INFLUENCES OF OVERLOAD IN THE SPOUSE OF THE CAREGIVER OF THE FRAIL ELDERLY

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ABSTRACT
Objective: to investigate the influence of overload on the caregiver's spouse of the frail elderly. Method: a qualitative study, carried out with ten spouses of caregivers of frail elderly, through open and individual interviews at home. The analysis of the data was subsidized by the technique of Content Analysis, in the modality Thematic Analysis. Results: several changes were identified in family daily life, especially the loss of freedom, which caused alterations in social life, with interruptions of leisure activities; changes in marital and child relationships understood by the lack of attention that the elderly caregiver can give to these people in the daily life of the family and notes to the negative and positive aspects of this relationship. Conclusion: even with all the changes that occurred in the family organization, the spouses were able to promote a realignment of family roles for the well-being of all family members. Descriptors: Health for the Elderly; Aging; Family; Family Relations; Caregivers; Spouses.

RESUMO
Objetivo: investigar as influências da sobrecarga no cônjuge do cuidador do idoso fragilizado. Método: estudo qualitativo, realizado com dez cônjuges de cuidadores de idosos fragilizados, por meio de entrevistas abertas e individuais no domicílio. A análise dos dados foi subsidiada pela técnica de Análise de Conteúdo, na modalidade Análise Temática. Resultados: identificaram diversas alterações no cotidiano familiar, com destaque para a perda da liberdade, que provocou alterações na vida social, com interrupções das atividades de lazer; alterações nos relacionamentos conjugal e com os filhos compreendidas pela falta de atenção que o cuidador do idoso consegue dispensar a essas pessoas no dia a dia da vida em família e apontamentos a aspectos negativos e positivos dessa relação. Conclusão: mesmo com todas as mudanças ocorridas na organização familiar, os cônjuges conseguiram promover um realinhamento dos papéis familiares para o bem-estar de todos os integrantes da família. Descritores: Saúde do Idoso; Envelhecimento; Família; Relações Familiares; Cuidadores; Cônjuges.

ORIGINAL ARTICLE

INFLUENCIAS DA SOBRECARGA NO CôNJUGE DO CUIDADOR DO IDOSO FRAGILIZADO

Conclusión: incluso con todos los cambios ocurridos en la organización familiar, los cónyuges lograron promover un realineamiento de los papeles familiares, para el bienestar de todos los integrantes de la familia. Descriptores: Salud del Anciano; Envejecimiento; Familia; Relaciones Familiares; Cuidadores; Esposo.

8 Influences of overload in the spouse...
INTRODUCTION

Population aging is one of the phenomena evidenced worldwide as a challenge for social health policies. Similar to other poor countries, Brazil has a greater number of elderly people with disabilities and difficulties in activities of daily living, with tendencies to increase chronic diseases, as the age advances. The prevalence of disability among the Brazilian elderly varies from 6.9 to 47%, depending on the population characteristics, such as: age, gender, income and socio-environmental conditions.1-2

The loss of functional capacity has profound implications for the elderly, family and community, since it compromises autonomy by making them seek the help of another person in the role of their caregiver.3-5 It should be noted that the caregiver plays a crucial role in the development well-being and quality of life of the frail elderly.2

Generally, the caregiver is a relative who, by assuming this function, ends up experiencing the daily life of the disease and its implications. Living with a fragile elderly requires a number of tasks that need to be adapted to the routine and the home environment.1-3 Among them, the emphasis is on personal hygiene care, adapted diets, meeting leisure needs, managing and / or supervising the use of medications and follow-up of visits to health services from time to time.4

Thus, caring for a fragile elderly person is a challenging, arduous and complex task that can provoke a series of reactions for the caregiver himself and interferences in relationships with other family members, leading to the emergence of disagreements, conflicts and even generate a process of disruption of family balance.5-6

This condition that the caregiver faces can often compromise care for the frail elderly, leading to the development of comorbidities and hospitalization needs considered avoidable. The care guidelines for chronic conditions emphasize the importance of ensuring the continuity, safety and integrity of home care. Thus, the health of the caregiver has been gaining prominence as the policies of dehospitalization are advanced.6-7

Given this context and considering that many caregivers of fragile elderly have spouses, the following research question emerged: What changes occur in the life of the spouse and other family members of the caregiver of a frail elderly? Thus, the objective of this study was to investigate the influences of the overload in the caregiver's spouse of the frail elderly.

OBJECTIVE

- To investigate the influence of overload on the caregiver's spouse of the frail elderly.

METHOD

A qualitative study was carried out with spouses of caregivers of frail elderly individuals living in a small municipality located in the north of the State of Paraná. Initially, a survey was carried out in all the Basic Health Units of the municipality, together with the Community Health Agents (CHA), on the families that had frail elderly people registered in the area of coverage. Based on this information, the composition of the families was analyzed.

