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ORIGINAL ARTICLE

"YOU HAVE TO TAKE CARE": EXPERIENCES AND KNOWLEDGE OF THE "TEM QUE CUIDAR": VIVÊNCIAS E SABERES DO FAMILIAR/CUIDADOR DE PACIENTE COM DOENÇA CRÔNICA

RELATIVE/CAREGIVER OF A PATIENT WITH CHRONIC DISEASE

"HAY QUE CUIDAR": EXPERIENCIA Y CONOCIMIENTOS DEL FAMILIAR/CUIDADOR DE UN PACIENTE CON ENFERMEDAD CRÓNICA

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ABSTRACT

Objective: describing the daily care developed by family/caregivers in the home environment. **Methods:** a descriptive study of a qualitative approach carried out through semi-structured interviews with 14 family members/caregivers. The enunciations were transcribed and submitted to discourse analysis. The study had the project approved by the Research Ethics Committee, Protocol n. 490258/2013. **Results:** being a family member/caregiver is not a choice, but something that was imposed on the disease situation. It was identified that the care is through recognizing the experience made over the years; the practice makes that the same are improving and discovering new strategies for care. **Conclusion:** it believes in the importance of home care, health team integration with the family/caregivers and the community, being nursing paramount for family members/caregivers in the home space. **Descriptors:** Chronic Diseases; Health Education; Nursing; Family.

RESUMO

Objetivo: descrever o cotidiano de cuidados desenvolvidos por familiares/cuidadores no âmbito domiciliar. **Método:** estudo descritivo e exploratório com abordagem qualitativa, realizado por meio de entrevista semiestruturada com 14 familiares/cuidadores. As enunciações foram transcritas e submetidas à análise de discurso. O estudo teve aprovado o projeto pelo Comitê de Ética em Pesquisa, protocolo n. 490.258/2013. **Resultados:** ser familiar/cuidador não é uma escolha, mas algo que foi imposto diante da situação da doença. Identificou-se que o cuidado se dá pelo saber da experiência feita, com o passar dos anos, a prática faz com que os mesmos estejam se aperfeiçoando e descobrindo novas estratégias para o cuidado. **Conclusão:** acredita-se na importância do cuidado domiciliar, da integração da equipe de saúde com os familiares/cuidadores e comunidade, sendo a enfermagem primordial para os familiares/cuidadores no espaço domiciliar. **Descritores:** Doenças Crônicas; Educação em saúde; Enfermagem; Família.

RESUMEN

Objetivo: describir el cuidado diario desarrollado por familiares/cuidadores en el entorno del hogar. **Métodos:** un estudio descriptivo con enfoque cualitativo llevado a cabo a través de entrevistas semi-estructuradas con 14 miembros de la familia/cuidadores. Las declaraciones fueron transcritas y sometidas a análisis del discurso. El estudio tuvo el proyecto aprobado por el Comité de Ética en la Investigación, Protocolo n. 490258/2013. **Resultados:** ser un miembro de la familia / cuidador no es una opción, sino algo que se impuso sobre la situación de la enfermedad. Se identificó que el cuidado es a través de conocer la experiencia adquirida con el pasar de los años, la práctica hace con que los mismos estén siendo perfeccionados y descubriendo nuevas estrategias para el cuidado. **Conclusión:** se cree en la importancia de la atención domiciliar, en la integración del equipo de salud con la familia/cuidadores y la comunidad, siendo la enfermería primordial para los familiares/cuidadores en el espacio de la casa. **Descriptores:** Enfermedades Crónicas; Educación para la Salud; Enfermería; Familia.

