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The care of dependent elderly on the family context

O cuidado do idoso dependente no contexto familiar

Cuidado de ancianos dependiente del contexto familia

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ABSTRACT

Objective: To understand how does the organization of caregiving families of dependent elderly occur in the family context. **Method:** Qualitative, with 5 participants and data collection in two stages. The first one had the purpose to identify age, gender, education level, marital status and income; the second focused on family organization. The analysis method used was the Discourse of the Collective Subject (DCS), CAAE: 33714314.4.0000.5564. **Results:** The discourses revealed the need for families to adapt to the routines imposed by the elderly presence and primary caregiver as a family member that changes their habits, and suffer deprivation of liberty. **Conclusion:** Families and caregivers need surveillance, health care and ongoing support teams that work in the family health strategy programs.

Descriptors: Home care for the elderly; Family caregiver; Nursing.

RESUMO

Objetivo: Compreender como ocorre a organização de famílias cuidadoras de idosos dependentes no contexto familiar. **Método:** Qualitativo, com cinco participantes e coleta de dados em duas etapas. A primeira com o propósito de identificar idade, sexo, grau de instrução, estado marital e renda; a segunda com foco na organização familiar. O método de análise utilizado foi o discurso do sujeito coletivo (DSC), CAAE: 33714314.4.0000.5564.

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Resultados: Os discursos revelaram necessidade de as famílias adaptarem-se às rotinas impostas pela presença do idoso e cuidador principal como membro da família que mais altera seus hábitos, e sofre privação da liberdade. **Conclusão:** Famílias e cuidadores necessitam da vigilância, atenção à saúde e suporte contínuo das equipes que atuam nos programas da Estratégia de Saúde da Família (ESF).

Descritores: Assistência domiciliar a idosos, Cuidador familiar, Enfermagem.

RESUMEN

Objetivo: Para entender cómo funciona la organización de las familias de cuidado Depend-dientes de edad avanzada en el contexto familiar. **Método:** Cualitativa, com 5 participantes y la recogida de datos en dos etapas. El primer fin de identificar la edad, sexo, nivel de educación, estado civil y los ingresos, y la segunda se centra en la organización familiar. El método de análisis utilizado fue el Discurso del Sujeto Colectivo, CAAE: 33714314.4.0000.5564. **Resultados:** Los discursos necesidad de las familias reveladas a adaptarse a las rutinas impuestas por la antigua presencia y cuidador principal como um miembro de la familia que más cambie sus hábitos, y sufren privación de libertad. Conclusión: Las familias y los cuidadores necesitan vigilancia, atención médica y equipos de apoyo en curso que trabajan en los programas de la estrategia de salud de la familia.

Descriptores: Atención en el hogar para los ancianos, Cuidador familiar, Enfermería.

INTRODUCTION

The Brazilian population has undergone transformations in the epidemiological and demographic scope, which has resulted in a considerable increase of the population over the age of 60 years.[1]These transformations are due to the technological advances of medicine and to the decline of fertility, which, when associated, increase the life expectancy of the population.[2]

Although the idea of longevity represents progress with the increase in life expectancy, the risk factors for noncommunicable diseases and the number of dependent elderly people with disabilities and/or limitations to the activities of daily living has also increased.[1]

Dependence can bring limitations to the individuals who bear it, either as a result of chronic noncommunicable diseases and its complications, or even by the diminution of the functional and cognitive capacity that arises with the advancing age. As a consequence, the elderly will demand home care and adaptations in the daily life of their families.[3]

The family is the first institution that provides care to the elderly in a situation of dependence, is a source of support, and has as main reasons the moral obligation, affective and consanguineous bonds.[4-5]

In this condition, it becomes the link between the health team and the person cared for, performing tasks and care recommended by the team on a daily basis, as well as being the one who will often seek the service for information that can improve the care provided.[6]

Families under these conditions need an efficient support network to stay healthy socially and mentally, providing adequate care to the elderly relative under their care. It is important to remember that the caregiver, most of the time, goes beyond the simple accompaniment of day-to-day activities and adds care to the activities that were already carried out before the illness of the beloved ones.

Support networks can be both formal and informal. The family, neighbors, friends and the community constitute informal support networks. Public policies, welfare and social assistance, among others, establish formal networks. In partnership, they help seniors and caregivers in solving problems that encompass their daily lives.

When one becomes aware of how and in what proportion the dynamics of the family that takes care of an elderly dependent family member are altered, it is easier to identify which ones present greater risks of imbalance, to propose actions and programs that meet these needs.

The understanding of this fact is extremely important, since the evaluation of the family composition and the functions of its members provides important information for better planning of care for the elderly and interventions that help in the restoration of the balance of this unity , when necessary.[7]

For society, this study is relevant since it sought answers to the health demands of families who are with a relative experiencing the frailties arising from the aging process.