As criteria for inclusion, the spouses of caregivers of frail elderly individuals who took care of the elderly for more than a year and were living with the elderly were selected and invited to participate in the study. The time limit established was intended to include those who were already adapted to the role of caregiver and could contribute to the research.

Data collection took place from June to August 2016. After the families were selected, a home visit was carried out to meet them and invite them to participate in the survey. With the acceptance of the subjects, a second home visit was scheduled for the interviews. In this second visit, the VES-13 (Vulnerable Elders Survey-13) was also applied to the elderly, with the purpose of confirming and identifying the vulnerability index, considering that the more fragile the elderly person is, the more he or she demands of the family.8 Thus, all the elderly were classified as fragile, which allowed the follow up of the research with the interviews with the spouses of the caregivers of the elderly.

The interviews were individual and occurred in their homes, on the day and at the time scheduled by them. They happened without the interference of other family members so that they did not influence the interviews. Thus, the data collection was finalized with ten spouses of the caregivers of fragile elderly, respecting the theoretical saturation of the data, that is, when no new data were added by the participants.

The interviews were opened, and the researcher had a question-and-answer guide in the hands of the following question: Tell me what has changed in your life after taking care of the elderly? All interviews were recorded...
on electronic audio devices, with an average duration of one hour and 30 minutes. After the interviews were finished, they were transcribed in full as easily as possible.

The analysis of data was subsidized by Content Analysis, Thematic Modality. This method comprises the following steps: pre-analysis; exploitation of the material; treatment and interpretation of the results obtained.

The development of the study followed the procedures established by Resolution 466/2012, of the National Health Council, with the signing of the Term of Free and Informed Consent (TCLE) by the participants, in two ways; the approval of the Standing Committee on Ethics in Research Involving Human Beings of the State University of Maringá, with the CAAE number 57740716.5.0000.104 and the approval of the Health Department of the municipality of reference. To ensure the confidentiality and anonymity of the participants, they were given the name of interviewee followed by the number of inclusion in the study.

RESULTS

Among the spouses of caregivers of fragile elderly, eight were male and two were female. In relation to the degree of kinship with the elderly, they were represented by four sons-in-law, three children, a daughter, a brother-in-law and a daughter-in-law. The participants’ ages ranged from 41 to 68 years, with the majority being over 45 years old. Eight family members were economically active, one was unemployed and one retired. As for schooling, six completed Incomplete Elementary School, one completed Incomplete Secondary School, two, Completed High School and one held Post-Graduation.

According to the analysis of the data, they were organized into three categories: "Participating in care implies changes in routine and loss of freedom"; << Negative aspects experienced by the spouses of the caregivers of fragile elderly >> and << Positive aspects experienced by the spouses of caregivers of frail elderly people >>

♦ Participating in care causes changes in routine and loss of freedom

Even though they do not directly take care of the frail elderly, the caregiver’s spouses are also influenced by this action. This is because, faced with the decision to reside and provide care, the participants reported experiencing several changes, mainly in their daily routines, because their commitments and schedules were organized according to the needs of caregivers. They also revealed changes in their rest routines, family activities and changes in work life:

Our family routine has changed completely. My professional life has changed, I get more close. Before, I worked traveling, I was very off (Interviewee 1).

We left our house and came to live with them to take care of them (Interviewee 10).

It changes everything … you, first, have to think about it [in the elderly]; Then, in you, we do not sleep any more right (Interviewee 6).

In addition to changes in the routines, the spouses addressed loss of freedom by living in favor of the elderly, which implies limitations in the times of exit for activities outside the home. They said that when they leave, they feel worried and have to return home quickly. Those who enjoyed leisure do not practice it more or practice it sporadically:

We can not leave, we have to take care of him. When there’s a party or something to stay the whole day, we will not (Interview 9).

Changed our function, changed a lot, the freedom of you to go to such a place and stay. Do not have it! It’s all because of him, we live because [...] we’ve already finished our social life four years ago. Travel? We never travel again! (Interviewee 4).

The loss of freedom also had repercussions on the marital relationship, since the dedication of the caretaker of the frail elderly is full time and influences other family relationships. This influence is referred to by the spouse as an absence of attention to the same and to the children:

Our couple routine has changed, the routine of mother and son also changed […], difficult the day I can get my wife and daughters and go out for a walk or a trip, there is no way! If I go out with my wife, I have to leave someone to care (Interviewee 1).

Given this context, it is observed that all family members suffered consequences in their lives when the family took care of the fragile elderly, because they had to adapt their routines to the life of the caregiver of the frail elderly.