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INTRODUCTION

The World Health Organization/WHO states that chronic diseases are the leading causes of death and disability worldwide. Chronic conditions account for health problems that require ongoing care for an indefinite period. They comprise a very broad group of conditions that have in common the chronicity and the need for permanent care. Included in this group communicable and non-communicable conditions, mental disorders, and functional disabilities.¹

The course of chronic disease puts uncertain paths and has important repercussions on the life and dynamics of families.² The family can live with various conflicts after diagnosis of chronic disease, including the abandonment of employment, generating financial deficit, suspension of recreational times, social and family misunderstanding, primary caregiver workload, family breakdown and weakness in relationships.³⁻⁵ In addition, the dependence of the phenomenon of family members with respect to the performance of activities of daily living is capable of generating great concern and cause changes in the rhythm of life of caregivers.⁶

Care is permeated by the attention, protection, concerns, attitudes and feelings that lead to a relationship between people, practices and social actions, commanded by symbolic representations. It stresses that the primary caregiver, bears the burden of care, renounces his personal life and suffers imposition of circumstances to take on this role⁷, especially in the home setting.⁸

The home is seen today as a space where people with chronic diseases and/or disabling, can live with good quality of life and maintain stability despite the disease.⁸⁻¹⁰ The care performed by family/caregivers include sporadic care situations or long-term injury, involving educational activities and/or performing procedures aimed at protection, self-care and the interaction between the chronic patient and society.⁷⁻¹⁰

Commonly, family/caregiver is a untrained person who takes on the task of caring for a relative presenting dependency associated with temporary functional disabilities or definitive.¹¹ Being family/caregiver in the home space requires absolute dedication, often exhaustive, considering the overhead the dependence of chronic patient requires. Also, take care of someone else can cause stress, physical complications, mental, emotional, loss of freedom, high financial costs and social selflessness.⁴⁻⁵ This

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accumulation of activities can result in workload, leading sometimes to the caregiver illness.¹²

Given the above, this study aims to describing the daily care developed by family/caregivers in the home environment.

METHOD

This concerns a descriptive study of a qualitative approach.¹³ The study subjects were 14 families/caregivers of patients with chronic diseases, belonging to the area of coverage of a Basic Health Unit (BHU), which is a target for tracing the Program User Diabetics and Hypertensive (HIPERDIA); in a municipality located in the western border of southern Brazil.

Data collection took place in January-March 2014, through individual interviews, respondents in the household. Interviews took their recorded audio, and after the end were transcribed verbatim. The sample saturation was used to establish the final size of the study sample, interrupting the attraction of new components as new information on the analysis of the products do not cause changes in the results previously achieved.¹⁴

For data analysis, it was used the Discourse Analysis (AD) in the French stream. The objective AD understand the mode of operation, the principles of organization and forms of production of their senses.¹⁰

They used orthographic symbols. Included to materiality to the speeches by spelling signs as - /: short reflective pause; //: Long reflective pause; ///: Very long reflective pause;...: Some thought; # Interrupt the speech of the subject; []: Explanation/correction word or sentence unfinished; [...]: Clipping of a speech segment. Analytical tools such as metaphor, paraphrase and polysemy were used to demonstrate the discursive process and the effects of meaning that derive from it.

In order to supporting an ethical conduct, this research is based on the current legislation which regulates research involving human subjects - Resolution 466/12⁽¹⁵⁾. The study was approved by the Research Ethics Committee of the Federal University of Pampa, under number 490.258/2013. To ensure anonymity there was used the abbreviation FC, regarding the family/caregiver followed by a random number.

RESULTS

Among the 14 respondents, 79% are women and 21% men. All family/caregivers reside in

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Uruguaiana/RS. Regarding marital status, 43% are married, 29% single, 7% widowers and 7% divorced.

Regarding education level, 57% had primary school education, 7% have completed high school and other 7% had incomplete higher education.

Regarding socioeconomic characterization, it is clear that 57% of family/caregivers earn up to one minimum wage, while 29% reported having an income of two to three times the minimum wage.

The characterization shows the presence of a predominantly female care of married women with low education and income. Usually, the role of the family caregiver is assigned to women, possibly due to cultural and social norms, so that young people should take care of the children and then when older are accountable also for the care her husband, the elderly and diseased within the family.⁴

Due to the demands of countless hours, daily care that patients require, most caregivers do not have time for paid work, leading to a mismatch between the making and keeping a job outside the home environment (which would increase the monthly income) and family care, justifying the low socioeconomic status of most caregivers.⁸

DISCUSSION

From the notes of family/caregivers it was able to identify the presence of self-denial, that is, family members renounce the daily activities of their life to exercise the care, which also turns out to achieve the routine of the whole family, as can be displayed below:

