

Home care for dependent elderly patients by caregivers with overload and stress

Cuidado domiciliar a idosos dependentes de cuidadores familiares com sobrecarga e desconforto emocional

Cuidado domiciliar a mayores dependientes por cuidadores familiares con sobrecarga e incomodidad emocional

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ABSTRACT

Objective: This study's aim has been to understand the experiences of family caregivers with emotional overload and stress when caring for dependent elderly patients at home. **Methods:** This study was carried out with nine caregivers by using the grounded theory method. Data was collected in family meetings through open interviews and analyzed by using the codification, open, axial, and selective processes. **Results:** The dependent elderly patients required that family members became caregivers, who later experienced overload and emotional exhaustion, consequently impacting their quality of life, also demanding attention, support, and training. They gained knowledge and care experiences by persisting in performing their role. **Conclusions:** Family caregivers need health care services, emotional support, and process learning. Research on interprofessional care plans is required for family caregivers considering the public policies for home care. **Descriptors:** Caregivers, fragile elderly, nursing.

RESUMO

Objetivo: Compreender as experiências de cuidadores familiares com sobrecarga e desconforto emocional, ao cuidarem de idosos dependentes no domicílio. **Métodos:** Pesquisa realizada com o método da *grounded theory*, da qual participaram nove cuidadores, considerando-se a saturação teórica. Os dados foram coletados em visita domiciliar por entrevista aberta e analisados pelos processos de codificação, aberta, axial e seletiva. **Resultados:** Substantivamente, obteve-se que o idoso dependente com necessidades de cuidados no domicílio estimulou movimento na família, pelo qual um familiar tornou-se cuidador. Com a vivência desse papel, desenvolveu sobrecarga, desgaste emocional, repercutindo na qualidade de vida, demandando atenção, apoio e capacitação. Produziu saberes e experiências de cuidado ao persistir no desempenho do papel. **Conclusões:** Cuidadores familiares necessitam de recursos assistenciais do sistema de saúde, suporte emocional e aprendizagem de processos. São necessárias pesquisas sobre planos de cuidados

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interprofissionais aos cuidadores familiares no âmbito de políticas e serviços de atenção domiciliar.

Descritores: Cuidadores, Idoso Fragilizado, Enfermagem.

RESUMEN

Objetivo: Comprensión de las experiencias de cuidadores familiares con sobrecarga e incomodidad emocional, por cuidar a mayores dependientes en domicilio. **Métodos:** Investigación realizada con el método de grounded theory, de dicha investigación participaron nueve cuidadores, se consideró la saturación teórica. Los datos se obtuvieron por medio de visitación domiciliaria y entrevistas abiertas, y se los analizó por procesos de codificación abierta, axial y selectiva. **Resultados:** Sustancialmente, se verificó que los mayores dependientes con necesidades de atención a domicilio provocaron movilización en la familia, por los cuales un familiar se quedó su cuidador. A partir de la vivencia en este papel, dicho familiar desarrolló sobrecarga, desgaste emocional, repercutiendo en su calidad de vida, demandando atención, apoyo y capacitación. El familiar produjo saberes y experiencias de cuidado al persistir en el desarrollo de su papel. **Conclusiones:** Cuidadores familiares necesitan de recursos asistenciales del sistema de salud, de soporte emocional y de aprendizaje de procesos. Se necesitan investigaciones sobre planos de cuidados interprofesionales a los cuidadores familiares en el ámbito de políticas y servicios de atención domiciliaria.

Descriptor: Cuidadores, Anciano Frágil, Enfermería.

INTRODUCTION

Brazil, like other countries, has undergone a demographic transition represented by the aging population. Among the factors responsible for this phenomenon are the decrease of birth rates, mortality and population growth.¹ The concomitant epidemiological transition is observed, with an increasing incidence of urban violence; the persistence of acute and infectious diseases and the increase of the burden of chronic-degenerative diseases occupy a prominent place.^{1,2}

Human aging, in a multidimensional perspective, is related to the loss of autonomy and independence, limiting the capacity for self-care, compromising the quality of life, triggering dependency relations that interfere with the elderly's social interaction processes.³

