diagnosis of PD.

Table 1. Characterization of study participants in terms of sex, age group and time since diagnosis. (n=30) Florianópolis, Santa Catarina, 2015.

Variables	n (%)
Sex	
Female	19 (63.3)
Male	11 (36.7)
Age group (years)	
Below 60	10 (33.3)
60 – 69	07 (23.3)
70-79	11 (36.7)
≥80	02 (6.7)
Time since diagnosis	
Up to 5 years	14 (46.7)
5 to 10 years	07 (23.3)
Over 10 years	09 (30.0)

Source: the authors.

It was observed that in the study population, there was a greater predominance of PD in women and older adults aged between 70 and 79 years. Most interviewees had been diagnosed with PD in the previous five years.

Through the codifications it was possible to reveal the central phenomenon: *Living with Parkinson's disease* and therefore, the categories that make up the forms of coping with living with PD: Sharing activities with people with Parkinson's disease; Having the support of the family; Seeking to live healthily: Activities for self-esteem and quality of life.

Sharing activities with people with Parkinson's disease

This category is revealed by the testimonies that identify the sharing of activities with people with PD, especially when living with members of APASC. This association invites people with PD and their families to participate in activities in order to promote health; living with other people with the disease, and sharing their experiences. It also allows people with PD to see themselves through others; help themselves and feel belonging to a group.

The first positive impact is to meet other people with PD, sometimes with a degree of limitation greater or less than their own.

“[...]I see the disease progressing as it will, which is not as scary as it first seemed, it is still scary, but less so, and I think it's good because we see it happening, the others see us, and we see the others, and one helps the other, people comment, talk, so we're alert”. (P6)

People with PD, through activities linked to APASC, share perceptions about the disease. For some, this can generate tension and negative expectations, and for others, comfort, through meeting people who are trying to accept the disease.

“[...] we are on the same level, we are in the same boat. So it's a situation, like this, that brings a certain responsibility, like family, as if we were all brothers or sisters. We get along well because we are in the same boat, our affinity is only the care of health, body, and mind. So it's really good to spend time with people here at Parkinson's, it's very important, and really like family, we are all like a family, it's very important”. (P17)

The coexistence in a group provides the sharing of wisdom, knowledge, experiences, allowing the mutual help between the participants of the group to be visualized.

“[...] these meetings that we held here, these meetings twice a month that we held here, we learn a lot, and we carry on going, integrating and having quality of life, trying to have quality of life”. (P17)

Through the interaction between people with PD the importance of interpersonal relationships, and having knowledge about the disease through others, was identified.

“[...] We are in the same boat, I notice friends, especially when we are playing bocce ball, when they have a relapse, it's time to take the medication... Our friend, he feels weak, he keeps dragging his feet and stuff, and I say: look, it's time for the medicine, it's time for the medicine. And... well, I'm not going to say his name either... at 11 o'clock I know he takes the medicine, and sometimes he forgets, and I don't want him to have a relapse, so he has to take it first to carry on. So we are in the same boat, so each one warns the other, one helps the other”. (P15)

In addition, friendship, companionship, and coexistence are extremely positive for coping with such a chronic condition, as it is perceived that people with PD take care of each other and value improvements in others, sharing common anxieties and joys. Through the testimonies, the importance of participating in the mutual aid group, and sharing the experiences, is perceived.

Having the support of the family

The family plays an important role for people with PD. Many report that the support of their families for the acceptance of and living with the disease and its limitations is essential. Others perceive that the discovery of PD and the changes imposed by the disease, such as the slowness and difficulty of

carrying out daily activities, have a great impact on family members. Some report that they notice the suffering of the family and the non-acceptance of PD by family members, including avoid commenting on the disease with other people.

“[...] At the Association there was a Parkinson's meeting, so I took my wife. There were people who were already experiencing difficulties, and I was still at the beginning of the disease, so for my wife it was quite difficult here, to see those people in that situation. So, at the end, the hymn of the Parkinson's Center was sung, and I know it made her cry. So it was a shock, especially for my wife, who was more sensitive to understanding the process”. (P18)

Individuals with PD perceive how their new health condition affects the feelings of their family members. Some interviewees saw how difficult it was for children, spouses and even for parents to learn about the disease and the limitations it can bring, showing that the anxieties arising from the new condition were shared with family members.

