

The Family Relationships When Dealing With a Chronic Disease: The Family Caregiver Viewpoint

Relações Familiares Vivenciadas no Percurso da Doença Crônica: O Olhar do Cuidador Familiar

Relaciones Familiares Vivencias en el Percurso de la Enfermedad Crónica: La Mirada del Cuidado Familiar

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ABSTRACT

Objective: The study's purpose has been to gain further understanding with regards to family relationships involving the care provided to family members with chronic illness. **Methods:** It is a descriptive study with a qualitative approach that was carried out in Chapecó city over the year of 2016, and having as participants six family caregivers of chronic disease-bearing people. Data collection was performed through an interview with a semi-structured script with the following guiding question: How does the family relationship take place during the care provision to a family member with chronic illness? The Minayo Content Analysis was the analytical method used. **Results:** Four caregivers were women and two men, two daughters, two spouses, one father and one daughter-in-law. The findings gave rise to two categories, as follows: the affective impact on family relationships expressed by the family caregiver; and, the social impact on the caregiver's daily life. **Conclusion:** The research evidenced that the care of family members with chronic disease does impact on family relationships with regards to the affective, social and financial dimensions.

Descriptors: Family Relationship, Family Caregivers, Chronic Disease.

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RESUMO

Objetivo: Compreender as relações familiares no percurso do cuidado de familiar com doença crônica. **Método:** Estudo qualitativo realizado no município de Chapecó no ano de 2016 com seis cuidadores familiares de pessoa com doença crônica. A coleta de dados foi realizada através de entrevista com roteiro semiestruturado tendo como questão norteadora: Como se dá a relação familiar no percurso do cuidado de familiar com doença crônica? O método analítico utilizado foi a Análise de Conteúdo de Minayo. **Resultados:** Quatro cuidadores eram mulheres e dois homens, sendo duas filhas, dois cônjuges, um pai e uma nora. Deu origem a duas categorias: Impacto afetivo nas relações familiares expressas pelo cuidador familiar e Impacto social no cotidiano da vida do cuidador. **Conclusão:** A pesquisa evidenciou que o cuidado de familiar com doença crônica impacta nas relações familiares nas dimensões afetiva, social e financeira.

Descritores: Relações Familiares, Cuidadores Familiares, Doença Crônica.

RESUMEN

Objetivo: Comprender las relaciones familiares en el recorrido del cuidado de la familia con enfermedad crónica. **Método:** Estudio cualitativo realizado en el municipio de Chapecó en el año 2016 con seis cuidadores familiares de persona con enfermedad crónica. La recolección de datos fue realizada a través de una entrevista con un itinerario semiestruturado teniendo como cuestión orientadora: Cómo se da la relación familiar en el recorrido del cuidado de familiar con enfermedad crónica? El método analítico utilizado fue el Análisis de Contenido de Minayo. **Resultados:** Cuatro cuidadores eran mujeres y dos hombres, siendo dos hijas, dos cónyuges, un padre y una nuera. De origen a dos categorías: Impacto afectivo en las relaciones familiares expresadas por el cuidador familiar e Impacto social en el cotidiano de la vida del cuidador. **Conclusión:** La investigación evidenció que el cuidado de familiar con enfermedad crónica impacta en las relaciones familiares en las dimensiones afectiva, social y financiera.

Descritores: Relaciones Familiares, Cuidadores, Enfermedad Crónica.

INTRODUCTION

The twentieth century was marked by the advancement of science and technology, resulting in the development of humanity in various aspects. This growth has had positive repercussions for society in general, including the considerable transformations in the age pyramid. A fact perceived by the growing longevity of the population. Despite being a great gain for humanity, life expectancy also entails complex problems in order to interfere in the social, economic, family and health areas, since it is faced with a contingent of people susceptible to chronic conditions.¹

In Brazil, there has been an increase in non-transmissible chronic conditions, some of which are incapacitating and have no curative response, leading to incurable, progressive and advanced conditions.² In this perspective, the management of the disabilities generated in the family context is increasingly common. This may require families to adjust and reorganize their members, redefining roles and tasks.

Faced with this reality, aiming at coping with the situation and experiencing this new context, there is the understanding that caring is an exhausting task, especially

if it is for a long period. Therefore, several studies reinforce the important role of the family as a determinant in the results of the rehabilitation process.³⁻⁴⁻⁵

In general, it is in this circumstance that the family caregiver appears, understood as the person whose responsibility is to perform the tasks that the individual with sequelae by the morbid episode has no more possibility to execute.⁶ Thus, it is observed that in most situations, this family member becomes the main caregiver, therefore, the caregiver and most of the tasks performed at home, in the sense of promoting comfort and well-being to the loved one.