In the Brazilian cultural scene, caring for the elderly with a functional disability at home is the family's responsibility.⁴ Family members are often tested for their ability to discern, adapt and confront obstacles in performing this role. Even the most resilient ones are likely to coexist with the difficulties, with some degree of physical and emotional overload caused by the role of a caregiver.⁵⁻⁶

The growing awareness of the importance of informal care at home for the elderly population's well-being was the subject of a Belgian study. The authors defended the formulation of policies to support informal caregivers and indicated the need for a coordinated and integrated approach in health care services for the elderly, which provides support in the difficult task of caring at home.⁷

Considering the context of the family caregivers' overload and stress, knowing their psychosocial responses enables an understanding of how to plan home care. It is understood that actions aimed at minimizing the impact of caring for the dependent elderly relative are essential, as are the intensity

and diversity of feelings that arise during the performance of this complex role.

Therefore, the study's relevance was reinforced by the opportunity to give visibility to nursing care as a profession and area of knowledge, which has in its essence the care and considers the reality of the aging population and the increase of the home care demands, exploring the issues underlying the process of caring for the dependent elderly in the home context by a multidisciplinary team.⁹⁻¹⁰

Hence, the following research questions were formulated: "How familiar caregivers with overload and emotional exhaustion take care of a dependent elderly in the home environment?"; "What strategies do they adopt in their daily life to meet the basic and therapeutic needs of the family member they care for?"; "What are the circumstances, difficulties and limitations inherent to the care routine of a family caregiver for the dependent elderly person?"; and "What types of care do they need and receive?" These questions led us to the objective of this study, which was to understand the experiences of family caregivers with emotional overload and discomfort when caring for dependent elderly people at home.

METHODS

This qualitative research was carried out with the contribution of grounded theory, a method disseminated in Brazil by the application of Database Theory (DT), whose roots are in Symbolic Interactionism¹¹, which allowed to explore the social processes present in human interactions evidenced within families who live with a care-dependent elderly, when one of its members starts to play the role of primary caregiver. Therefore, the home environment was the main scenario of this investigation.

The first stage of this study was carried out in the geriatrics and gerontology outpatient clinic of a public hospital in the countryside of *Minas Gerais* State, Brazil. Seventy-eight elderly people and their family members were evaluated after being informed about this research and agreed to participate in it. Considering those, 27 had a degree of dependence from moderate to very dependent for self-care according to the Katz index.¹² Their primary family caregivers were assessed for overload and emotional discomfort levels by the Zarit Burden Interview (ZBI)¹³ and the Self Reporting Questionnaire (SRQ-20).¹⁴ Twelve family members with moderate to severe overload and emotional discomfort were included as potential participants in the second stage of this research, performed in the patients' residences, through signing the Free and Informed Consent Form.

According to the theoretical saturation criterion proposed by the DT,¹¹ the sample group consisted of nine family caregivers, who presented the highest levels of emotional overload and discomfort, of elderly patients presenting dependence in their Activities of Daily Living (ADLs).

Data were collected by using scripted interviews containing the following questions: "How the caregiver was chosen?"; "How do you feel about playing this role of being a caregiver?"; "What has changed in your life after playing

this role?"; and "What positive and negative aspects do you emphasize during the care process?" Each interview was transcribed and analyzed through open, axial, and selective coding before the next one.¹¹

This study was approved by the Research Ethics Committee in accordance with the Resolution No. 466/2012 of the Brazilian National Health Council (CAAE [certificate of presentation for ethical consideration] number: 02763212.4.0000.5133). Also, the participants' anonymity was assured by using codenames.

RESULTS AND DISCUSSION

Four categories emerged from this study's results: "Becoming a family caregiver"; "Experiencing the role of being a dependent elderly's family caregiver"; "Demanding attention, support and care for a dependent elderly relative"; and "Seeking support and education".