[...] You have to take care! [...] I do everything for him, do not go out, do not leave him alone ... [...] I arrive [first] with the son, always caring, failing to leave everything because of them, we cannot abandon. (FC2)

[...] Oh, when I took care of her, I walked; I was so walking there in the center, occupying my life. [...] (FC3)

Yes, because the mother was very young, she was 15. [...] it is the granddaughter but equal, the, we are committed to care, right? I stopped working to take care of her ... [...] [sad face] (FC7)

It realizes the impact that such care plays in the life of the family/caregiver, where it deprives itself of many activities to devote himself exclusively to the care, believing it to be responsible for the health of the family.

The family/caregiver is the one who puts the needs of others first⁽¹⁶⁾. Become

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family/caregiver is not always a choice, but when adopting this decision, the person has a composition of feelings. Among the most prominent are: the care as an obligation and the care for love.⁶ This experience comes to mean, in most cases, give up plans and dreams because of a sick person, totally dependent on someone, either by love or by no other family member who is able to take this position. Become family/caregiver in the home environment requires learning to live with the suffering of others and often hide their own pain and their needs.⁸

It is known that the affection between the subject who cares and the family member is essential, but does not guarantee to [...] Yeah, when my mother was widowed, (tears in his eyes) [...] I felt obliged to care for her because she is a child [metaphorically], right? That depends on another person... [...] (FC6)

[...] We are married do thirty-five years [...] The routine is large and heavy, right? [...] (FC10)

[...] I'm with her, just me daughter. [...] My obligation right?! (laughs) It has to be me [...] (FC12)

Competence for care. With the guidance and support obtained from health professionals, family caregivers gradually learns to operationalize the necessary demands and manage the problems that arise during the management of the patient⁽⁸⁾, making possible the recovery and treatment at home.⁶ In this context, it identified further social selflessness, such waiver is guided in the relationship and often as the only option for family/caregiver:

The family/caregivers often feel unprepared for this role, but the decision involves the whole family together, this influences the decision of who will take care or who have more availability. Thus, the determination to be caregiver can generate a high level of stress, since it does not spontaneously decided to take on this function.¹⁰⁻⁷

The caution comes from the sum of efforts of these families/caregivers, who perform daily care, and begin to give up their professional activities and personal desires for the sake of maintaining life and family survival⁽¹⁸⁾. The leisure and fun activities are the most affected, since the disabled family members apply largely care within twenty-four hours a day, a fact that complicates the existence of moments of relaxation for the caregiver.⁶

Family members/caregivers showed that learned to take care at home, from their staff lived. This practice is guided in the knowledge

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of experience made, that is, over the years, the practice makes the family are improving and discovering new strategies to care.

The meanings of someone as a family caregiver, including roles it plays within the family and society, go through a redefinition process, establishing a new role for itself. The mechanisms or strategies developed by caregivers represent their survival to the situation that presents themselves in their lives and, over time, they will acquire practice in their work and wisdom to cope.⁶

The following are the utterances of the family about the diverse knowledge to the care process at home:

[...] The day-to-day think taught me to have more experience with it, deal with it... [...] I learned with my grandmother, I think with my grandmother who passed it to me. [...] I learned from my grandmother and myself, dealing here with her, every day I was learning a little bit, every day we learn, will... will develop [...] (FC6)

[...] I left near my parents ten years to live with my brother, so we had to learn! We out we had to learn everything and then some [...] almost alone. (FC10)

Family members/caregivers learned to perform the care everyday practice with daily living, ie the need to care for a sick family member at home. The art of caring is a fact naturally occurring family/caregiver can grow into practical knowledge in scientific knowledge to be prepared for such an act.¹⁶ The care process developed by family/caregiver comes from strategies for conservation of survival, backed by the knowledge gained from the experience/successful experience of their everyday practice.¹⁸

The care provided by family members/caregivers will be improving over time, whereas chronic diseases require monitoring throughout life. In this sense, care is being cut and strengthened in the family caregiver experiences:

[...] He was passing on right? Because the grandmother taught her aunt [to care], then I taught [...] Then there [at the hospital] the grandmother learned [to care], and the time after she passed [care] to me... (FC11)

