

SUPPORT FOR ELDERLY FEMALE CAREGIVERS OF DEPENDENT FAMILY MEMBERS

SUPORTE A IDOSAS CUIDADORAS DE FAMILIARES DEPENDENTES

APOYO A CUIDADORAS ANCIANAS DE FAMILIARES DEPENDIENTES

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Objective: to know the support for the elderly female caregivers in the care of dependent family members. **Method:** a qualitative research conducted between March and June 2017 with six elderly female caregivers of dependent people enrolled in the public home care program in Salvador, Bahia, Brazil. The interview data were analyzed based on Bardin's Content Analysis. **Results:** the study showed that, in the process of caring for the dependent, the elderly female caregivers have the support of family members, formal caregivers, domestic workers, home care program and 24-hour mobile emergency care. **Conclusion:** in the process of caring for the dependent, elderly female caregivers have several supports, which minimize the burden of care and enable them a better quality of life.

Descriptors: Female Caregivers. Patient Care Team. Home Nursing. Elderly Health. Geriatric Nursing.

Objetivo: conhecer os suportes para as idosas cuidadoras no cuidado de familiares dependentes. Método: pesquisa qualitativa, realizada entre março e junho de 2017 com seis idosas cuidadoras de pessoas dependentes cadastradas no programa público de atenção domiciliar em Salvador, Bahia, Brasil. Os dados das entrevistas foram analisados com base na Análise de Conteúdo de Bardin. Resultados: o estudo apontou que as idosas cuidadoras, no processo de cuidar do ente dependente, contam com o suporte de familiares, cuidadores formais, empregadas domésticas, programa de atendimento domiciliar e o atendimento móvel de urgência 24 horas. Conclusão: as idosas cuidadoras, no processo de cuidar do ente dependente, contam com diversos suportes, os quais minimizaram a sobrecarga do cuidado e possibilitam-lhes maior qualidade de vida.

Descritores: Cuidadoras. Equipe de Assistência ao Paciente. Enfermagem Domiciliar. Saúde do Idoso. Enfermagem Geriátrica.

Objetivo: conocer el apoyo a las cuidadoras ancianas en el cuidado de familiares dependientes. Método: investigación cualitativa realizada entre marzo y junio de 2017 con seis cuidadoras ancianas de personas dependientes registradas

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en el programa público de atención domiciliaria en Salvador, Babía, Brasil. Los datos de las entrevistas se analizaron con base en el Análisis de Contenido de Bardin. Resultados: el estudio indicó que, en el proceso de cuidar a la persona dependiente, las cuidadoras ancianas cuentan con el apoyo de familiares, cuidadores formales, empleadas domésticas, del programa de atención domiciliaria y de la atención móvil de urgencia las 24 horas. Conclusión: en el proceso de cuidar a la persona dependiente, las cuidadoras ancianas cuentan con diversos tipos de apoyo, que minimizan la sobrecarga del cuidado y les permiten gozar de una mejor calidad de vida.

Descriptor: Cuidadoras. Equipo de Atención al Paciente. Enfermería Domiciliaria. Salud de los Ancianos. Enfermería Geriátrica.

Introduction

The alterations in the senescence process indicate the physical and mental overload resulting from the care of the dependent family member, which is most strongly expressed in the elderly caregiver. Given this conjuncture, strategies that favor the support to these caregivers and consequently the promotion of their quality of life are needed.

These changes in population aging also occur with a significant and necessary growth in the number of caregivers for the elderly⁽¹⁾. With the increase in life expectancy, caregivers are also becoming elderly and most of them play their role informally, a situation indicated in the literature⁽²⁾. A caregiver is defined as any individual, family or community, who cares for the dependent person without any guidance or preparation⁽³⁾. Informal caregivers differ from formal caregivers because the latter are trained through courses that prepared them to provide care. Therefore, they are paid for their work⁽³⁾.

In the context of informal care, it is necessary to punctuate the national reality, regarding the unpreparedness of caregivers to perform the tasks required. A national study conducted with 20 female caregivers of the elderly, most of whom were over 50 years old, showed that they did not receive training and were unprepared to perform family care⁽⁴⁾. Another study warns that caregivers need to be oriented and trained to care for dependent family members⁽⁵⁾.

In addition to caregiving without any preparation or training, caregivers experience a daily work overload, often with little or no support. In addition to the household tasks,

among the activities usually performed by the caregivers in relation to the elderly, we find the following: preparing food, bathing, administering medications, changing diapers, among others, besides the management of this care⁽⁵⁾.

