

The opinions and feelings about their educational needs and role of familial caregivers of Parkinson's Disease patients: a qualitative study

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Summary. *Background and aim of the work.* In the advanced stages of Parkinson's Disease, patients need complex care and support, especially at home, where they often receive assistance by familial caregivers. However, caregivers may be or feel unable to cope with their role and, despite the needs of caregivers are often assessed in the literature, their opinions and feelings about these needs are not widely explored yet. This study aimed at exploring the opinions and feelings about their educational needs and role of familial caregivers of Parkinson's Disease patients. *Methods.* A qualitative study was conducted from October to December 2017 in a polyclinic of central Italy. Fourteen caregivers voluntarily participated in the study; semi-structured face-to-face interviews were conducted, and audio recorded until data saturation. Two investigators reviewed the transcribed notes, created Meaning Units, Sub-categories and finally the Categories with emerged themes. *Results.* The analysis of the 14 interviews generated three categories: supportiveness of healthcare educational programs; sense of inability to manage caregiver tasks; need for interaction with other familial caregivers. *Conclusions.* The caregivers declared their belief that healthcare educational courses can be useful in helping them live and understand the caregiving tasks and expressed their need to share their experiences with other caregivers. In fact, they often they felt abandoned and poorly trained for the patient's management at the home. The clinical practice should allow healthcare professionals to meet the training and emotional needs of caregivers and create a trust relationship with them to make caregivers skilled in caring for patients. (www.actabiomedica.it)

Key words: caregiver needs, caregiver role, caregiver perception, qualitative assessment, caregiver educational programs.

Introduction

In Europe, almost 80% of the care provided to patients who are chronically ill and not self-sufficient is given by spouses, children and other family members called "familial caregivers" or "informal caregivers" (1), even considering the shift in the focus of chronic care from the hospital to the home care setting. Familial caregivers play a vital role and have a strong influence

on the treatment path, as they have to face the responsibility of the care and satisfy the patient's needs throughout the phases of the illness (2, 3). However, providing care to older adults affected by one or more chronic diseases might influence the caregiver's life in terms of social activities, lifestyles and psychological sphere (1, 4). Moreover, the continuous treatments, progressive changes in patient's conditions and loss of autonomy are related to an augmentation of caregiver's

stress levels and feelings of dissatisfaction. Although some caregivers can face caregiving tasks with resilience and coping strategies, most of them are not able to cope with such a challenging role (5, 6). This could lead to the “Caregiver Burden”, which is a condition of stress that holistically involves the familial caregiver and that negatively influences caregiver’s quality of life. The burden is related to chronic fatigue, a sense of frustration, depressive symptoms and distress, and it can affect patient’s health and outcomes (5). Very often it is related to the fear of not being sufficiently trained and nor able to take care of the loved one in the best way. What emerges from the existing literature is that familial caregivers often express the need to be more supported in daily life care and helped in understanding their role and feelings. They also wish to have technical and emotional support (7, 8). Most of them, in fact, are often untrained and feel abandoned by the health care systems (7, 9). Many studies show that caregiver’s educational and support programs can positively influence their depression, burden, distress and can quality of life, reducing psychological symptoms (10-12).

Parkinson’s Disease (PD) affects 3% of the world’s population. It is the second most common neurodegenerative disease after Alzheimer’s and its incidence rate varies between 8 and 18 new cases in every 100000 people a year (13). In the advanced stages, PD is associated with a progressive reduction of patient’s independence and ability in everyday life activities, thus generating a high caring complexity and the consequent need to be helped and supported, especially at home (2). PD patient’s familial caregivers perceive the task of caregiving as a heavy task and are often victims of the “caregiver burden”. Moreover, as stated in the literature, there is a link between the needs perceived by caregivers of PD patients and the unpredictability of the motor and non-motor symptoms of the disease, the care-receiver’s degree of disability, the progress of the disease, the number of hours of care a day and the duration of the illness. The most mentioned need by caregivers is to acquire an adequate training about the evolution of the disease and the management of the symptoms and emotions at home (14-17).

However, even if caregiver’s needs are explored in literature, their emotions and perceptions about these

needs are not widely explored yet. Moreover, there are not lots of studies that investigate the participant’s opinions and perceptions, through qualitative studies, before being trained. This study aimed at exploring the opinions and feelings about their educational needs and role of familial caregivers of PD patients.

Material and Methods

Study design

Before the conduction of a pre-post study aimed at assessing the effectiveness of a healthcare educational course, a qualitative study was conducted from October to December 2017. The research findings were reported according to the relevant items of Consolidated criteria for Reporting Qualitative research (COREQ) recommendations (18).