♦ Aspectos negativos vivenciados pelos conjujes dos cuidadores de idosos fragilizados

The survey participants reported some negative aspects from the time the family took care of the frail elderly. Physical and emotional exhaustion were considered as negative aspects, the latter marked by constant stress and tension:
It is a permanent tension, it is a permanent concern, you do not know how you will wake up tomorrow, we do not have a quiet life (Interviewed 1).

It irritates, it stresses, I say that we are going to hospitalize [the elderly], arrange a place to put it […]. I say it straight because you get tired! But, at the same time, give it […]. So we'll take it as we give (Interviewee 6).

It is very stressful, we feel very tired of all this, of this situation. It's very difficult (Interviewee 5).

Another negative aspect mentioned by the spouses was the lack of support offered by the extended family. They felt harmed by the non-involvement of other family members in direct care of the elderly, stating that there is no division of responsibilities, help, and commitment to care for the frail elderly. The extended family was limited to making phone calls. In some cases, it still instigated family conflicts:

They each live their normal lives, they just make a call to know how they are, but they do not get involved. No one assumes the commitment to help care, this happens a lot, always (Interviewee 1).

We're doing what we can because the other kids do not want it, there's one who lives here in the garden, but we can not really count on them. So, the bad thing is getting bored and the family slackers that do not help and still come here to disturb (Interviewed 5).

Come to visit family and still complains and criticize us. Helping is very little […]. No one asks if he's alive or dead (Interviewee 10).

All the spouses interviewed stated that taking care of the frail elderly is a difficult situation for all the family members characterized by moments of intense stress.

Positive aspects experienced by the spouses of caregivers of frail elderly

Most of the study participants cited some support from the nuclear family. Help was present in activities such as food; help for changes in decubitus and movement, which require physical effort; relay to sleep in the same room as the elderly and attend to their requests during the night and company to the elderly when the immediate caretaker needed to distance himself from the home:

He also can not do that strength he needs to hold his father. So when I need it, I or the boys [children] have to take over and help […]. But, what I find most beautiful of all is that our children offer to stay there and sleep with it (Interviewee 4).

Sometimes, when one goes out, the other stays, so it is a relay […] in what I can, I help, I take food, I warm up, I do all this, it's made a lot easier, I help and I help more (Interviewee 7).

According to the spouses, the support of the nuclear family - at this stage of life and in the face of the circumstances experienced in relation to the dependence of the frail elderly - is recognized with the act of caring that receives a connotation of love, charity and gratification:

It is only love, the person learns to love more and give value in life … it is much more than a gesture of love because my husband dedicates himself body and soul to take care of him (Interviewed 4).

It's good, when you take care of a person who is sick it's like helping others, we have to take care of them (Interviewee 7).

It is very good to help a person that no one wants anymore (Interviewee 5).

There was also a report that the care offered to the elderly was a way of rewarding the care received in childhood as a normal and expected step in the life cycle:

For me, it's an advantage to take care of because she already did it for us when we were little (Interviewee 6).

For some interviewees, the family support brought, as a positive aspect, a significant improvement in the health of the frail elderly, which had repercussions in the adherence to the drug treatment and allowed an improvement in their quality of life:

He did not drink water at all before coming here; I think he got sicker for it. He lived apart from my brother and they only saw each other at night. Sometimes he would spend three days eating the same food, and today he eats well, drinks water without having to fight (Interviewed 8).

As he was very lonely, he ended up not taking the drugs; now, with us here, he started to take it right (Interviewee 3).

According to the testimonies, when taking care of the fragile elderly, all family members, despite experiencing negative moments, also experience positive gains. The nuclear family develops mutual help within the home, as well as sharing feelings of loving retribution and care already practiced by the elderly. In addition, the family can identify benefits to the quality of life for the elderly as a consequence of the care offered by them.
DISCUSSION

The findings of this study demonstrated that the unexpected fact of welcoming the frail elderly causes changes in the daily routine of the family group. It was evidenced that one of the relatives always assumes, with greater responsibility and commitment, the demands of this care, a fact that exposes him to great changes in his life. However, it should be noted that spouses and other family members, living in the same household, also experience significant changes in their life routines and can be understood as a reflection of what the caregiver experiences.

Studies point out that changes in caregivers' lives in caregivers are related to an exposure to physical and emotional overload that directly interferes with the quality of life of the members involved.2,10

In this study, changes in the routine of life were also experienced by the caregiver's spouses, with changes in the daily routine, in which the commitments outside the family environment were placed in the background; rest times have changed; the activities they did in the family were not the same as before and the work life, in some cases, also changed, with job changes so that they could adjust the schedules and better meet the demands of the family.

Another change referred to by the caregiver's spouses of the fragile elderly was the loss of freedom, which occurred from the moment family members began to live for the elderly, renouncing their own wills, and the priority was to take care of their relative and perform the tasks that he needs.