Becoming a family caregiver

This category contributes to understanding the process of choosing the main family caregiver, which occurred slowly or abruptly and unexpectedly, from the perception of the worsening of the elderly's health condition and self-care capacity, who is no longer able to perform basic or instrumental activities of daily living in an independent and autonomous way. Engagement or withdrawal actions were identified in the family nucleus, which culminated in the definition, by choice or obligation, of the member that would become the main caregiver, as also pointed out by other studies.^{6,15-16}

The family dynamics changed throughout the process of the elderly's dependence, making the actions for providing, decision making and power carried out by other people or family members. The participants' reports showed that the context of choosing the caregiver was established in a scenario of family conflicts or disagreements or by solitary decision without discussions, reinforcing previous results on this aspect.^{6,9,17}

Faced with the need to define who would be the main caregiver, when a maximum degree of dependency emerged, the kind that requires interaction with the health services, the participants referred to the importance of the professionals' presence, including nurses, emphasizing that one of the roles could be to support and assist the family in the organization and management of care, which would avoid conflicting situations and the worsening of the care for the elderly, who gradually became more dependent:

"There are nine people in the family, so if you had daily or hourly turns, you would not overload anyone. But choosing who will care is a difficult and very exhausting process. It's not easy". (Crystal)

The primary caregiver's choice or self-designation is something that can occur subtly because they live in the same house, but this may also be surrounded by feelings and rules established in the sociocultural context of the duty of

the spouses to care for the other partner and of the children to care for their aged parents:

"I always lived with her. As soon as she started to be like this, it was me who took care of her, that everyone was working or was married, had children, had their things to do, so I was the one to take care of her. [...] So it was my decision and, and also for love, because, besides, she is my mother. [...] As a daughter, I had to take care of her". (Tourmaline).

For women, caring for the relative is often seen as something natural and is being constructed as another culturally and socially accepted domestic role that is transmitted throughout family generations.⁵ In this scenario, having previous experience in caring for someone certainly influenced a future choice of who would assume this role, as suggested by other studies.¹⁰

The lack of guidance and support from the health services was identified as a contributing factor to the emergence of feelings of overload and emotional discomfort by the family caregiver, considering the increase in the demand for time and the insecurities when facing the difficulties in the care activities without the knowledge needed. Thus, a gap is identified, requiring studies and specific investments in order to for them to be overcome. It is understood that the support of the nurse, through a home care plan that includes the family caregiver, with specific guidelines about the distress' trigger point, is an important tool at this stage in order to relieve the caregivers, who is experiencing overload mainly because they do not know how to proceed to fulfill the needs of their care-dependent elderly relative.¹⁸

Despite the numerous difficulties faced by family caregivers, they achieved care knowledge and experiences, from the initial phase of the caregiver role, when fear, insecurity, and inexperience are still frequent. As time goes on, the caregivers become experienced, exposing their movements and strategies used to adapt to their new living conditions and seeking to overcome these obstacles:

"Now I know it, I know that if it happens again I can stay calm, you know. [...] I got used to it". (Jade)

"Even I get used to it, I no longer suffer from certain events". (Agatha).

"Getting used to it" led them to a phase in which, supported by their continuous experiences of caring, they adapted to a state or situation that included overload and emotional discomfort. This adaptation led them to become, in fact, the main caregiver by showing an empirical process of caring. Even with physical and emotional stress, feelings of overcoming the difficulties were experienced by the caregivers. Based on the reports that the needs of the elderly and the caregiving routines have gradually been adapted, it is also understood that the family caregiver develops strategies, such as delegating responsibilities and taking turnsj other family members, or even asking for external help to minimize their

feelings of overload, emotional discomfort and avoid a state of suffering.^{15,18}

Experiencing the role of being a dependent elderly's family caregiver

After the process of choosing the family caregiver and some of its implications, we proceed with the analysis of the "the experiences of being a caregiver for the elderly dependent." According to the participants' understanding, their experiences as a caregiver in the home context presented "positive aspects" and "negative aspects".

These aspects arose throughout this role. At first, the negative aspects were more evident, but when thinking about how they became a caregiver and what their routine was during the interviews, they recognized the existence of positive feelings in their relationship with the dependent elderly. Their positive view of caring for the elderly relative resulted from the feelings of affection between caregiver-elderly and the maintenance of self-esteem in difficult and painful situations:

"Ah! 'I feel' like that, that I'm doing the right thing, that she deserves it, because she cared for a lot of people, she was a fighter. [...] So, I like to take care of her, I love to take care of her". (Turquoise)