Family members / caregivers are recognized as important partners in care, as are communication links with other family members. It is through this communication that doubts are exposed and the problems arising from family inexperience with the new situation presented are known.⁶

From the questions listed on family care routines/caregiver was possible to see a variety of care. Most of the time, the

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family/caregiver relates to devices it believes to be the best, as they bring greater comfort and a better life for the sick family member. As can be seen in the words that follow:

[...] I wake him in the morning, I make his hygiene, I give the coffee, so I put him some leisure music, television [...] whenever I can that have any activity in the city I try to lead him to participate, to include him in society. (FC9)

Coffee, snacks, his food, clothing, these things is that I'll take care, take care for him not fall [...] take care when he comes out to walk, because he falls, I go along with him. [...] I take him to the front [of the house] he sits down, then up again I bring him, always taking care of him, right?! (FC14)

One can see many called simple or daily care for nursing professionals who make all the difference in the patients' daily life with chronic illnesses and their families.

Nursing is classified as regular daily care and care repair of life. The daily care is those that sustain life, filling their physical energy, chemical or food, emotional or psychosocial. As for the repair of care ensure the continuity of life, help to overcome obstacles such as illness, accidents, hunger and other types of care.¹⁹

The care taken by the family aiming at the preservation of life of its members for the full development of them.²⁰

Far beyond those considered basic care, it was observed that some families/caregivers perform more complex care, as mentioned below:

[...] spend the night standing up, looking at her, right? [...] her not to drown, is that okay with raised bed, all, because she is a person who was at the ICU [...] to all her little medicine after food, I change (change clothes) her [...] (FC4)

[...] In the morning is that I get up, fix up her [...] step the probe in her [...] help her get dressed, put on the chair and only. [...] (FC13)

More specific care needs greater understanding of the technique by the family/caregiver, revealing how much it is necessary to have a broad view of health professionals in order to verify that these procedures are being carried out correctly, and non-compliance can cause serious health problems.

In this sense, the training of family/caregiver is a need of society, considering that the aging population and the increasing incidence of chronic-degenerative diseases.²¹ In the relationship between the nurse and the family caregiver must be

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present an area of education, in which the assistance is done through educational work exploited by knowledge and techniques aimed at physical proximity, creativity, respect for customs and cultures and the family being prepared to take responsibility with the patient's health.⁶ To the nurses become the challenge of developing strategies to approach these people through the formation of support groups for caregivers and strengthening of existing ones. This means creating spaces for dialogue, exposure of problems, answering questions and practice of host.⁶

It is believed that the support and the identification of feelings experienced by caregivers and the patient are fundamental to the attention they intended. It is necessary that provides emotional support to the patient and the caregiver, aiming to facilitate this process and enhance their quality of life.⁹

Based on the above-mentioned factors, family/caregiver is an ally of extreme importance in the care process at home, becoming a sort of care unit with the patient by the health team. Thus, nurses should find out what the patient experiences and also the family/caregiver, so understanding the problems faced by it daily, to thus be possible to carry out interventions in a systematic context, valuing the physical, emotional, social, cultural, spiritual and ethical situations.²²

CONCLUSION

Through this study it was found that often be the primary caregiver is subject to consanguineous ties and the family closely it matches with the patient who has chronic illness. It emphasizes the impact of chronic disease in the life of the family/caregiver who has to take responsibility of caring where abnegate from their personal activities for the development of the family member's daily care with chronic illness.

When performing the daily tasks of care, these families/caregivers end up developing skills, guided by a knowledge of the experience made, where family members care for and learn to care, through its lived. The constant search for improvement of care is involved in the conservation of the patient's life with chronic illness.

It is recommended that nursing develop strategies for approaching these families/caregivers, as they require special care along to patients with chronic health illnesses, given the diversity of care that play beyond the physical and emotional stress, linked to function to be family/caregiver.

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Finally, it aims that the contributions of this study serve to improve the conditions of service in primary care, given that the service should be the gateway of these subjects, and is committed to be close to the users and their families, rescuing the potential to be family/caregiver in the home space.

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