

# THE EXPERIENCE OF THE CHRONICALLY ILL PATIENT AND FAMILIAR FORWARD THE NEED OF CARE

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## ABSTRACT

The objective of the study was to know how chronically ill and family experiences the care and how this care influence in family relationships. It is a descriptive study of qualitative nature, accomplished with 12 chronically ill individuals and 10 family caregivers, the period of April to November 2010. We conducted semi-structured interview, based on the APGAR instrument and analysis of family caregiver burden, being recorded, transcribed and analyzed according to thematic Bardin. Five categories emerged: The interfaces of chronic illness on the family and the family member who receives care; Changing roles: when the caregiver is to be careful; The duality of feelings towards the care; When the caregiver begins to feel overwhelmed. It was noticed that both the ill and the family caregiver, have difficulties in dealing with the new condition that imposes chronic illness, due to changes in the roles, functions and operation of the entire family system.

**Keywords:** Family. Chronic Disease. Nursing.

## INTRODUCTION

Care is a science which, besides being performed in hospitals and health care units, is practiced in a historical and cultural manner by people without professional training, both within the family and community. It constitutes a practice which began at home, when the family structure was widely recognized as the source of care for dependent people<sup>(1)</sup>.

Over the years, the increase in life expectancy and the economic, political, social, and cultural changes produced by societies have significantly modified the morbidity profile of the Brazilian population, contributing to a progressive decrease in deaths due to infectious and communicable diseases and increase in deaths due to non-communicable chronic diseases (NCCDs)<sup>(2)</sup>.

In face of the high impact and the need for changes in lifestyle as a whole that a NCCD has on the individuals' life and on those with whom they live, one understands that the family

represents an important unit of care for the patient affected by a chronic health condition<sup>(3,4)</sup>. When involved in the treatment and knowing what is needed so that this treatment is effective, the family can contribute to an increased chronic patient's adherence to the assistance procedures needed to keep her/his pathology under control<sup>(5)</sup>.

However, it's worth stressing that the family, besides being the unit of care, must also be regarded as a unit to be cared for; the presence of a chronic disease can compromise the health of all or some of the family members<sup>(1)</sup>. This is so because, often, responsibility of care is focused on only one person, something which can lead to overload and major changes in her/his daily life<sup>(1)</sup>.

Thus, the professional has to identify the particular needs of each family and provide an assistance which leads to an improved quality of life<sup>(3)</sup>, because health teams share with the family responsibility of care for ill patients<sup>(1)</sup>. Therefore, a home visit by the professional, to exchange ideas on the problems and difficulties

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faced by the family, may help decreasing the difficulties found by the caregiver, contributing to the development of education activities<sup>(6)</sup>.

For a person being cared for, a chronic disease can interfere with self-care, especially with regard to the independence related to one own's care, something which may be associated to different feelings, including fear of disability, which generates anxiety due to the realization of dependency on others both to meet one own's life needs and to provide body care, as well as daily company to move, among others, thus representing a decrease or loss of the autonomy and self-care ability, making her/him dependent on decisions made by other people to survive and be cared for<sup>(7)</sup>.

Thus, this study aims to know how chronically ill patients and family caregivers experience care, as well as analyze the influence of this care on family relations.

## METODOLOGY

This is a descriptive study with a qualitative nature carried out with 12 individuals with a NCCD and 10 family caregivers assisted by the university extension project "Assistance and Support for the Chronic Patients' Family at Home", connected to the Center for Studies, Research, Care, and Support for the Family (NEPAAF) from the Department of Nursing of Universidade Estadual de Maringá (UEM).

Data were collected within the period from April to November 2010, through a semi-structured interview and reading of documents using a script which consists of semi-open questions, constructed through two previously validated instruments: the Family Apgar<sup>(8)</sup>, which measures the family functioning, and Zarit<sup>(9)</sup>, which identifies the family caregivers' overload. The documents read were medical records of families assisted by the university extension project and the home visit reports, both filed in NEPAAF.

The adaptation of instruments was due to the wish of carrying out a study which allows identifying the chronically ill patients' perception, and their caregivers', about care and its influence on family life. It's worth stressing that caregiver and patient were separately interviewed at a reserved place, after consent,

and the interviews were recorded, fully transcribed, and submitted to the thematic content analysis process. For this, successive readings were conducted with identification of thematic units, grouping of data, and categorization of similar inferences, according to Bardin's Content Analysis<sup>(10)</sup>.