The experience of commitment anchored in affectivity, solidarity and the feeling of gratification and appreciation towards their actions gives them the feeling of well-being. This finding contributes to the advances in the practices of home nursing care, pointing out that these responses must be identified, guiding the decision-making of nurses and valuing them. These are fundamental feelings for the maintenance of affective bonds between family caregivers and the elderly dependent, in addition to helping family members feel important about the performance of their duties and enable them to relieve tension in the role of caregiver.¹⁹

Feelings of anguish, sadness, anxiety, guilt, remorse, irritability, and nervousness were identified by the caregivers during their role. They emphasized that they put aside the private life, with emphasis on the affective life. As they became more and more involved with the care, they left their work so that they could provide integral care for the elderly patient. They also rejected leisure activities and reported changes in their state of health:

"I left my work to take care of her and my sister". (Emerald)

"I quit, I left everything: leisure, travel. I traveled a lot, but I stopped". (Tourmaline)

The emergence of limitations in daily life with resulting risks and aggravations to the health and well-being of the caregiver deserves to be highlighted. Confronting this problem is not yet a routine in professional practice, requiring urgent actions from the health services. It is inferred that the physical, emotional and illness burden resulted from the care for the

elderly relative may be due to the increase in the percentage of caregivers who abandon their self-care, social, leisure and work activities, according to recent studies.^{6,15,20,21}

Regarding the aspects that change the health-disease process, the caregiver's limited self-care is highlighted. The participants' speech reinforces studies, which concluded that this phenomenon is mainly caused by the lack of time, lack of taking turns with other family members, lack of a person to help in more difficult physical tasks, and the difficulty in establishing a routine of self-care.¹⁵

When analyzing the health-disease process of the family caregiver, it can be understood that maintaining their health is of fundamental importance for maintaining the care for a dependent elderly relative. In addition to learning about care and technical procedures, caregivers need to seek and obtain external support and learn to combine the care for themselves with the care for the dependent elderly relative.

Demanding attention, support, and care for a dependent elderly relative

This category allowed us to understand the procedural and dynamic characteristic of this care. It is processual since the empirical care encompasses a chain of actions developed by the family member, who goes through previous decision-making actions followed by definitions about what and how to do and how best to proceed, in order to meet the dependent elderly's care needs. It is not restricted to the caregiver-elderly binomial; it is modified according to the pattern of the family organization and how it is inserted in an expanded social context.

Important changes were also observed in the family members' daily lives. As these changes and new routines were established in the context of the caregiver's life, the demands, an existing gap in health services, gave rise to feelings of physical overload and emotional discomfort.

A demand referred to by the participants is the need to decrease the number of overlapping activities: domestic activities, Basic Activities of Daily Living (BADLs), and Instrumental Activities of Daily Living (IADLs) of the dependent elderly relative. The caregivers did not identify a social support network and health services and reported difficulty in obtaining support from other relatives:

"The housework, only I do it". (Ruby)

"That's what you see. I have to take care of the house, take care of the food and at the same time I have to take care of her. The bills, I have to take care of everything. That really tires one". (Pearl)

Another demand was for technical support in performing care, which is complex and has multiple characteristics, requiring emotional and physical effort. The caregivers' stress and overload were increased by not being able to distribute the tasks, including, as already mentioned in the literature, their need to rest for a few moments without worrying with the dependent relative.⁹

Furthermore, the family caregivers' demands may vary according to their gender. When the caregiver is female, they accumulate other roles such as being the mother, wife, and caregiver. This overload compromises the caregivers' self-care because they reported having little time to care for themselves, including more women-specific aspects such as physical appearance, clothing, among others. Thus, it is highlighted the need for secondary caregivers to assist the primary caregiver in the division of tasks.^{15,15}

In addition to the caregivers' lack of time for self-care and social activities, family conflicts and economic repercussions are present. Conflicts were generated by the lack of congruence between the caregiver's and other family members' desires, causing stress, tension, dilemma, disagreement, and discussions. This reinforces the need for secondary caregivers:

"I was in a very bad situation. Because she is not like this... She's almost my 'relative'! She's my mother-in-law. [...] In order to hospitalize her, I had to confront the family. Half of the family is against me". (Cristal).