The large demand for care required by the frail elderly person generates a family involvement, which affects the consumption of time to perform the care, which results in a consideration of the social activities previously performed.2 This study identified that the spouses also abdicated social activities, characterized by deprivation of leisure time, travel, religious commitments and, also, the attention that was given in the conjugal relationship and with the children.

Faced with all the demand that the frail elderly person presents, the spouses identified some aspects considered negative in this new family rearrangement that were pointed out as the physical and emotional exhaustion that all the family members experience and the absences of the other members of the extended family. Some studies have shown that caring for patients with chronic illness is an exhausting and stressful process and causes changes in the personal and professional environment of the caregiver.1-5

The overload generated in the daily life of the family causes stress and decreases the tolerance of the caregiver. (11) Studies point out that caregivers feel overwhelmed by the demand for care, having to perform personal tasks of the elderly, such as bathing and hygiene, which are characterized as absorbing activities that fill the day and sometimes the night of the person who takes care of them, intensifying their immersion in the caring function, exposing the caregiver to the negative consequences of these activities and increasing their level of tension.

Regarding the discontent generated by the lack of support from the other members of the extended family, there was evidence of the absence both in the execution of tasks to the elderly, as well as the caregiver, besides the lack of dialogue in these relationships. This reality provokes frustration in the participants of the study because, in addition to not receiving help, they are still victims of criticism, a fact that causes conflicts and disharmony in family relationships. However, it is in the family context that their members grasp well-being behaviors, they support each other in health promotion activities, in the processes of diseases experienced during their development and in the different transitions that occur throughout the life cycle. 12

This study indicates that living with a caregiver of the frail elderly is exhausting and generates an overload on all members of the family. However, even in the face of all the difficulties exposed, the research participants were able to identify positive aspects resulting from this coexistence recognized by them as the support received within the home environment with food, physical strength to move the elderly, the relay during the night and the company to the elderly when the caregiver needs to leave home.

Studies have shown that families, after facing the difficulties of the care routine, ended up organizing and integrating care so that all the family members could exercise some kind of participation.12-4 Integration and mutual help within the family environment, provides well-being to all members and is understood by them as a positive aspect of family life.

Thus, support within family relationships, provides its members with confidence, favoring an environment of unity and solidarity, as well as interference in the mood / mood of its members; collaborating significantly to maintain the physical and psychological integrity of individuals.2,4,13
Research on the influence of social support on the quality of life of the family caregiver of elderly persons identified that caregivers who reported receiving some informal support from their relatives, but also from other agents and distinct networks of formalized care services, presented themselves more satisfied with their interpersonal relationships and their social lives.15

For the study participants who recognized positive aspects in living with the caregiver and the frail elderly, they mentioned that this experience aroused in them feelings like love, charity and gratification. Other studies mention that in taking care of the elderly, people are able to come up with good feelings, such as pleasure, joy, solidarity, and a sense of social responsibility for the satisfaction of fulfilling their role as children.2, 4, 13

In this study, good feelings were recognized as important to the whole family. For, they assume that the commitment to care involves a retribution of affection, and with this attitude they can teach their children that caring for an elderly is the responsibility of the family and is part of the life cycle, stimulating them so that one day they can also take over this responsibility with other elderly in the family.13-6

It was also recognized that when the family assumes care, the quality of life of the elderly is also evidenced, since they are better fed, hydrated, and improved medication adherence.17 It should be emphasized that the best care at home elderly population reduces the prevalence of comorbidities resulting from the aging process, avoiding hospital readmissions considered potentially avoidable, consequently optimizing the use of financial resources in health.

Brazilian public policies have been promoting wide discussions about caregiver health, since the individual and family health of this important social actor is directly related to the health of the person being cared for. Thus, it is important that health professionals consider this subject in their care plans in order to promote better support and care at home with better quality.

CONCLUSION

Investigating the influences of overloading on the caregiver’s spouses of the frail elderly allowed us to consider that changes in life routines affect all members of the family. The changes identified were related to the changes that occurred in family daily life, especially the loss of freedom, which caused alterations in social life, with interruptions of leisure activities; changes in the marital relationship and with the children, understood by the lack of attention that the caretaker of the elderly can dispense to these people in the daily life of the family and notes to the negative and positive aspects of this relationship.

However, even with all the changes in family organization, caregiver spouses were able to promote a realignment of family roles for the well-being of all family members.

The results presented in this study may contribute to the reorganization of care for families who care for frail elderly in their homes, with notes for health professionals, who should extend their actions to all members of the family, instigating actions that promote and strengthen support mutual relationship between family members so that their relationships are preserved even in the face of the overloads and changes that occurred after taking care of the frail elderly.

As a limitation, considering the sample size and unique regional characteristics of the participants, it is suggested that research investigating this theme be carried out with a larger population and involving other family members, including children.

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