For Nursing, the present research points out ways of assisting families and caregivers of the elderly, maintaining the health of the family nucleus in facing the process of dependence of the elderly.

Thus, the present study aimed to understand how the organization of families occurs in the care of dependent elderly people through the experience of the primary caregiver.

METHOD

It is a qualitative study with descriptive-exploratory approach developed with 5 individuals who performed the role of caregivers of elderly people in a situation of dependency, attended at a Family Health Center (FHC), in which the researcher was doing the supervised curricular internship II.

The interviews were conducted via previously scheduled home visits. The sample consisted of 5 subjects who played the role of primary caregivers, and the size of the sample was defined by the saturation of the data, as recommended in qualitative studies.

For the choice of families, an initial investigation was carried out on the number of dependent elderly caregivers in the area of coverage of a health unit in the municipality of Chapecó/SC through information provided by the Community Health Agents and the unit nurse. The subjects were established through the following criteria: being a caregiver of the dependent elderly for at least six months and that the elderly were partially or totally dependent to perform daily living activities, regardless of the degree of dependency, but rather the need for a caregiver.

The data were collected from September to October 2014. The responses were recorded in a digital recorder and later transcribed integrally.

The data collection instrument was composed of two parts. The first one encapsulated closed questions for information that identified participants, such as: age, sex, education level, marital status, income, and Katz scale. The second part was composed of open questions, aimed to identify how the organization of families occurs in the care of the dependent elderly.

The research complied with the norms and guidelines of the Resolution of the National Health Council - Ministry of Health - Res. CNS 466/12, and was approved by the Research Ethics Committee of the Federal University of the Southern Frontier, under the asserted opinion of CEPCAAE: 33714314.4.0000.5564.[8]

For the analysis of the data, the Discourse of the Collective Subject (DCS) method was used, which is a proposal for the organization and tabulation of qualitative data (verbal in this case), which seeks to account for the preservation of collective thought and extract the key expressions\central ideas from each of the statements in order to compose one or more speech-synthesis in the first person singular [(9)].

The DCS's were structured as follows:

The transcribed questions were repeatedly examined by selecting the relevant 'parts' of each individual response with faucets. These excerpts constitute the key expressions (KE) that are part of the discourses that serve to 'fill' each of the central ideas.[9]

After re-reading these excerpts, we identified the central ideas (CIs), which have the important function of individualizing discourses, that is, allowing the construction of discourses and the distinction between one and another discourse.[9]

Later, the KEs were present in the statements, which had CIs of similar or complementary meaning, giving them the form of sentences in the first person singular, in which the thought of a group or collective appeared as if was an individual speech, shaping the DCS's.

When interviewed about the care provided and structuring the family dynamics after becoming caregivers for the elderly, the following ICs emerged: 1 - Deprivation of freedom and increased responsibility of the caregiver; 2- Adaptations in the routine according to the needs of the dependent elderly; 3- Suffering, 4- Faith in God, 5- Informal support network: family, friends and neighbors and 6- Formal support network: FHC-Public Policies.

With the conclusion of the speeches, they were analyzed separately based on the theoretical framework of this study.

RESULTS AND DISCUSSION

Of the caregivers, two are in the age group between sixty and seventy years, two between seventy and eighty years, and only one between the ages of forty and fifty.

Caregivers are gender-separated into three females and two males. The degree of kinship between the caregiver and the elderly under their care is represented by two spouses, a son, a brother and a friend.

Of the caregivers, two have completed elementary education, one high school, one higher education, and one have not attended any educational institution.

As for religious choice, four of the participants denominated themselves as catholic and one, evangelical.

Considering that the care dependent elderly people are all female, the age group verified was composed of one between sixty and seventy years old, two between seventy and eighty years old, and two with eighty years or more.

As for the income of the dependent elderly, four live with resources coming from their own retirements, around two minimum salaries, and one does not have any income, being also financially dependent of its caretaker.

When asked about the main changes in the family dynamics after the dependency of the elderly relative, the following speeches emerged:

CI: Deprivation of freedom and increased responsibility of the caregiver.

DCS 1:

"Freedom has changed a lot and, at the same time, the responsibility increased, not that caring is a burden, but we end up depriving ourselves of many things, we cannot leave when we want, you have to stay home alone, I even had to stop working. Sometimes someone comes to talk, sometimes not. So, it's all about staying 24 hours at home. When I need to leave, I have to arrange someone to stay in my place, because at any moment I can be asked. At night, I became a light-sleeper, any moan; I'll keep an eye."

