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## RESEARCH

### A dependência do cuidado familiar na perspectiva do doente crônico

Dependence of family care in the perspective of chronic disease

La dependencia del cuidado familiar en la perspectiva del enfermo crónico

Hellen Pollyanna Mantelo Cecílio <sup>1</sup>, Guilherme Oliveira de Arruda <sup>2</sup>, Sonia Silva Marcon <sup>3</sup>

#### ABSTRACT

**Objective:** to understand how the chronic patient feels the fact of being dependent on daily care. **Method:** this is a descriptive, exploratory and qualitative study, conducted with 12 chronic patients assisted by an extension project. Data were collected in the period April-November 2011 through interviews guided by the research question: "How do you feel to need care from your family?" and subjected to content analysis. **Results:** categories emerged: "Participation of people with chronic conditions in the family"; "Family care dependency: autonomy threatened"; "Family Distancing: it is not just living in the same environment". Participants revealed feeling excluded from family decisions, bothered by relying on care and often refer to loneliness. **Conclusion:** the progression of chronic diseases, which is generally associated with reliance on care, often requires a family restructuring and redefinition of roles, changing the routine and family dynamics. **Descriptors:** Family, Chronic disease, Home nursing, Nursing.

#### RESUMO

**Objetivo:** apreender como o doente crônico sente o fato de ser dependente de cuidados cotidianos. **Método:** trata-se de um estudo descritivo, exploratório, de natureza qualitativa, realizado com 12 doentes crônicos assistidos por um projeto de extensão. Os dados foram coletados no período de abril a novembro de 2011 por meio de entrevista guiada pela questão norteadora: "Como você se sente por precisar de cuidados de seus familiares?" e submetidos à Análise de Conteúdo. **Resultados:** emergiram as seguintes categorias: "Participação da pessoa em condição crônica na família"; "Dependência de cuidado familiar: autonomia ameaçada"; "Distanciamento familiar: não basta conviver no mesmo ambiente". Os participantes revelaram se sentirem excluídos das decisões familiares, incomodados por depender de cuidados e muitas vezes referiram solidão. **Conclusão:** a progressão das doenças crônicas, que geralmente está associada à dependência de cuidado, exige, muitas vezes, uma reestruturação familiar e uma redefinição de papéis, alterando a rotina e a dinâmica familiar. **Descritores:** Família, Doença crônica, Cuidados domiciliares de saúde, Enfermagem.

#### RESUMEN

**Objetivo:** aprehender cómo se siente el paciente crónico al hecho de depender de cuidado diario. **Método:** se trata de un estudio exploratorio descriptivo, cualitativo, realizado con 12 pacientes crónicos con la asistencia de un proyecto de extensión. Los datos fueron recolectados en el periodo abril-noviembre 2011 a través de entrevistas guiadas por la pregunta de investigación: "¿Cómo se siente de necesitar cuidados de sus familias?" y sometidos a análisis de contenido. **Resultados:** surgieron categorías: "La participación de las personas con enfermedades crónicas en la familia"; "La dependencia de la atención a la familia: la autonomía amenazada"; "Distanciamiento Familiar: no basta sólo vivir en el mismo entorno". Los participantes revelaron que se sienten excluidos de las decisiones del hogar, molestados por depender de la atención y con frecuencia se muestran con soledad. **Conclusión:** la progresión de las enfermedades crónicas, que generalmente se asocian con la dependencia de la atención, a menudo requiere una reestructuración de la familia y la redefinición de los papeles, el cambio de la dinámica de rutina y de la familia. **Descriptor:** Familia, Enfermedad crónica, Atención domiciliar de salud, Enfermería.

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## INTRODUCTION

**T**he health profile currently experienced is predominantly characterized by high rates of hospitalization and death from chronic diseases, which arises from the epidemiological transition, where chronic non-communicable diseases overcame communicable diseases as the leading causes of morbidity and mortality. This change process plays an impacting role on the life of the individual, his family and society in general.<sup>1</sup>

The involvement of human beings by a disease of chronic evolution, is especially accompanied by disabilities and physical dependence,<sup>2</sup> often accompanied by various feelings such as sadness, suffering and concern,<sup>3</sup> since chronic diseases are multifactorial and the individual does not feel prepared for its coping.<sup>3</sup> Problems associated with communication, lack of information about the disease or treatment, conflicts in family relationships, with other patients or with the health team are some of the difficulties encountered by the chronically ill and their families.<sup>4</sup>

The family is in a complex and dynamic system, a product of historical, social and cultural influences that produces different interpretations and responses to experiences by each of its members.<sup>5</sup> Thus, the presence of a chronic disease in the family causes an imbalance in how each person plays a role in the normal functioning of the group,<sup>6</sup> since that chronic illness implies changes in everyday life and changes in the way of living,<sup>7</sup> not only for the individual but also for his family.