The primary caregiver is often studied for being in a unique relationship with his/her sick relative, which places him in a condition of vulnerability, both physical, emotional, social and financial, implying changes in lifestyle, generating an overload which can lead to illness.^{4,5,7,8} Nonetheless, research that focuses on the role of other family members in the care setting and the relationships between them in the family care pathway with chronic illness are poorly described.

Given the aforementioned, the study's goal is to gain further understanding with regards to family relationships involving the care provided to family members with chronic illness, then making it possible to recognize family needs and interventions of health professionals, especially nursing, in order to promote a good relationship in the family routine.

METHODS

A descriptive study with a qualitative approach was carried out in two Family Health Strategy Units (FHS), located in the Municipality of *Chapecó*, located in the West Region of *Santa Catarina* State, Brazil, from August to December 2016.

The FHS units selected were part of those that constituted the researcher's field during the last year of the Nursing Graduation Course.

The purposefulness of the study was clarified to the nurses responsible for the units, as well as the assistance requested in the survey of family caregivers who met the following inclusion criteria: being a primary caregiver with a family bond, over 18 years old and enrolled in one of the FHS already defined for the study. After this identification, the home visits in the families selected for the survey were scheduled through telephone contact.

By the time of the visit, the caregivers were presented and invited to participate in the research and informed about the approval of the Research Ethics Committee from the *Universidade Federal da Fronteira Sul (UFFS)*, under the Legal Opinion No. 817.161. When they accepted, then they went on to sign the Free and Informed Consent Term.

Data collection was performed through a recorded interview, the researchers used as a tool a semi-structured script with the following guiding question: How does the

family relationship take place during the care provision to a family member with chronic illness?

After the transcription and validation of the interviews, we used the framework proposed by Minayo for analysis and interpretation of the information, following the steps described below: Data ordering; mapping of all the data obtained in the work field, such as transcription of recordings, re-reading of material, organization of reports and participant observation data. The subsequent step was the classification of the data: through exhaustive and repeated reading of the texts seeking to establish questions to identify relevant aspects. Based on the relevant findings, the specific categories were elaborated, and safety as the last step the final analysis: articulations between the data and the theoretical references of the research, responding to the research questions based on their objectives, then grouping the data into two categories.⁹

RESULTS AND DISCUSSION

The study had as participants six family caregiver of family members with chronic disease, being four females and two males. Regarding the age group, the caregivers were 20, 30, 43, 53, 62 and 79 years old, respectively. Concerning the kinship, two caregivers were daughters, two spouses, a father and a daughter-in-law.

In relation to the work activity, three participants were entitled to the household and were women, two were male retirees and one caregiver performed autonomous work.

Considering the time that the familiar caregiver assumes this role, it was from 3 months up to 11 years of care.

The findings gave rise to two categories, as follows: the affective impact on family relationships expressed by the family caregiver; and, the social impact on the caregiver's daily life.

Category 1- the affective impact on family relationships expressed by the family caregiver

The category reveals affective dysfunction in the daily care of family members with chronic illness:

"Before my sisters came here more often, now they come less because they are afraid that I will ask them to help care for them. They should have to come more to help me, nobody stays with him more than two days (...) we miss their company, before the illness the house was full" (Caregiver 6).

"The difficulty I encounter is that sometimes when I have to consult or the mother stays in the hospital, I have to be alone because the other sisters do not want to help, they say they cannot" (Caregiver 3).

It is evident in the speeches of the caregivers the suffering experienced by the estrangement of the relatives, generating feelings of solitude and the desire that they become more present. Literary discussions point out that changes in family relationships and in the circle of friends during the process of caring for a chronic patient contribute to social isolation, in fact causing the suffering that the study reports.¹⁰

The lack of participation of other family members in the care provision was cited by some interviewees as the main factor triggering conflicts and discussions:

"Our relationship was no longer good, but now it has got worse, they talk offensive things, they even call me a "slut" (...) and my brother said that I leave my mother alone at night and I go out and come back to the clearing of the day... I feel humiliated, it makes me want to take everything and leave and go away" (Caregiver 3). They are not interested in anything, they only think of them, they are selfish... they like to humiliate me, but they take care of their mother, they do not want to, they take care of her everyday and take an interest in her, it's always about me" (Caregiver 2).

The statements suggest a crisis in the family system, denoting the existence of a fragile relationship, full of heartache and resentment. This brings to the surface a reality of abandonment and loneliness since, although the caregiver cares for the loved one, she is still attacked by her relatives, from whom she hoped to count on support and recognition.