This study was developed in accordance with criteria from the Resolution 196/96, from the National Health Council, and its project was approved by the Permanent Ethics Committee on Research with Human Beings (COPEP) of UEM (Opinion 084/2006). All study participants signed a free and informed consent term in two copies. For identifying the subjects and preserving their identity, the following codes were used: letter P, referring to the patient, and letter C, referring to the caregiver, followed by the interview number.

## RESULTS AND DISCUSSION

Twelve chronically ill patients and ten family caregivers participated in this study, since two caregivers were assisting more than one ill patient.

These chronically ill patients' age group ranged from 50 to 89 years, being 7 of them between 70 and 79 years, and there was a female predominance (7 individuals). The health problems presented by patients requiring more attention were: hypertension, Alzheimer's disease, and diabetes mellitus, and there's also associations to other diseases, such as stroke, heart failure, dyslipidemia, and rheumatic diseases.

Regarding family caregivers, all of them are female, with ages ranging from 28 to 56 years. This fact demonstrates that the responsibility of caring for chronically ill patients has lied, in most cases, on women, reaffirming their social role, traditionally reinforced by our society<sup>(9)</sup>.

Concerning the female family caregiver's bond to the chronically ill patient, one identifies that they were daughters (4 individuals), granddaughters (4), daughter-in-law (1), and niece (1). This aspect was also found out in another study<sup>(11)</sup>, which revealed that a daughter is the option of choice as caregiver, followed by a daughter-in-law, granddaughter, and niece, who were observed as alternatives. Out of the 10

caregivers, 8 are married and 2 are single. They presented these education levels: complete High School education (6 individuals), Higher Education (1), complete Primary Education (1), and incomplete Primary Education (2).

Regarding family income, 8 families earned from 1 to 3 minimum wages. Low income may limit access to food and social care, significantly compromising the people's quality of life<sup>(12)</sup>, especially when they're chronically ill patients or elderly people, since they deal with a compromised monthly income due to expenses with medicines and health services<sup>(6)</sup>.

### **The chronic disease's interfaces with regard to the patient and caregiver**

Even being regarded as the main unit of care for the chronically ill patient, family may face difficulties to live with the disease.

[...] He has his problems, indeed, but he tries to solve most of them by himself, he's very independent, takes care of himself. So that when a bubble emerged in his foot, he didn't tell me anything, he stood there, quiet, then, when his finger turned black, it was almost falling down, necrosing, he showed it to me. (C1)

One observes the existence of a paradox in the perception that the family member has with regard to the patient's silence and isolation, which are seen as an autonomy way, a wish to take care of oneself, whereas for the ill patient this is a manifestation of her/his wish to avoid "disturbing", because she/he doesn't want to become a burden on her/his family caregivers.

I feel very, very bad, a "hindrance", after I had cancer my life was never the same, I know muddle my daughter's life, the little poor woman has to do everything. (P6F)

I feel bad, I've always done everything by myself. When I need, they help, but it's bad. (P11M)

My daughter has her things, my granddaughter, too, so, I avoid disturbing them with simple things, when there's something which is annoying me I'd rather keep in silence. (P4M)

In face of the sensation of "being a burden", evidenced by the testimonies, one realizes that autonomy, as perceived by the family member, isn't always real, rather, it's a way to demonstrate the patient's dissatisfaction with her/his need for care provided by other people,

as well as with the fact of starting to demand work from close relatives. Thus, one may infer that family members, somehow, make themselves comfortable when faced with the realization that the ill patients' silence and isolation means independence and autonomy. This attitude, in turn, absolves them of guilt for failing to notice a sign of worsening pathology.

Family is a dynamic system in dialogic interaction which effectively acts to care for its members, especially in disease cases. However, when there's dependence, there's a need for an adjustment in order to promote care, a redefinition of roles among family members<sup>(6)</sup>. This adjustment doesn't always occur in a natural and concomitant manner; the family goes through an adaptation process, in which caregiver and patient may disagree with regard to the need and satisfaction of providing and receiving care.

Turning the character of husband/wife or the active, working and breadwinning, father/mother into a person undergoing a physical dependence condition generates feelings of sadness and irreparable loss in chronically ill patients, who, often, don't accept their new status<sup>(4)</sup>. This situation may be mistakenly regarded by caregivers as an ill patients' wish to take care of themselves. It's worth stressing that, in an unconscious manner, the caregiver also didn't easily assimilate the fact that an ill patient starts being someone who needs to be cared for.