Therefore, the family needs to reorganize and, depending on this, it begins to show some characteristics and behaviors specific aimed at adaptation. However, the ill individual needs to rethink, restrict or even abandon some habits. Indeed, from diagnostics, the need to obtain knowledge about the characteristics and care required for adequate treatment arises in order to keep the disease under control.<sup>1</sup>

The way of experiencing the disease process can vary depending on the ways how each individual understands and copes it.<sup>8</sup> This unique experience of illness emerges multiple meanings with roots in the individual experiences and sociocultural contexts.<sup>7</sup> As the family is part of this context, the meanings and feelings emerging permeate the family relationship and the care offered to people with chronic disease.

From this perspective, care is permeated essentially by the relationship with the other, which requires the family that takes care, coping and detachment ability, which in turn involves different feelings. However, we believe that the feelings of the ill person are also relevant in this process. Thus, the objective of this study was to understand how the person with chronic illness feels the fact of being dependent on daily care.

## METHOD

Exploratory descriptive study of qualitative nature, carried out in Maringá-PR, along with people with chronic diseases, care dependents and assisted by the extension project “Assistance and Support to Chronic Illness Family at Home”, linked to the Center for Studies, Research, Assistance and Support for the Family (NEPAAF), State University of Maringá (UEM). The inclusion criteria adopted was the patient being cared by relatives.

Data were collected from April to November 2011, through semi-structured interviews, previously scheduled in the homes of people with chronic diseases, in a private place. To ensure the accuracy of the answers and avoid the embarrassment of the subjects, the interviews were conducted without the presence of family caregivers who was in a different room talking to another member of the research team. They were recorded by digital means after consent and conducted by the guiding question: “How do you feel needing care of your family?”

For data processing, the interviews were transcribed and subjected to editing, in order to reduce errors and language vices. However, without changing the original meaning of the statements collected, and after undergoing Content Analysis, which works the words and their meanings, that is, it is a search for other realities through the message, deducing particular messages based on the indicators.<sup>9</sup> In this study the thematic modality was used, that is, it was sought to identify indicators of meanings or feelings of this experience.

Although there are no strict rules to develop the content analysis, the analytical route involved extensive, thorough, systematic and exhaustive reading of the material obtained<sup>9</sup> and followed the following organizational steps: pre-analysis, material exploration and data treatment<sup>9</sup>. The initial organization of the material included the acquisition of messages and identifying them through superficial reading followed by thorough reading.

Then, there was a data coding, in which the raw data were transformed and aggregated into units, allowing a description of the content characteristics.<sup>9</sup> After completing the coding, the thematic analysis began, which enabled the identification expressions in the statements that characterize important issues of the realities experienced by subjects with chronic disease and the relationship with the family. After this stage, there was a categorization based on themes found, which gave rise to the categories: “Participation of the person with chronic conditions in the family”; “Family care dependency: autonomy threatened”; “Family distancing: it is not just living in the same environment”.

The development of the study took place in accordance with the guidelines established by Resolution 196/96 of the National Health Council and the project was approved by the Permanent Ethics Committee on Research in Human Beings of the signatory institutions (Opinion 084/2006). All participants signed the Informed Consent Form (TCLE) in two ways. Letter M or F to indicate the gender and the indicative age number were used for the differentiation of subjects and preservation of their identity.

## RESULTS AND DISCUSSION

There were 12 chronic patients in the study, aged between 50 and 89 years old, with more frequent age group of 70 to 79 years old. Most of them (seven) were female. The most commonly cited health problems were hypertension and diabetes mellitus, with also the presence of comorbidities like stroke, heart failure, dyslipidemia and rheumatic diseases.

With regard to family income, nine participants reported receiving between one and three minimum wages, two receiving on average four minimum wages and only one said to receive more than five salaries. Although the economic situation has not been referred as an aspect that interferes with the relationship of care to a person with chronic disease, it is noteworthy that low-income study participants is an important factor, since the financial issue can limit access to care and compromise significantly the organizational skills of the family and the quality of life of its members.<sup>10</sup>

It is also important to consider that the disease affects in home finances, causing stress and conflict,<sup>11</sup> but in some cases, families with low incomes employ effective strategies to deal with chronic and suffering resulting from diseases, as shown by a study of families in the northeastern of Brazil.<sup>12</sup>

The family composition varied, where the family of complete nuclear type, formed by biological parents and unmarried children was the most common, cited by six participants, followed by the extended family, with the presence of more than a generation in the same environment found in four families and the single-parent family that consists of unmarried children and a parent in two cases.