The family is affected by the occurrence of a chronic disease in one of its members. Although one of its attributes is to mediate situations of tension; when they assume a high and prolonged level can destroy the functional capacity of these family units as a screen for them.¹⁴ Such reality tends to worsen in the sense that, the care is perpetuated, enhancing the fragility and vulnerability, reinforcing the dysfunctional family.¹⁵ The possibility of minimizing the issue is perceived in the face of such events when family members strive to maintain a friendly family relationship, through which the caregiver feels valued.

Contrary to the situation described above, other interviewees report receiving help in care for the family member.

"When they come here to help, it is a sign to me that they still love us, care about us, do not abandon us" (Caregiver 1).

"Oh, I feel very happy! I know that if you need to just call, that they are present, that they come to help me" (Caregiver 5).

The meaning of family support received by caregivers is perceived as an act that alleviates suffering and distress.

Home care provides the family life, support, and protection that the individual needs. However, when there is no articulation among their members, situations of crisis can be evidenced in family dynamics, then generating tension, embarrassment, stress, frustration, reduction depression, and altered self-esteem, among others.¹²

Family care is a complex phenomenon, where several factors are articulated to determine the feelings that will be unleashed and experienced in this world of care. For some caregivers, receiving support from their family members in the experience of this moment means the existence of commitment, which reduces the feeling of abandonment in the face of an adverse situation. The fact that having someone to tell in the difficult moments of need makes these caregivers feel empowered, because in general, the family is a source of support for its members.

Category 2- the social impact on the caregiver's daily life

This category identifies the way in which family relationships interfere with daily care, as there are many challenges experienced in the day-to-day care of the family caregiver. In some circumstances, they are led to live according to the possibilities that arise in the course of the care. A fact that can imply in granting your particular universe of life to the detriment of your loved one. This situation is fulfilled by the absence of other relatives in the process of care.

I no longer do what I want, I just go out, it's all in a continuous rush (...) wake up in the morning and first change, then give food, always first after my other tasks, even my work stay afterwards, when you give "(Caregiver 6). *"When I get sick, I cannot do what I would like to do, because in the first place comes their needs "* (Caregiver 2).

In the speech, it is clear that the caregiver, through the natural process imbricated to the care of the loved one, prioritizes the needs of this being to the detriment of his own. Baptista's study reveals that the difficulty of caring is not only related to the tasks of care but also to the obligation to be willing to take care of the needs of the other, to the detriment of his own needs.¹³

In this context, the caregiver's life projects can also be compromised, requiring redirection, readjustments in order to meet their needs and those of their relative.

Some of these events are shown as the main challenges to be faced and are revealed in the following manifestation:

"After I became a caregiver, my life is not the same (...) because sometimes I would like to go somewhere and I cannot go, because the mother cannot go together, because she does not walk anymore " (Caregiver 2).

"When I go out, I have to call someone, see if they can stay... I often call and they cannot, so I limit myself, I end up being very much at home..." (Caregiver 6).

The report shows that one of the limitations is the impossibility of participating in activities outside the home, thus demonstrating the difficulty in promoting adjustments that meet the needs of all, also elucidating that the difficulty of locomotion and accessibility of the family member represents an obstacle to social life.

The life context of the caregiver and the problems he faces in his daily life have not yet acquired social visibility, since this daily life full of unique characteristics is hidden in the home of this caregiver, due to the remoteness and social isolation.¹⁶

The financial situation is another challenge, which restricts not only the caregiver, but also the victimized family member himself who lacks subsidies to maintain a minimally comfortable and adequate life through his current clinical condition.

"... before I was working, so I had my money to buy many things... now I cannot work anymore. Consequently, sometimes I have money to buy the good things to do for her, but sometimes I do not have it. "(Caregiver 3).

"(...) Sometimes we almost kill ourselves in here, because there is no money, I ask and nobody helps, but then we reconcile, because it's no use fighting" (Caregiver 4).

The financial burden is described as a stress causing factor for the caregiver and the whole family, associated with difficulty with employment, since the need to stay at home longer periods requires either abdicating or restricting the workday.⁸

CONCLUSIONS

The research evidenced that the care of family members with chronic disease does impact on family relationships with regards to the affective, social and financial dimensions.

The study identified that taking care of family members with chronic illness tends to make vulnerable caregivers vulnerable.

Taking care of the family member at home constitutes a healthy family attitude; nevertheless, requires uninterrupted care, with the need for help and sharing of responsibilities in the care process.