The financial issues reported by the participants were related to the low family income, the fact that they had to leave their work to dedicate exclusively to the caregiver role, and the increase of the costs throughout this process. For example, the caregivers often needed to buy diapers and medications that were not supplied by the *Sistema Único de Saúde (SUS)* [Unified Health System], which is in accordance with other studies.^{6,9} The costs of home care for the family together with other factors accelerate the caregiver's stress, since the economic aspect, as already shown, is another element that causes concerns and tension for the main caregiver.^{17,21}

The diseases that cause dependence for the elderly generate increasing costs, whose impact on the family economy is not yet fully known in Brazil. The lack of an effective government program for this population, even with the existence of some policies, makes the family the main source of financial aid for an effective care.^{4,6}

Seeking support and education

The previous categories showed that the family caregivers' needs demand that they receive attention and care because they live with an increasing risk of overload and stress. Given the relevance of the constant demand for support and the need for learning, guidance, and monitoring, it is highlighted the way that the caregivers sought support in the social networks and health services to relieve their stress.

According to the participants' speech, the caregivers' responsibility for caring for the dependent elderly relative demanded them efforts beyond their capacity due to their lack of previous experience in this work. Their doubts give rise to insecurity and stress due to not knowing how to care for the patient or how complex these actions can be.

The caregivers showed their need for training when they reported participating in lectures, meetings, and groups of elderly caregivers. They looked for information on the internet, handbooks for caregivers and in the social support network.

Also, they interacted with other caregivers experiencing similar situations in the community:

"Now I try to gain knowledge, you know, by looking for information about the phase she's going through, sometimes on the internet, or else, on people who got through or is getting through it." (Sapphire).

Support and education for the caregiver's qualification, while being included in the list of systematic services offered by the health system, should be delivered carefully to the family. Furthermore, specialized care, which is the family's right, should not be delivered as a measure for relieving or eliminating overload and for promoting the maintenance of quality of life.^{21,22}

Family caregivers participating in groups of training, support or interaction need to be encouraged, since they function as spaces in which the caregivers feel more secure and exchange good care experiences. Also, alternatives for overcoming difficulties and negative aspects such as distress, fear, insecurity, conflicts, and tension could be found in these groups.^{9,22}

Sharing experiences can provide caregivers with relief, decreased feelings of emotional overload and discomfort, and promote their well-being once they realize that they are not alone, that the doubts and difficulties are not only theirs and that their experiences can be valuable to other caregivers. Thus, the caregivers can form a support network among them.^{9,22}

Religiosity/spirituality was pointed out as the main strategy adopted by this research participants:

"I leave all in the God's hands and he gives me strength and... as I told you, as I'm Protestant, we seek strength in God and he gives us it. So, I seek support in God, because my support is in him. Totally in God". (Emerald)

This theme emerged in the form of a confronting strategy for relief, showing that the caregivers searched for a type of support that involved more than technical aspects. Therefore, further studies on reconsidering the overloaded caregivers' religiosity/spirituality are needed.

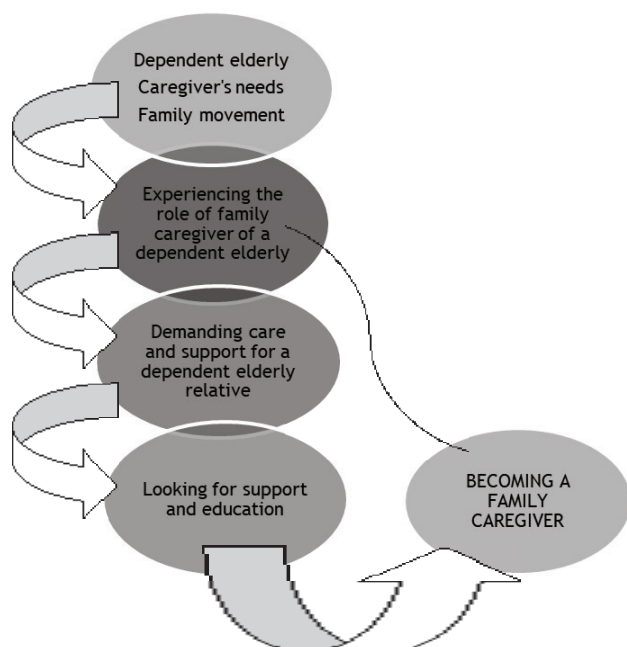
Religious practices, faith, spirituality and beliefs in a higher being were perceived by caregivers and evaluated in other studies as very effective strategies for stress, distress, depression and the overload resulting from the caring process. Thus, the study caregivers viewed religion as a source of help and comfort.^{16,20, 21}

The support of religiosity/spirituality contributes not only to cope with the difficulties experienced by family members but also in the search for a meaning to life and the need to play this role. It also favors the interpretation of the facts experienced in a more positive way and that seems to give them strength to continue following with what they considered to be a mission and even obligation according to the sociocultural context in which they were inserted.