CI: Adaptations in the routine according to the needs of the dependent elderly

DCS 2:

"After she got sick, she moved in with us. At first, every day we had a house full of visitors, now we need to adapt our routine to the reality and her needs. You have to manage the diaper changing times, to give water, food, medicine, everything."

CI: Suffering

DCS 3:

"Being a caregiver is a hardship because it is difficult to see the person like that, we remember everything that the person did and now he/she is in this situation, he/she suffers with the fear that it will get worse, it is not easy, only those who go through it know that."

CI: Faith in God

DCS 4:

"I have great faith in God. I think this is what helps me to have strength, because if we forget God, which is the main thing, then we do not achieve anything, we must have faith."

CI: Informal support networks: family, friends and neighbors

DCS 5:

"It's a good thing I'm a person who has a lot of support, my husband and my children are partners, they

understand me and help me the way they can, despite working outside, when I need to leave, they ask for time, they always find a way, there's also my friends and neighbors who always give support, when it worsens they give me strength, say that everything will be fine. Thank God we're surrounded by good people who help us. "

CI: Formal support networks: FHC-Public policies
DCS6:
"The health clinic is good for us, they are all attentive, I have always been well treated, when we need a doctor's or nurse's visit, they always come. Sometimes it takes a while, maybe it is not out of spite, but these days I needed a home visit of the doctor, but he only had a vacancy for the next month because he had a busy schedule, so what can I do? When you need prescriptions or medicines, health agents take these to you at home, the nurse comes in if you need them, and they always do their best. They even ask me if we have health insurance, I say: yes, UHS (Unified Health System). Only thing that could improve is that the government should provide more resources for health, because we realize that the health center has the cheapest medicines, but the expensive ones they do not have it, so it is difficult to buy, but you have to make sure that we take it because we need it and not because we want to. "

Care is inherent to the human condition and presents itself as a device of support, sustenance and protection, without which the human being does not live attitudes of humility, hope and courage.[10-11]

Caregivers can be defined as those who care for a sick or dependent person in the course of their daily activities.[10]A study carried out in Portugal shows that, at the present time, the experience of caring at home has become increasingly frequent among families.[12]

The study revealed that most caregivers are older than or equal to sixty years of age, suggesting that there is an elderly person assuming the responsibility of caring for another elderly person in a situation of dependency, thus becoming a potential patient with functional capacity at constant risk.[13]

When presenting limitations due to the aging process, one is susceptible to the installation of chronic non communicable diseases, requiring support from other family members and special attention of the health teams.[14]

It is worth mentioning that the caregiver must be someone the dependent elderly can count on and the nursing should attend to the age group of these people in order to organize assistance that subsidizes home care and provides adequate guidelines for each case.

As for speeches, DCS 1 reveals that the care entails the burden of freedom loss arising from the need for constant attention that the family member demands, making the life of the responsible for the dependent elderly often limited to care for the dependant, hindering leisure and even preventing the caregiver from leaving the house to go to the market and pay bills.

In this sense, being a caregiver means much more than simply following the daily activities of individuals under their responsibility. It means offering attention and care for the other's life, which leads to important changes in the daily lives of these people.

The difficulties go beyond performing the tasks themselves; they involve the fact that the elderly need constant attention, requiring alertness and willingness to attend at any time. The statements show that the higher the demand imposed, the more the caregiver tends to be isolated at home, performing attention and care activities that the elderly need.

When care is taken by a single relative, the activity becomes even more exhausting, since it is often deprived of satisfying its own needs, compromising its health and causing frustrations and social losses that may also reflect in the way of offering the care.

In this process, the health team plays an important role and should serve as a source of support, providing guidance and clarification on activities related to caring, and assisting family members in order to alleviate feelings of abandonment, sadness, loneliness and deprivation of freedom that emerge in this period.[15-16]

With regard to changes in the family routine after the family dependency, DCS 2 showed that the caregiver and family adapt their lives to the needs of the dependent family member and see their routine modified. Often the environment is adapted and the objects of decoration of the house are mixed with medications, curative materials, and other objects that are part of everyday life.

The functions of family members may change. Often the daughter goes to take care of the mother, the wife takes care of the husband in bed and the husband takes care of the wife and of the housework previously performed by her.[17]

Families reorganize their routine. Most of the time, everything is planned and executed based on the activities now required. Despite this and the family commitment as a whole, it is the primary caregiver who stops living his/her own life.

It can be said that the dependence of an elderly person causes a high commitment of the familiar functionality, changing the dynamics, the economy and the own health of the members that are responsible for the care. When one has a good relation between the family and the dependent elder, the adaptation to this new reality is not complicated, due to the relation of confidence and pre-established respect. In the same way, great difficulties may arise if there are unresolved conflicts in the family history.[17-18]

In this sense, dealing with the increasing needs of a family member is not an easy task. DCS 3 reveals that caregivers suffer to adapt to the new reality - the familiar that was often the provider, now needs the care of others to live, generating difficulties to accept the reversal of roles, even feeling guilty for not being able change this situation.