Despite the influence of the types of families have not emerged in the speech, it was observed that most of the subjects studied were inserted into the nuclear family type (complete or one parent). These are valued because of the social significance of the behavior of people in different situations, that is, they are still seen as the main way to share and interact daily, being the center of living of people.<sup>5</sup> However, a study of people with nephropathy diabetic shows that extended families often provide greater financial support and resources for the care of people with chronic disease, especially when it comes to elderly people, because there is a decrease of the family workload, reducing overload and improving the quality of care through the relay among its members.<sup>11</sup>

### Participation of the person with chronic conditions in the family

When the chronic illness is inserted within the family and the sick person needs care, the caregiver emerges almost naturally and usually is accompanied by changes in family relationships, whether positive or negative. In many cases, it is noticeable that the person with chronic

conditions feels useless against the resolution of the problems, since it is common for families trying to hide the difficulties and solve them before the person becomes aware.

This is something that worries me because always when you have problem of money and these things, my daughter tries to hide from me, to keep me worried, then I discover and I'm feeling useless here. (F, 59 years old)

When the chronicity is part of the daily family life, the family starts sharing, indirectly, the suffering and pain of those who are ill.<sup>13</sup> Thus, the way how family relationships occur, interfere in the quality of care provided. The type of link between the caregiver and the patient may favor the presence of greater trust among them,<sup>10</sup> reiterating that each family reacts differently to situations they face.<sup>14</sup>

In addition, the person with chronic condition, particularly when elderly, feels excluded not only of the decisions but also of dialogue that featuring a living.

I've talked, the things that happen I'm the last one to know. (F, 72 years old)

They hardly talk to me. (F, 78 years old)

Although in some situations the family relationships are unshaken by the disease, in others, the person with chronic condition can feel excluded from the family dialogue. In these cases, they feel uncomfortable with the reduction or termination of their participation in solving the problems of the family. However, it is observed in the reports that the fact of not being excluded from family decisions is very important for the person with chronic conditions.

My husband and I never hide anything from each other, so all that's his problem is mine also, and mine is also his. (F, 77 years old)

They always share problems and consider my opinion. (F, 73 years old)

All share with me the problems. (M, 60 years old)

The sick family member, usually the oldest member of the family, feels like the more experienced and more knowledgeable of the problems, which leads him to judge his fundamental view, which should be considered in making any decision. Not participating in the resolution of problems makes the elderly feel disrespected and without prestige in the family, as also evidenced a study conducted with caregivers of active elderly in shelter institutions.<sup>15</sup> Thus, it is important that the caregiver and the person with chronic illness have a strong emotional bond and the family that cares have enough sensitivity to see the implicit feelings,<sup>15</sup> often unspoken and can determine the quality of care and family relationships.

In home environment, care founded on the dedication, commitment and affection involves the subjectivity of each family. It is observed that, over time, families adapt to living with the disease and treatment, taking them as something routine, often forgetting the peculiar feelings of the person who directly experiences the chronic conditions. Thus, the individual who no longer has a habit of socializing their opinions or troubles reinforces the habit, and the one who has a need to express his feelings, shall retain them for himself.

I'm not much of talking. I do not like to talk about things, so I do not like a lot of conversation. (M, 50 years old)

When I am angry or sad I keep it to myself. (M, 79 years old)

The person with chronic disease, dependent on family members care, get used to being excluded from decision-making and family no longer feels entitled to annoy the other members with their feelings, characterized as something devoid of importance. In this regard, we remember that no verbalization of feelings, isolation and the failure to seek dialogue with the caregiver are easily associated to the development of certain conditions like, for example, a depressive state, as already seen in the literature.<sup>15</sup>

Also in this line, a review study found that studies on people with chronic diseases and their families reveal important elements concerning the care to these people, among them the co-participation of the family and the health team in the care provided, besides the appreciation and access to family support networks.<sup>16</sup>

#### **Family care dependency: autonomy threatened**

It could be observed in some reports that patients perceive the caregiver as a person who often feels “owner” of their lives, who controls their steps and try to control their feelings, which is not well accepted.