“[...] I think they (my daughters) haven't come to terms with it yet, neither of them, they just say things like: “Oh, mom, you better have treatment.” Sometimes, I say to them: you have to help your mother a little more, I'm experiencing a lot of limitations... But they still haven't taken it in. They think I have normal Parkinson's, which will not limit me in any way”. (P19)

Perhaps due to the difficulty of knowing that a family member has a chronic and neurodegenerative disease, or even due to the lack of knowledge of the characteristics of the disease, some see that their relative does not understand their health condition. The family, like the individual with PD, goes through a conflictive process until the disease is accepted.

The support of family members is seen as essential for living better with the disease, either by stimulus/incentive, or by the need for help from the family caregiver in carrying out daily activities and health care.

“[...] I have a lot of support from my children. My children are wonderful... They call in the morning, they call at night, and they come here every day. So we feel comfortable, with the affection they give us, we feel more relaxed, and not so upset”. (P5)

The support of family members makes PD easier to deal with, as the daily lives of these people with the disease are permeated with new situations, in which there is a need to socialize with the family. It is important to be able to count on someone who is willing to listen, talk about, understand and assist in providing solutions for the daily events that arise from the disease.

Seeking healthy living: activities for self-esteem and quality of life

The new condition of health and disease makes people seek activities that improve their self-esteem and quality of life. Some reported that, before suffering from the disease, they worked too much, with no time for walks or enjoyable activities. The participants reflected on whether it is possible to have a healthy life with PD:

“[...] You start to behave differently, from the moment that you... Like, I got more depressed, I take antidepressants, because you get quite down. So there are times you think: But why me? I've done nothing wrong! You keep questioning yourself, but you know the answer is because it is a lottery, it can affect better people than me. There are times you think about it, you think: I have Parkinson's! Your life is different now, you can evolve, you try and keep thinking that”. (P8)

“[...] then you start to question your quality of life, knowing that it is a neurodegenerative disease, it is progressive, there is still no cure”. (P18)

It is important to recognize how the process of dealing with the disease takes place, based on the meanings and experiences of each person. The testimonies show that when rethinking their lives, people try to relate more to family and friends,

making positive use of those around them. The limitations imposed by the condition make people try to adapt to healthy living even when in a chronic condition of health.

“[...] I'm trying not to fight the disease so much anymore. Over time, I learn to live with the disease, with the difficulties, and comprehend, understand and accept it, respect my limits, because there is no point in wanting to do things that I can't do anymore. So there's no point, I have to learn to respect these limits, these difficulties that appear”. (P16)

According to each type of limitation or difficulty imposed by the disease, the individual seeks ways to learn and adapt to daily activities, such as performing tasks using the side of the body where there are fewer tremors. Another way of learning to live with the disease is to seek religiosity and hope that it is possible to live well even with PD. The performance of activities that give pleasure is seen as a facilitator of living with the disease.

“[...] there is no other way, except proper treatment, exercises, stretching, stretching is very important, stretching before getting up, stretching well, for at least 10 minutes, and pulling here, pulling there (demonstrating with the arms), so as not to tighten the muscles, you know, and we manage it”. (P17)

“[...] people are very understanding like that, those closest to you, aren't they, and they even understand certain things. For example, we have another group, a group of couples who do work in the church. So there are certain jobs that I can't do, we make lunch for the party, and I can't manage the kitchen, but then I just fold the napkins, arranging them... So, in view of that, they all understand why, and sometimes, if I overdo it a little they stop me, they are very understanding people, good companions”. (P1)

People with PD seek emotional resources to cope with the disease, adapt to their new health condition, harmonize their experience with the disease and have a healthy life.

DISCUSSION

The present study had a greater number of women with PD. However, a study conducted in France and the UK in 2020, found that males are associated with a higher incidence and prevalence of PD, as well as an earlier onset and more severe progression of the disease than females¹⁰. Another relevant aspect found in this study was the predominance of people with PD diagnosed in the previous five years. This characteristic is important in relation to coping with the disease, since the period from diagnosis until acceptance is long and usually filled with arduous and complex feelings and experiences¹¹.

The GT framework made it possible to understand people's experiences of coping and living with PD. Data analysis revealed the actions and interactions reported by these people when living with a chronic, neurodegenerative, progressive and stigmatizing disease. The deductive reasoning of the data proposed by the GT enabled the formation of categories and the identification of themes that arose from the identification of basic elements - the codes. The reflective consideration of these codes allowed the categories to be reordered based on their content and ability to explain part of the phenomena.