In caring for the family member under his or her dependence, several feelings may arise, suffering is one among them.[13]Seeing the loved one in a situation of physical and emotional fragility shakes the whole family and can

provoke diverse and contradictory emotions like anger, guilt, fear, anguish, confusion, fatigue, stress, sadness, nervousness, irritation and crying.[18]

DCS 3 shows that caring for a family member, even if it is by choice and done with affection and dedication, mobilizes a combination of feelings, not always positive, that, if not shared, can lead to illness.

Therefore, it is reaffirmed the importance of nursing to invest in actions that improve the caregiver's confrontation, in order to optimize their collaboration in the planning and execution of the care.[1]

In DCS 4 the caregivers reported seeking in a divine entity the support and strength needed to overcome pain and suffering, since faith helps in the process of acceptance of reality and in overcoming the difficulties of everyday life.

When the human being gets sick or a family member becomes ill, one begins to live with situations of imbalance, a fact that motivates one to seek alternatives to face the situation. At this moment the spirituality\religiosity emerges, helping patients and caregivers in facing this process[19].

Spirituality\religiosity is then perceived as a complementary resource to the actions developed by traditional medicine since it goes beyond, touches the soul, influencing positively and significantly in coping with situations of suffering and imbalance.[19]

DCS 5 reveals that the possibility of having an external partner is extremely important for caregivers, even if this support is not properly "to provide care", because it is perceived that the fact of having with whom to share feelings and discoveries make the caregiver feels more secure and protected.

The family is considered the main provider of social, functional, economic and affective support for the elderly and their caregivers.[19]The support of other people or groups helps in coping with the difficulties that the task of caring entails, minimizing the negative aspects and contributing positively to the health of the elderly and their caregivers.[20]

Support mitigates the tensions associated with everyday life, favoring the maintenance of the health balance of the caregiver, who, in turn, will have better conditions to care for the frail elderly.

In addition to the informal networks composed of family members, neighbors and friends, caregivers reinforce the importance of receiving support from formal networks in the case of the Family Health Center, as can be seen in discourse 6, in which participants criticize the lack of certain inputs as medicines and also of insufficient human resources to meet the social demands imposed, reflecting the families' lack of assistance.

With the objective of improving the quality of life of individuals during the aging process, government institutions are promoting, through public policies, a healthier and safer way of living, in order to improve the quality of life as people get older.

The Basic Health Care network should provide the elderly and their family with humanized assistance, with home-based health guidance and material resources for effective care.

There are advances in public health policies, however, these are still unsatisfactory and denote weaknesses, not being able to attend to the growing demands of the elderly and their families.

It is necessary to improve the quality of care for the elderly and their caregivers by focusing attention on families in an interdisciplinary way, proposing effective measures that provide for comprehensive care, with actions for the promotion, prevention and recovery of elderly, caregiver and family, in the socioeconomic, cultural and environmental spheres, of which they are part.[20]

CONCLUSION

The increase in life expectancy entails a dependence that can accompany the individuals who enjoy it. These individuals will consequently require home care and routine changes from many families.

The development of this study evidenced that several aspects change the routine of the family that has an elderly person in a condition of dependency, the day-to-day ends up changing according to the needs of care of the elderly and they lose the freedom according to individual needs.

In DCSs, decreased freedom and increased responsibility in the lives of primary caregivers have emerged as a significant change and it is perceived that, no matter how much the family helps in care activities, they do not take effective responsibility. In this sense, given the extent that the needs of the dependent elderly increase, the responsible person tends to be isolated and restricted at home to perform his/her caregiver assignments.

However, the primary caregiver, most of the time, is not prepared for this function. Because of this, he/she ends up feeling insecure about the care provided, needing advice on the disease and care, as well as help to perform some tasks. It is clear in DCS 6 how much caregivers and families need the attention and support of health teams, which are not yet ready for this new scenario.

Home care with all these particularities requires the reorganization of health services in order to identify and cure the health needs of the population.

The study showed that the main changes affect the life of the family member who assumes the role of primary caregiver. Perhaps, through interviews with the primary caregiver, this finding suggests that new research, done with other family members, should be carried out to confirm the findings of this study.

DCSs also did not reveal conflicts that could have negative effects on the organization of the family nucleus, possibly due to the fact that caregivers were 60 years or older. So we asked ourselves what would be the changes in the dynamics of a "young" family that take care of a dependent elder? Would other demands arise?

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