My daughter wants to control everything I do, sometimes even what I think. If I have an idea of something and it is against hers, she tries to make me change my mind. (M, 79 years old)

It has to be on their way, I must ask for everything. (F, 72 years old)

Generally, chronic diseases are multiple and are directly related to the loss of autonomy and the difficulty in performing daily activities, interfering in social relationships.<sup>3,11</sup> The process of adaptation to this condition can be easily and naturally, if there is a good relationship between the person with chronic disease and the caregiver, or difficult and problematic because of family history of conflicts and crises among its members.<sup>10</sup>

Before the care to be provided, the family caregiver often feels entitled and empowered to make decisions for the patient, since this is “vulnerable” and therefore, in the eyes of the caregiver, the patient occupies a passive position. In this sense, he tries to minimize the generating conflict and concern for the individual facing the disease,<sup>17</sup> trying to decide what is better or not for this individual.

Those who need assistance in performing daily activities are the ones that are uncomfortable, since neither the physiological need for food or hygiene such as bathing, depends solely on him.

I feel very upset, nervous. I am giving a lot of hard time for them, my granddaughter help me to have a shower, she does everything. (F, 73 years old)

In this study, for example, it was found that the person in chronic condition feels uncomfortable with the transformation of his role of parent/provider to “son” and dependent. On the other hand, a study conducted along with northeastern families showed that the displacement of the attention dedicated to the children for the care of elderly mother and coping

by chronic condition, led to significant gains in the overall health picture of this mother, as increased weight, greater autonomy for the bath, willingness to perform physical exercises, that is, important physical and emotional improving.<sup>12</sup>

This divergence with the literature points to the peculiarities of each family environment, which should be considered in professional health care. Moreover, it points to the need for the family to encourage the person in chronic condition that depends on care, so that he strives and tries to carry out the activities of daily living, even though few and at his own pace, in order to maintain active, contradicting the idea that old age and/or chronic health condition is associated exclusively to rest<sup>10</sup> and permanent inactivity.

Realizing of their threatened autonomy, the patient cannot accept the decisions and caregiver impositions. They can also have a reaction of independence, perhaps by the feeling of revolt against the situation. Some of them feel that this exclusion may be accompanied by excessive body control and feelings of these individuals, which creates dissatisfaction.

They seek to control me, but I have for me what I want and not let them change it. (M, 50 years old)

I do not need them. At that age, we are adults, we know what we do, we know everything in life, you know. (F, 64 years old)

They think they have to do things all in their own way. (F, 64 years old)

Although family support is essential for a person with chronic conditions to maintain their physical and psychological integrity, it is necessary to set limits, because the effect of family support is only beneficial when perceived as satisfactory by the sick person.<sup>17</sup>

The way the family takes care, hiding or excluding the patient out of the problems, cannot mean a disregard or disrespect, but a protection. However, it is necessary that the family knows the feelings of the person with chronic disease in relation to this, allowing both to understand the intention of certain behaviors.

Commonly, when trying to protect the person with the disease of negative situations, the family cares and at the same time watches, not realizing that in doing so, often, besides disregarding the feelings, they try to control the thoughts, attitudes and behaviors.

For example, when my daughter calls, sometimes she asks why I'm more quietly, if I'm sad, and when I say no, she starts saying I do not trust her, I should have a problem and do not want to talk not to worry, and sometimes it is just a low mood on the day. It makes me uncomfortable. It seems she wants to have control of my feelings. (F, 77 years old)

Therefore, the protection plays by the family constitutes a strategy used to reduce stress and wear of the person with chronic disease. However, it is not always viewed favorably by the person that feels disrespected and useless in front of his or her own problems and feelings. Therefore, health professionals must recognize these difficulties and try, stimulate a good living subtle and effectively, permeated by the presence of affection and mutual respect, so that all members feel quiet and involved in decision making, including, about the proper care that is being provided.<sup>15,18</sup>



In the interpretation of M, 50 years old, dependence on “someone” for daily care is a counterpoint in the wake of his life, which was conducted with full independence, self-made and autonomy to meet his needs. This new situation is uncomfortable and discontent and dissatisfaction reason.