### **Changing roles: when the caregiver starts being cared for**

The fact of being dependent on care causes changes in the ways of addressing this individual, with a tendency to infantilize the patient.

[...] Then, he became our "big baby" [...]. (C5)

Every different thing I want to do involves waiting for my daughter's approval, I even play with her and say it's like I was the daughter and she was the mother, I wish to go out, do things different from those I do every day, but she says I have to wait for her. (P6F)

Sometimes, I wish to do something on my own way and I can't decide, it seems I have to ask for permission before doing anything! (P12F)

Usually, family is the primary source of support to which their members resort to solve problems, whether personal or even due to illness<sup>(9)</sup>. When someone is undergoing illness and physical dependence, family's action may range from the preparation of meals, lifestyle adaptation, and general care to the routine use of medicines and consultations aimed at evaluating the health status<sup>(4)</sup>. When this happens, it isn't unusual to emerge such a high accountability on the caregiver that she/he starts making decisions related to the ill patient's daily life.

It's observed, considering the reports, monopolization with regard to decision-making, associated to patient's infantilization, so that the person who formerly was the family's caregiver or breadwinner becomes the "big baby" of her/his own daughter, who believes this is the best way to care for her bedridden father. During the interviews, facial and bodily expressions clearly showed how troublesome was the lack of freedom for making decisions related to one own's life and the apparent change of roles, as well as the satisfaction feeling evidenced by some caregivers with regard to being able to "give back" all care they were provided with in childhood.

A fact like this may generate an acceptance relationship on the part of patient, however, it's combined to silent dissatisfaction and withdrawal; or it may cause unrest and conflict, in an attempt to resume the role of caregiver, breadwinner, and family issues' solver.

In both situations, it isn't unusual to detect obstacles in the disease-driven therapy, since the family becomes intimately involved in a care which promotes adherence to drug and behavioral treatment of diseases. Families take a significant responsibility in providing its members with health care<sup>(5)</sup>. However, as it isn't an easy task, it requires changes in the caregiver's life, with regard to the physical, mental, psychological, and relational aspects. The caregiver also needs to balance all these aspects and she/he has to overcome possible resistances on the part of an ill patient, related to values and beliefs which get structured during her/his everyday life<sup>(5)</sup>.

#### **The duality of feelings towards care**

Usually, the family caregiver is regarded as the most suitable person to perform care,

however, at the same time, she/he needs someone to share this task with, because she/he feels overloaded.

[...] My uncle doesn't care for as we, women, do, my mother has some limitations, I don't think my aunt is able to care for her, then, I'm the only person able to care for my grandmother. (C3)

[...] It doesn't mean he can't be cared for by someone else, it's possible, but not with such a dedication we try to care for him. I'm not the best person to care for him, neither I nor my husband, but we try to make our best [...] Thus, today, we think it's better taking turns to do this. (C5)

My brother takes him by car here and there, but staying at the hospital, caring for him, indeed, he doesn't share it with me. [...] I'd like him to help me. (C1)

The family, having one of its members with some kind of dependence due to chronic diseases, needs to take a caring relationship which involves changes in its daily life, demanding greater accountability, time, and effort. Coupled with this, it isn't unusual to find cases in which only one family member plays the role of caregiver<sup>(6)</sup>. This fact may lead to a situation involving stress and dissatisfaction on the part of the person who cares for, requiring more support and assistance from other family members. However, this relationship, being an only caregiver, may suggest that her/his care is unique and that "no one else is able to care for this way".

In a study<sup>(9)</sup> carried out with caregivers of patients with Alzheimer's disease one also identified that the family members regard themselves as the right people to play the role of caregiver, as they're able to better understand what the other needs. However, with the routine and the many functions performed by these caregivers, over time they start feeling discouraged due to fatigue and the difficulties they need to face on a daily basis<sup>(13)</sup>. Then, in order to avoid a burden on the caregiver, it's important she/he has someone to "lean on", even for a short time during the week.

It's worth highlighting that big and complete families have greater possibilities to provide greater financial support and means to care for the person with a chronic disease<sup>(12)</sup>, since the fact of living together and caring for a dependent elderly relative may be a factor triggering

changes in the family system, leading it to an imbalance<sup>(14)</sup>.

When there's this kind of family constitution, one regards the family members' workload as decreased, improving the quality of care through the adoption of turns among family members. These cases are also characterized as an important emotional and instrumental support, since family members work as facilitators of care<sup>(6)</sup>.