The study also revealed the need for family support and responsible public policies, so that living this reality brings less suffering and loss to the lives of all involved. Support

mechanisms should cover the family core, since in the case of a health situation, it is assumed that Family Health Strategies can configure the indispensable link between the loved one, the caregiver and the family members. The concrete existence of a support network for family caregivers in a systematized form, especially in social inequality contexts, is fundamental.

Careful experiences, when shared, are able to strengthen existing relationships among family members. In times of turmoil, which will inevitably come with the challenges of daily life, when there is a disease situation, the family will constitute itself as a nucleus of protection and help.

Given the scarcity of studies and the pertinence of the theme, considering the upward trend in home care, it is important that family relationships in the course of the chronic illness be studied in the sense that their members do not experience the vulnerability implied in the live with the responsibility of being a family caregiver.

Studies may qualify services by preparing health professionals for the care of these families. It is believed that if the caregiving process were shared among family members and supported by effective health staff and public policies, the primary caregiver would experience less inconvenient situations and would have more autonomy.

REFERENCES

1. Alvarez A, Gonçalves L. Enfermagem e o cuidado ao idoso no domicílio. *Rev. bras. enferm.* 2012; 65(5):715-6.
2. Instituto Brasileiro de Geografia e Estatística (IBGE). Pesquisa Nacional de Saúde. Percepção do estado de saúde, estilos de vida e doenças crônicas Brasil, Grandes Regiões e Unidades da Federação. 2013.
3. Machado A, Jorge M, Freitas C. A vivência do cuidador familiar de vítima de Acidente Vascular Encefálico: uma abordagem interacionista. *Rev. bras. enferm.* 2009; 62 (2): 246-51.
4. Brito D. Cuidando de quem cuida: estudo de caso sobre o cuidador principal de um portador de insuficiência renal crônica. *Psicol. estud.* 2009; 14 (3):603-7.
5. Stackfleth R, Diniz M, Fhon J, Vendruscolo T, Fabricio-Whebe SCC, Marques S, Rodrigues R. Sobrecarga de trabalho em cuidadores de idosos fragilizados que vivem no domicílio. *Acta Paul Enferm.* 2012; 25(5): 768-74.
6. Andrade L, Costa M, Caetano J, Soares E, Bezerra E. A Problemática do Cuidador Familiar do Portador de Acidente Vascular Cerebral. *Rev. Esc. Enf. USP.* 2009;43(1): 37-43.
7. Moreira S, Turrini R. Paciente oncológico terminal: sobrecarga do cuidador. *Ver. Enferm. glob.* 2011; 10(22): 1-13
8. Araujo J, Vidal G, Brito F, Gonçalves D, Leite D, Dutra C, Pires C. Perfil dos cuidadores e as dificuldades enfrentadas no cuidado ao idoso, em Ananindeua, PA. *Rev. Bras. Geriatr. Gerontol.* 2013;16(1): 149-58.
9. Minayo M. O desafio do conhecimento: pesquisa qualitativa em saúde. 13a ed. São Paulo: Hucitec, 2013.
10. Fonseca N, Penna A, Soares M. Ser cuidador familiar: um estudo sobre as consequências de assumir este papel. *Physis.* 2008; 18(4):727-43.
11. Santos N, Tavares D. Correlação entre qualidade de vida e morbidade do cuidador de idoso com acidente vascular encefálico. *Rev. Esc. Enf. USP.* 2012; 46(4):960-6.
12. Vieira C, Fialho A, Freitas C, Jorge M. Práticas do cuidador informal do idoso no domicílio. *Ver BrasEnferm.* 2011; 64(3):570-9.
13. Olegário B, Beuter M, Girardon-Perlini N, Brondani C, Budó M, Santos N. A sobrecarga do familiar cuidador no âmbito domiciliar: uma revisão integrativa da literatura. *Rev. Gaúcha Enferm.* 2012; 33(1):147-56.
14. Rosado Marques M. As necessidades dos cuidadores familiares da pessoa com depressão: uma revisão sistemática da literatura. *Ver. Cultura de los Cuidados.* 2009; XIII (25), 88-97.
15. Salgueiro H, Lopes M. A dinâmica da família que coabita e cuida de um idoso dependente. *Rev. Gaúcha Enferm.* 2010; 31(1): 26-32.
16. Borghi A, Sassá A, Matos P, Decesaro M, Marcon S. Qualidade de vida de idosos com doença de Alzheimer e de seus cuidadores - *Rev. Gaúcha Enferm.* 2011; 32(4): 751-8.

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