All these tasks are almost always performed without any assistance, leaving these caregivers vulnerable to compromising their health⁽⁴⁾. This situation was also revealed in a longitudinal study, with women who were, on average, 53.2 years old and caring for their in-laws and parents. In this study, the authors warned that the provision of informal care had impacts on the health of these people, such as the emergence of psychic symptoms, aggravation of pre-existing diseases and the risk of illness and involvement with musculoskeletal disorders⁽⁶⁾.

Playing the role of informal caregiver is a daunting task, regardless of age, and requires skills⁽¹⁾. However, older caregivers have peculiarities that may initiate or even aggravate existing health problems, causing limitations and making it difficult to perform certain tasks⁽⁷⁾. This is related to work overload, so that elderly caregivers deal with their own changes in their senescence process, since chronic diseases are more frequent in the elderly.

A study conducted in Asia with 285 informal caregivers, in which more than half were between 40 and 65 years old, concluded that they had some physical health impairment, such as mobility, as well as psychic, such as anguish, which compromised their quality of life⁽⁸⁾. In Brazil, a survey conducted with 99 elderly caregivers showed that they had health problems

like pain, back problems, hypertension and insomnia⁽⁷⁾. Faced with such problems, it is necessary to look at the elderly caregiver, as he is more vulnerable to the development and/or aggravation of physical and emotional problems through the act of caring.

It is healthy to think about the complexity that exists when care is performed by someone who is experiencing aging, especially when care is exercised exclusively or almost exclusively by that person. Understanding that the process of caring for the dependent family member alone can cause repercussions for the life of the elderly caregiver, the research aims to know the support for the elderly caregivers in the care of dependent family members.

Method

This is a qualitative research, conducted with elderly female caregivers of dependent people registered in one of the bases of the home care program called "Best at Home", a public program of the Federal Government, whose bases are in large public hospitals in Salvador, Bahia, Brazil. Each base is supported by a multi-professional team of physicians, nurses, physiotherapists and other professionals⁽⁹⁾.

As the caregivers were mostly women, following the profile of caregivers reported in the literature^(1,7,10), they will be addressed from now on as females. All the female caregivers assisted family members registered in one of the bases of the referred program. Those aged 60 years old and over who cared for their dependent family member were included.

Data collection began by consulting all 53 medical records of the people enrolled in the locus of the survey, which contained an instrument called Social Eligibility Assessment, completed by the social worker. This form contained information for all residents of the place, age, and responsible caregiver, who may or may not be a family member⁽³⁾. During this search, only the record of an elderly

female caregiver was found, requiring a new consultation of the medical records, focusing on the identification of elderly individuals in the family, possible caregivers, ten situations being located. In order to identify whether these elderly people exercised direct care to the dependent family member, a telephone contact was made, and it was found that seven took care of their loved ones, totaling eight elderly female caregivers. Of these, two refused to participate and the other six agreed and signed the Free and Informed Consent.

For data collection, a semi-structured interview was conducted, consisting of the characterization of the participants regarding their health and the following guiding questions: tell me each care action you provide to your family member throughout the day; tell me about the health repercussions of your care; tell me how you perceive your health before and after caring for your relative.

The interviews were conducted at the homes where the dependent relatives lived, between March and June 2017. These were recorded and later transcribed. To ensure anonymity, fictitious flower names were used, as they are delicate and convey vitality, an essential element for the care of dependent people.

Data was organized according to the content analysis guidelines proposed by Bardin, composed of three stages: pre-analysis, material exploration and treatment of the results. In this way, five categories were found for analysis and discussion: family support; support of formal caregivers; support of domestic workers; home care program support; and 24-hour mobile emergency support.

This research was approved on October 5th, 2016 by the Research Ethics Committee, under Opinion No. 1,762,501. This is a clipping of a master's dissertation that aimed to know the implications related to the musculoskeletal system experienced by elderly caregivers of people with impaired functional capacity.

Results

The six study collaborators were aged between 60 and 79 years old, had family care the 7 days of the week and the mean time of dedication ranged from 1 year and 5 months (17 months)

to 6 years (72 months). All the female caregivers were supported by the home care program and by the 24-hour mobile emergency care. Among them, 2 provided the private service, 4 received assistance from family members, 3 from formal caregivers and 3 from domestic workers (Chart 1).

Chart 1 – Characterization of the elderly female caregivers of dependent relatives related to sociodemographic, health and care process aspects

| Variables | Codename | Sunflower | Jasmine | Daisy | Orchid | Rose | Tulip |
|-----------------------------|----------|-----------|---------|----------|----------------|---------|---------|
| Age (years old) | | 73 | 72 | 79 | 63 | 63 | 60 |
| Gender | | Female | Female | Female | Female | Female | Female |
| Care time (hour)/day | | 14 | 14 | 16 | 18 | 18 | 16 |
| Care time (months) | | 54 | 36 | 36 | 48 | 72 | 17 |
| Program support | | Yes | Yes | Yes | Yes | Yes | Yes |
| Mobile care support | | Yes | Yes | Yes | Yes | Yes | Yes |
| Family support | | No | No | Daughter | Sister, nephew | Sister | Husband |
| Caregiver support (n) | | No | Yes – 2 | No | Yes – 1 | No | Yes – 1 |
| Domestic worker support (n) | | No | Yes – 2 | No | Yes – 1 | Yes – 1 | No |
| Professional orientation | | Yes | Yes | No | No | Yes | Yes |

Source: Created by the authors.