### **When the family caregiver starts feeling overloaded**

Caring for a dependent relative demands economic resources, time, family organization, and people, which, added to other activities that the person already has to perform in her/his daily life, ends up generating an overload that can negatively reflect on her/his physical and mental health.

It's a lot of overload, indeed! Not only due to care itself, but because of everything which happens at home that is just left to me. Nobody helps and everything gets accumulated and weighs only on me. (C3)

This is so because people stop doing pleasurable things and even essential things to perform activities related to care.

I feel relieved to do my part and, at the same time, I feel overloaded by having to leave my life on hold because of them. [...] I feel damaged because I gave up my professional life to be able to stay home with them. My focus, now, is it, my home, the home service [...] their life is my life, now, since going out to pay a bill, doing grocery, or go getting some medicine. It's a great burden, a lot of work! (C1)

How many things I didn't do for me because of her, such as walking, exercise, going out for a while. Promenading? No way! When she accepts to go along, okay, but when she doesn't want to I have to stay with her. (C9)

The feeling of burden experienced by caregivers is apparent in the testimonies, something which is exacerbated by the sensation of loss of freedom to live her/his own life. The change in the caregivers' life, due to the need for devoting almost her/his entire day to the ill relative, causes a decrease or absence of activities which formerly provided them with

pleasure and were part of their daily life, such as leisure, promenading, studying, and working.

Therefore, what was previously regarded as natural and usual in the caregiver's life undergoes deep changes due to the caregiving activities.

A study carried out with patients with stroke sequelae<sup>(6)</sup> points out that overload of household chores makes caregivers feel busy, experiencing a limitation of free time, as a direct consequence of caring for the family member. For this reason, the caregiver needs to keep a balance between caring for her/himself and caring for the dependent relative, as it isn't known how much longer she/he'll need to perform this activity and the energy spent on care tends to decrease over the years<sup>(16)</sup>.

When one stands in the background, there's a decrease in the psychological, physical, and social well-being, and, as a result, lesser effectiveness in the performance of activities related to care<sup>(17)</sup>. In a study carried out with elderly people's caregivers being followed up in the public health care system<sup>(12)</sup>, one found out that their quality of life was damaged, more specifically in the physical and environmental domains, and they reported the presence of pain and discomfort, use of multiple medicines, as well as changes in the sleep and rest patterns.

The overload may also be associated to an excessive concern with trying to protect the ill patient. In this study, one identified the presence of a thin line between two points: good care versus dictating actions regarded as the best caring way.

[...] We really become jealous. I'm jealous and my husband, too, because we think that if it isn't done the way we think it's right, then, we think it's causing suffering. (C5)

She doesn't do anything by herself, I have to do everything for her. I'm the one who has even to make decisions. As she doesn't speak, I have to force her to eat even when she's unwilling to, because if it depends on other people or on her will, she doesn't eat. I have to force her to do it, indeed. (C6)

This excess of care actions, besides posing stress on the caregiver, tends to embarrass the ill patient, as she/he realizes the "interference" caused to her/his relative's life:

I feel really bad. It looks like I'm "binding" them, they get stuck because of me and my husband. (P12F)

In fact, the patient feels good when she/he realizes that her/his relatives still have a life of their own.

For me, what matters is that my daughter and my granddaughter go out, they have fun and cook for me. Whenever possible, we talk. (P4M)

Through this testimony, one can observe that the individuals believe they're "binding" their caregivers' life and activities, and that this doesn't make them feel good, a situation which goes on up to the point where they prefer to "give up" the relative's company, in order to see her/him going out and living her/his own life in a natural way. One can infer from the testimonies that the chronic disease, especially when causing dependence, brings changes to the whole family. Sometimes changes are successful and sometimes they're conflicting, and, in these cases, one or more family members aren't satisfied with the fact of having to play the role of caregiver.

The family caregiver is tested on a daily basis with regard to her/his ability to discern and adapt to the new reality, something which requires dedication, accountability, patience, and even abnegation. Often, she/he makes her/himself comfortable and, despite the burden this role can imply to her/his life, she/he tries to overcome or deal with problems with resignation, particularly taking the patient into account. She/he accepts the challenge of caring for another person, without any guarantee of retribution and, at the same time, she/he's filled with an emotional charge which can trigger ambivalent feelings with regard to the ill family member, testing her/his psychological limits and coping attitude towards life<sup>(18)</sup>. This resignation may be associated to a feeling of obligation to care for her/his ill relative:

I have no courage to leave him. Although it's difficult, I'm aware of it and I don't want to give up, say enough! and regret afterwards, keep thinking it was my duty to have done more. (C1)

The warm relationship between the caregiving individual and the ill relative is

crucial, since the family positively influences treatment<sup>(19)</sup>, however, when accompanied by a gratitude and obligation sensation, it tends to become a burden on the caregiver, which compromises her/his quality of life, reflecting on the care provided.