Participants

Among the 30 caregivers of patients affected by Parkinson’s Disease and multiple chronic pathologies voluntarily enrolled in the pre-post study, caregivers who gave their informed consent (two of them refused) were interviewed at baseline until data saturation was achieved (19, 20). Therefore, 14 caregivers participated to this qualitative study. Inclusion criteria included: age higher than 18; being an active “informal caregiver”, e.g. a relative or unpaid caregiver of patients affected by Parkinson’s Disease at stage 2.5/3 with Montreal Cognitive Scale (MoCA) >24. All the caregivers that were “formal” or that were not caring actively for a patient were excluded.

Ethical approval

An Ethical Committee was informed of the study, which was approved as nonhuman research, as no patients were involved in it. Each participant was asked to read an informative paper where the aim of the study was described. Then the informed consent was obtained. All data were recorded anonymously and during interviews; each participant was free not to answer if he did not want to. All the investigators gave

their contact numbers so that every participant could ask for information or express any doubts or opinions about the study. Each caregiver was free to drop out of the study whenever he wanted.

Data collection

Data were collected using semi-structured face-to-face not repeated interviews conducted in a polyclinic of central Italy by the first author in the presence of a Masters Degree student. The first author is a female PhD student in Nursing employed in the polyclinic who had never established any relationship with the participants prior to study commencement nor communicated them her personal goals about research activity or career. The nurse studied in depth the method of conducting the interviews to avoid bias and carried them out in a quiet place to allow each caregiver answer without fear and conditioning. The interviews lasted from 15 to 30 minutes for a total recorded time of 348 min and consisted in open-ended questions about the experience of "being a caregiver", the perceived caregiver's training needs, and the perceptions of the usefulness of a training course. All interviews were audio recorded and then immediately transcribed. The number of participants was dictated by the saturation of the collected data due to their significance that was discussed among authors. The questions permitted exploring in-depth the considerations and perceptions of caregivers about their own role, the healthcare educational programs, and their training and support needs. Demographic data, which included age, level of education and caregiver's kinship, were recorded using a written self-assessed questionnaire.

Data Analysis

The qualitative method of "conventional content analysis" was used to explore each caregiver's perception about the topics (7, 21, 22). Content analysis is performed through a systematic method of coding and identifying themes in order to provide a subjective interpretation of text data (23). The recorded interviews were transcribed by the two researchers and then, starting from the answers, the two investigators reviewed the transcribed notes. The notes were read several times

in order to extrapolate frequency, emotions, specificity and extensiveness of comments and themes (24). Subsequently, the investigators divided data into different meaning units and then condensed them keeping the core of the different meanings (25). Finally, Categories and Sub-categories were created according to semantic and conceptual similarities. Categories were then further analysed and grouped into themes to highlight the latent content of the text (26, 27). No participant feedback was asked in this phase.

Results

The age of the 14 participants ranged from 41 to 81 years and 71.4% (n=10) of them were female. Mostly, the caregiver was a spouse (n=12; 85.7%), their age ranged from 61 to 80 years (n=6; 42.9%), and the care-receiver was needed for daily care (n=7; 50.0%). Detailed sociodemographic characteristics are reported in Table 1. The analysis of the 14 interviews generated 3 categories: supportiveness of healthcare educational programs; sense of inability to manage caregiver tasks; need for interaction with other familial caregivers.

Supportiveness of healthcare educational programs

Healthcare educational programs are considered as real support by familial caregivers. What emerges from the interviews is that the participants think that an educational program, if well done and structured and inspired by their expressed needs, might help caregivers in correctly facing the tasks of caregiving. The course should teach how to recognize and how to deal with changes of patient's conditions, and then it should help in facing the caregiver burden.

"I think that a course would really help me. Technical and practical classes should help in facing caregiving tasks and might let us feel stronger and more capable" (Caregiver 2)

"I think that a good educational course should include theoretical and practical lessons, to better know the illness and to be able in practical care. Moreover, it should even be done with experiential laboratories that could help in understanding our feelings" (Caregiver 4)

Table 1. Sociodemographic characteristics of patients (n= 14) and caregivers (n= 14).

Variables	N (%)
Caregiver's Gender	
Male	4 (29.6%)
Female	10 (71.4%)
Caregiver's Age	
41-60 years	5 (35.7%)
61-80 years	6 (42.9%)
>81 years	3 (21.4%)
Caregiver's Job	
Housewife	3 (21.4%)
Retired	8 (57.1%)
Employed	3 (21.4%)
Years of Caring	
<1 year	1 (7.1%)
1-2 years	7 (50.0%)
3-5 years	2 (14.3%)
6-11 years	2 (14.3%)
>12 years	2 (14.3%)
Time spent for Caring per day	
<3 hours	5 (35.7%)
7-12 hours	2 (14.3%)
Daily care	7 (50.0%)
Kinship of Caregivers respect to Patients	
Wife	8 (57.1%)
Husband	4 (29.6%)
Father	1 (7.1%)
Mother	1 (7.1%)
Patient's Age	
41-60 years	1 (7.1%)
61-80 years	12 (85.7%)
>81 years	1 (7.1%)

In particular, when asked to indicate the most important topic or task to know or learn, the majority of the caregivers referred to the training about first aid at the home and how to act in case of delirium, loss of consciousness, hypoglycaemic crisis, and heart attack.