Substantive theorization of the investigated phenomenon

Figure 1 represents the substantive theoretical analysis through four categories, whose centrality is the experiences of the family caregiver in performing this role.

Figure 1 - Conceptual diagram with the representation of the phenomenon studied.



Source: produced by the authors.

Care for the dependent elderly at home by a caregiver with physical or emotional overload is a progressive process, as the dependency progressed and that was influenced by multiple factors, inside and outside the family. The family member was not able to recognize the exact moment when dependency broke out to its greatest extent. As the elderly had limitations in ADLs and difficulty in supply their self-care needs, the family progressively assumed them, dispensing with interventions and care on a compensatory basis.²³ By moving away from and approaching the members, the main caregiver was chosen for this function.

The family members, who gradually assumed the responsibility of providing general care for the elderly relative, began to play the role of caregiver. While experiencing this role, the caregivers relied on aspects from the empirical process of caring for the culture in which they are inserted, reporting on the emergence of positive or negative elements and feelings that evaluated their performance. The home care experience favored the development of knowledge and experiences that resulted in care, which is not always what health professionals expect. From this experience that was gradually established, the family caregiver was able to define their main demands. The need for all kind of support from other family members, health services or other sections of society, including Social Assistance, which is the greatest demand, followed by the need for learning how to effectively care for family members without exposing them to risks.

Therefore, becoming a caregiver is a result of the dynamics of the daily living with the elderly family members' demands and dependence that gradually occurred due to their illness. It is a continuous and cyclical process of search for support and education triggered by the stress, overload, and tension during this role in a home context.

The family caregiver was, therefore, a new function within the family, which changed their daily life routine. This role was performed in the daily life of these families, without prior preparation or learning. The experience that was established by the role of caregiver in the home context stimulated the development of reactions and feelings that enhanced the process of caring at home or other feelings that behaved as factors triggering their stress and overload. Among these were the repercussions due to the increasing number of domestic and care activities, lack of social support network, family conflicts, economic repercussions and even lack of time for social and spiritual activities. Their need for health support and education is highlighted, and the coping strategies for self-care were restricted to spirituality/religiosity, and, in rare cases, to the participation in groups and lectures.

CONCLUSIONS

The results obtained allowed us to analyze the experiences of caring for the dependent elderly at home by an overloaded, stressed relative who was performing the role of a family caregiver. This study contributed to understanding the reality of each family investigated and observe the daily care for the dependent elderly people, allowing a relationship of trust, which stimulated dialogues marked by feelings, emotions, moans, and reports that expressed the difficulties, limitations, needs, and potential of family caregivers.

Research on a specific group could constitute a limitation of this study, but the saturation obtained is related to recurrence in the same group in two temporally different moments, allowing the necessary comparisons for theoretical validation. This study's findings contributed to the raising of at least three other questions for future research in order to broaden the comparison with other samples of caregivers for dependent elderly or other methodological approaches: "How the care for the dependent elderly is delivered when the family caregiver is also an aged person?"; "What are the costs for the family when the elderly's dependency is related to dementia or complex wounds?"; "Is the family space ideal for caring for elderly people with high level of dependency?"; and "How should be the relationship between family and State regarding the care for the dependent elderly?"

This study may contribute to the construction of knowledge in Gerontological Nursing and Home Care, including the practices of stressed, overloaded nurses covered by the *Estratégia de Saúde da Família* [Family Health Strategy] caring for families with dependent elderly people. Furthermore, this study may influence the development of new ones, as well as public policies so that the dependent elderly receive a humanized and resolute home care from the SUS in a structured, supportive family environment.

It is concluded that family caregivers need healthcare resources, emotional support, and training. Research is needed on policies and home care services for interprofessional care that includes family caregivers.

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