Individuals who live with people who need constant health care can demonstrate the most varied feelings which permeate this process, ranging from fatigue, stress, and exhaustion, but also well-being, affection, and tenderness. Fatigue as a result of the caring process is a human condition requiring reflection and help to the family caregiver<sup>(4)</sup>.

Thus, the need for supporting and guiding the family members who care for ill relatives with love become apparent, and, thus, make possible the patient's recovery and treatment. In face of this, besides preparing professionals able to provide this assistance, there's a need for developing a program for caregivers, so that the caring act isn't only a synonym for resignation, absence of social life, and lack of freedom to take care of oneself. The very health professionals working at the basic health unit nearest to home can help the family to discuss and find the best way to conduct care.

## FINAL REMARKS

Both the individual receiving care and the caregiver are affected by changes resulting from chronic disease. Both show difficulties for dealing with the condition posed by the disease. There're changes with regard to roles, functions, and the whole family system's operation. The family has the important task of preparing its members to face crises, which are produced both internally and externally. The absence of this preparation may have structural and functional impact, reflecting on the family's well-being and health.

The family caregiver needs to be "prepared" to face this situation and health professionals, particularly the nursing ones, are essential so that even when faced with difficulties observed in daily life, caregivers feel assisted, informed, and supported for providing care.

## A VIVÊNCIA DE DOENTES CRONICOS E FAMILIARES FRENTE A NECESSIDADE DE CUIDADO

### RESUMO

O objetivo deste estudo foi conhecer como doentes crônicos e cuidadores familiares vivenciam o cuidado e como esses cuidados influenciam nas relações familiares. Estudo descritivo de natureza qualitativa, realizado junto a 12 doentes crônicos e 10 cuidadores familiares, no período de abril a novembro de 2010. Foram realizadas entrevistas semi-estruturadas baseadas nos instrumentos Apgar de Família e análise da sobrecarga do cuidador familiar, sendo gravadas, posteriormente transcritas e analisadas segundo a temática de Bardin. Emergiram quatro categorias: As interfaces da doença crônica diante da família e do membro familiar que recebe o cuidado; Trocando de papéis: quando o cuidador passa a ser cuidado; A dualidade de sentimentos perante o cuidado; Quando o cuidador familiar passa a se sentir sobrecarregado. Percebeu-se que tanto o familiar adoecido quanto o familiar cuidador, apresentam dificuldades em lidar com a nova condição que a doença crônica impõe, devido às mudanças nos papéis, nas funções e em todo o funcionamento do sistema familiar.

**Palavras-chave:** Família. Doença. Crônica. Enfermagem.

## LA EXPERIENCIA DE ENFERMOS CRÓNICOS Y LOS FAMILIARES CON LA NECESIDAD DE CUIDAD

### RESUMEN

El objetivo de este estudio fue el de conocer cómo los enfermos crónicos y los cuidadores familiares viven la atención y cómo estos afectan a la atención en las relaciones familiares. Estudio cualitativo descriptivo, realizado con 12 pacientes crónicos y 10 cuidadores de la familia, en el período de abril a noviembre de 2010. Las entrevistas se realizaron semi-estructuradas usando instrumentos basados en el Apgar familiar y el análisis de la carga familiar cuidador, que se registró, transcritas y analizadas de acuerdo con el tema de Bardin. Cinco categorías surgieron: La interfaz de la enfermedad crónica en la familia y el miembro de la familia que recibe la atención, Cambio de roles: cuando el cuidador se convierte en el cuidado, la dualidad de sentimientos hacia el cuidado, cuando el cuidador comienza a sentirse abrumado. Observó que tanto el enfermo y el cuidador familiar, tienen dificultades para hacer frente a las nuevas condiciones que impone la enfermedad crónica, debido a los cambios en los roles, funciones y funcionamiento de todo el sistema familia.

**Palabras clave:** Familia. Enfermedad Crónica. Enfermería.

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