I feel really bad. I never liked depending on someone. In all my life, I never depended. I always ran behind my things. I do not like to depend on anyone. (M, 50 years old)

Although the care provided by the caregiver are coated with feelings of gratitude, esteem and affection,<sup>14</sup> the person in chronic condition can feel disturbing the lives of others by needing care and centralizing the attention of the family upon himself, which for assist him, the family needs to abstain from other activities. Inevitably, the fact of being responsible for the care creates limitations in daily tasks and activities and, above all, reducing family leisure time exercising this care.<sup>19</sup> In these cases, the care process can be characterized by feelings of stress and worry, generating negative effects on family interactions.<sup>20</sup> Thus, when the person in chronic condition realizes the dynamics of this process, he shows uncomfortable with the situation.

As an exception, the fellowship and the complicity among family members arise as a good strategy in combating the chronic condition.

Whenever I need something he is helping me, he goes for medicine, he takes me to the hospital when needed, but I also do it for him, it is a companionship relationship. (F, 77 years old)

In these circumstances, the care and the interactions arising from the exchange between the sick person and the caregiver allow them cultivating complicity which strengthens the relationship and strengthens the bonds, while recognizing and accepting the new and old roles played by each of them.<sup>14</sup>

### **Family distancing: it is not just living in the same environment**

The appreciation for care many times lives with the distancing between the members in the resolution of family issues. Some people with chronic disease revealed no “give freedom” to others to make decisions.

Sometimes I do not give my opinion, I let them solve the problem. (M, 76 years old)

[...] When I have something bothering me, I do not like to keep saying, I'd rather solve it alone. (M, 50 years old)

Aging linked to chronic disease causes social isolation, among other problems. Such behavior, as well as depressive episodes, reinforces the passivity before the life.<sup>21</sup> However, feelings of isolation and loneliness seem to scare as much as the presence of chronic disease and thus having the family closer, allows opportunities to share feelings, both of joy as of sadness and fear.

Despite the physical proximity of the family, some patients live with loneliness, they do not have anybody to talk to and often want the family to be more united.

I am very alone, but because they need to work. I wanted them to have more time to spend with me to talk. (M, 75 years old)

I wanted to have a closer family because my boy does not stop at home, he worked in the taxi and now he is unemployed and is still in the street all day, my daughter is looking for a job, her husband barely talk to me, then I am very lonely. (F, 59 years old)

The necessary adjustments in this interactive process and the strengthening of the bond in many cases, can and must rely on the performance of health professionals in order to improve the care to be provided without the ties between family members becoming fragile. However, one interviewee expressed a desire to be alone and stressed that the family does not have the habit of meeting, to stay together.

I was always out, because I traveled a lot. The part that I get together is when I am not traveling. We are not used to getting along. Now that I'm home because of the illness, even we get not very together, each one has our own life. I'd rather be alone. (M, 50 years old)

It is perceived ambivalence in the speeches of chronic patients about the need of the presence of family members, in which the possibility of living closer to the family living side by side with the option to face life alone. In this sense, the family needs to find a way to minimize this difficulty, thus improving the harmony in the family environment, requiring the participation of health professionals in identifying and supporting this relationship.

The approach to people with chronic disease accompanied by a single extension project can be considered a limitation of the study, which no longer contains other individuals, accompanied by other projects or even for health services. Although health professionals also have not been addressed, it is highlighted that at many times it was deemed necessary to refer the importance of professional support regarding family care provided to people facing chronic conditions.

## CONCLUSION

It is concluded that the need for care of the chronically ill has important influence on the dynamics of family relationships. The role of this person in solving the problems that afflict the family can be configured in two ways: active and shared participation, in which the person with chronic disease is present in the discussions; and the non-participation, when there is the socialization of problems and, under the gaze of the person, his role remains in the dark.

The presence of chronicity in family life makes caregivers play a control over the actions and feelings of the person who is ill, limiting the effectiveness of certain activities and suppressing decision-making. In addition, the presence of an advanced stage of aging can make the patient vulnerable to chronic conditions such as depression, for example, since the individual feels an obstacle, and fragile and unable in front of the family.

In this sense, it is understood that care to family under an expanded look with biological, psychological and social dimensions of the family unit is the responsibility of the health professional and the implementation of the plan of care to the patient. Aware that dependency care for chronically ill permeates many changes in family relationships, health professionals, especially nurses, can develop relevant role of supporting.

Favoring the opportunity for the person with chronic illness express feelings about their condition in the family context in everyday professional practice allows it to ease tensions that in the day-to-day would not find room for it. It facilitates the professional point of view, the possibility of knowing the functionality of the family relationship and how this can assist or hinder the process of home care.

It is also worth noting that the health of each family member affects the functioning of the whole family, as well as the family functioning affects each of its members individually. This instigates us to see the need to emphasize conditions that stimulate reflection on family care in nursing education.



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