Living with people who are going through the same situation was positively assessed for maintaining a network of relationships. Coexistence makes those with the disease feel the same and see themselves through others. Mutual help groups and the association of people with PD help with the well-being of the participants, as they promote a sense of control over the situation, resilience, self-confidence and knowledge about the disease¹². Among the benefits of participating in mutual help groups, the following stand out: reducing costs for the treatment of the disease; lifestyle interventions and, a reduction in the length of hospital stays^{12,13}.

Such groups can be important for people with chronic diseases, as they provide opportunities not only for obtaining valuable information, but also offer perspectives from those who experience similar conditions¹. These tools should be implemented and encouraged to allow a better understanding of the condition of people with PD, and thus, enable alternative care to be proposed.

The inclusion and participation of family members and caregivers in the groups is important so that they develop skills and help in the process of coping with PD^{4,14}. The family nucleus experiences all the changes and feelings caused by the existence of a chronic disease, meaning family members play a crucial role in supporting sufferers, and in this sense, their needs must also be met to reduce their stress levels, as well as allowing them to have a better quality of life¹⁵.

The family member of a person with PD may have different feelings, questions about the disease and its progression. It is essential that the interaction and sharing of wishes among family members is valued. The care process and the acceptance of the new condition can be less painful and distressing when support is offered to the caregiver, both by other family members and by health professionals¹⁶.

The study highlights the importance of the company of family in promoting the patient's stability and self-esteem, where family support helps in coping with health conditions. The interaction of the family with the patient is directly related to their quality of life, or in other words, the more the family is involved with care and attention, the greater the quality of life of the individual with PD. Support and family life reduce social isolation and contribute to participation in daily activities, as they help with actions that the person may have difficulties performing due to the physical limitations imposed by the disease¹⁷. Such support is seen as fundamental for the acceptance of and adaptation to PD. In addition, it improves the response of people with the disease to treatment and the limitations arising from it^{18,19}.

In a study related to PD, performed by the Health Service of Navarra (Spain), in 2014, it was identified that many people seek a healthier life, based on positive attitudes and feelings of harmony and balance as a result of the changes required by their new situation. Learning to live with the disease means adapting to their new condition, and such learning encourages control of the symptoms of PD, and improves knowledge and the response to changes in daily life¹⁹.

In view of these aspects, knowledge of how people live with PD is fundamental for the understanding

and approximation of the patient and their family, in order to assist them in the process of adhering to treatment and maintaining a good quality of life, and considering family caregivers who also need care, guidance and strategies for stress relief^{16,20}.

A Swedish study in 2015, with people with PD and their spouses, pointed out the importance of identifying the needs of individuals with the disease, involving their family members in making decisions about care, as well as relieving the impact of the disease and promoting emotional support for all involved²¹.

Certain limitations of the present study should be considered, namely that, as a qualitative study, the selection of participants is prone to selection bias. However the methodological framework chosen, the Grounded Theory, helps to minimize such a limitation. Another limitation that affects generalization is that the sample includes people with PD from a single geographic region, and a group that participates in the interdisciplinary activities offered by the Association, which directly affects living with the disease, and therefore the results of the study may not be representative of the experiences of people with PD who live in situations without social and professional support from a specialized Association for the illness.

CONCLUSION

Participating in activities with people who have a similar condition, whether through mutual help groups or an association of people with Parkinson's

disease (PD) is of paramount importance for coping with living with the disease. The vital role of the family, from the perception of the first signs and symptoms, to the confirmation of diagnosis and follow-up care throughout the day to day process, is seen by the participants as fundamental to living with the chronic condition.

The ways of coping of people who experience chronic PD should be perceived in the context of their daily lives, as it is in the nuances of their particular environment that they cope with their day to day difficulties.

Due to the qualitative approach of the study, generalizations cannot be made, therefore, we recommend that future studies, in dyads, with individuals with PD and their caregivers examine the ways of coping of people who experience the chronic condition of Parkinson's through investigations with different designs, comparing focused interventions in groups with other alternative therapies that share common elements.

The implications of the results of the present study for geriatric and gerontological health services are that strategies such as self-help groups and multidisciplinary activities in associations of people with Parkinson's disease are useful for improving aspects of emotional functioning and promote healthy living between individuals and their caregivers, creating environments that contribute to coping with the disease.

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