“My father is old, and I have the fear of what to do if something happens at the home, as for example a heart attack or a bad fall or if he loses consciousness” (Caregiver 11)

“I think it could be important for all of us to know what to do in case of an emergency at home! I don't even know how to take the blood pressure!” (Caregiver 5)

“We are not doctors or nurses so how do we know how to act if something bad happens at the home?” (Caregiver 6)

Sense of inability to manage caregiver tasks

As regards the perception of their role, caregivers mostly stated to have been experiencing fear and a sense of inability or loneliness since the diagnosis and throughout the evolution of the disease for several reasons, e.g. denial, lack of knowledge about the disease and symptoms, patients' loss of autonomy.

“When doctors told me that my wife had Parkinson's, I felt abandoned and totally unable to face this illness” (Caregiver 3).

“When I see my father doing something 'strange' or acting in some curious way, I understand that maybe I am not ready to care for him” (Caregiver 10).

“I am afraid. I don't know what's going to happen to my mother and I am afraid that I won't be able to help her” (Caregiver 7).

As a minor theme, few caregivers described as an issue of their role the reduced available time for themselves and their hobbies.

Need for interaction with other familial caregivers

During interviews, most of the participants expressed their willingness to share their experiences, fears and feelings with other caregivers who daily face the same problems. In fact, they said they felt alone and not understood by society as regards their feeling and needs, especially by people who had never been a caregiver.

“I would like to share my experiences and feelings with someone else; I think this could encourage me a lot” (Caregiver 14).

“I think that sharing my fears and my thoughts could help me in understanding myself better”

“Sometimes I wonder if there is someone else feeling the same fears as I do” (Caregiver 8).

Discussion

When a diagnosis of Parkinson's is communicated, it is never easy to accept for both the patient and the caregiver. The progression of the illness determines higher levels of complexity of the care needed and causes a loss of patient's autonomy even in everyday activities, creating the need for continuous care. This, combined with the commitment and emotions, can produce negative feelings in caregivers and cause a high stress level (28). In fact, feeling abandoned is very common in familial caregivers. Very often they feel abandoned, poorly trained and unable to face their parent's illness or help their loved ones (9). In this regard, the key role of familial caregiver training is a topic treated in literature. Some studies have highlighted how healthcare educational courses decrease the caregiver's burden and increase their awareness and role acceptance (5, 11). Moreover, some studies focused on education and psychotherapy as a means to face caregiver burden (29-32); others highlighted the positive support of online and telematics training courses (33). Also, other researches showed the power of sharing experiences of caregiving through theoretical and practical courses during which caregivers could attend classes, learn technical skills and share experiences, opinions and fears of caregiving, thus decreasing burden levels (11). In particular, sharing experience and interacting with other familial caregivers through brief multifamily psychoeducation could be very helpful in improving the quality of life and managing burden (11, 34). In fact, the manifestation of symptoms at home, such as unusual behaviours and crises, are the trigger events that scare familial caregivers the most. The fear of not knowing how to act and what to do in such unusual situations is one of the main causes of caregiver burden (35).

Caring for caregivers is one of the most challenging themes for nursing and healthcare professionals nowadays. Therefore, it is advisable that during clinical practice healthcare professionals could have the chance to empower caregivers with enough skills to care for their relatives. Moreover, in the limelight of the results shown, healthcare professionals should have the time needed and the possibility to build a complete and trusting relationship with the familial caregiver. In fact,

being aware of the caregiver's training needs, emotions, and opinions could allow the multidisciplinary team to implement strategies, e.g. healthcare educational courses, that could positively affect patients' outcomes as well as caregivers' and patients' quality of life.

The qualitative approach of this study allowed caregivers to know themselves better and express their doubts and fears about their role due to several reasons, including a lack of knowledge. However, as a weakness of this study, it was not possible to evaluate caregiver's perceptions and feelings after attending the healthcare educational course to detect any difference in their opinions and feelings.

Conclusions

What emerged from the interviews conducted is that caregivers believe that healthcare educational courses can be useful in helping them live and understand the caregiving tasks, especially as regards first aid skills. In fact, they often feel abandoned and poorly trained for the patient's management at home. Finally, they expressed their need to share their experiences with other caregivers. Therefore, also considering the shift in the focus of chronic care from the hospital to the home setting and the pivotal role of caregivers, future research about these topics is advisable. Particularly, it should be useful to evaluate caregiver's perceptions and feelings after attending a healthcare educational course.

Conflict of interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article

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