Family support

The study reveals that, in the process of caring for the dependent families, the elderly female caregivers had the support of family members in specific tasks such as hygiene and medication. Importantly, such aids, which relieved the physical and emotional burden, were not limited to first-degree relatives, also contemplating the care provided by men, including without inbreeding, as sons-in-law.

My sister and nephew help me a lot. We made a table and whoever was with her would help with everything she needed: changing her diaper, changing her position, bathing. (Orchid, 63, caregiver of her 91-year-old mother).

[...] my husband and sister help me. She comes twice a week [...] gives the medicines, watches if he needs to change diapers or position and still writes everything in the notebook for me to know. I get carefree when she's here because, besides helping me, I trust her! [...] as I sleep very late, my husband is the one who takes care of him until 8 o'clock and only wakes me up before if I need to vacuum him, because that only I know how to do. (Rose, 63, caregiver of her 31-year-old son).

Formal caregiver support

By alerting to the costs that permeate the hiring of a formal caregiver professional, the study alludes to its relevance in the accomplishment of the tasks demanded by the dependent entity, from the company to the performance of technical care, sometimes even uncommon in the elderly's daily life, such as enteral nutrition. This support, which sometimes transcends the technical practice, as it is also affectionate, reassures the elderly female caregivers so that sometimes they can turn to taking care of themselves.

Having a caregiver is necessary, because we don't know how to do some techniques. They clean, bathe, bandage, feed through the tube, and keep her company [...] I get more supervisory and so, sometimes, I have time for myself. (Jasmine, 72, caregiver of her 98-year-old mother).

As I work, I hired a caregiver for the day. Like her money [mother] is little, we can afford it, because we use ours and we also have the help of one of the brothers, although none comes to participate in the care. She cares so lovingly that she looks like a daughter. With her help, I can control myself more emotionally because it's very

difficult to take care of my mother in this state [crying]. (Tulip, 60, caregiver of her 86-year-old mother).

Domestic worker support

The testimonies also highlighted the importance of support from domestic workers, whose actions are not limited to homework, as they help the elderly female caregivers also in the direct care to the dependent. This support also favors the availability of time for the caregiver to fulfill her personal needs.

I can take care of him because I have the support of two people in the housework. And when I must, they'll help me with him too: getting him out of bed to the chair, changing his diaper. (Rose, 63, caregiver of her 31-year-old son).

There are two maids who take turns [...] they take care of the house, the clothes and the food [...] so I get more time to do my things. (Jasmine, 72, caregiver of her 98-year-old mother).

Home care program support

The home care program is seen by the elderly female caregivers as an important resource for the continuity of the professional care provided to the dependent because, in addition to providing guidance, it also provides multi-professional home care. The relevance is notorious of this government program that, by providing human resources, materials and medications, also represents a financial support, especially for families whose income makes it impossible to fund such assistance.

When he left the hospital, the program provided all assistance [...] there was the doctor, the nurse, the physiotherapist [...] also directed me and him how to do everything. I paid nothing because it was all the responsibility of the program. And that's great, because the money is little. (Daisy, 79, caregiver of her 19-year-old grandson).

[...] when I needed something, I would call the program and the nurse would bring all the necessary material [...] now that they have unlinked him, everything is very difficult. I can't take him to the health service because he's a quadriplegic and there's little money to buy so much. I miss the program so much! (Sunflower, 73, caregiver of her 49-year-old son).

24-hour emergency mobile support

Older female caregivers attach importance to the mobile emergency service and consider it

accessible and resolute. For those interviewed, being able to count on this support, either free or private, helps to reduce anxiety and distress in the face of urgent and emergency demands.

I called the ambulance because he was very agitated, nervous. They came, they medicated, and he got better. I liked it very much! (Sunflower, 73, caregiver of her 49-year-old son).

If she needs it, I call the 24-hour ambulance [...] they arrive fast and serve well [...] in some cases, they even say what I should do over the phone. These guidelines can save your life! Once they told me what to do and she got better. If I didn't have this support, I wouldn't know how to handle this situation. (Tulip, 60, caregiver of her 86-year-old mother).

Discussion

The study revealed that, in the care process provided to the dependent person, the elderly female caregivers have various forms of support, including family support, which goes through different degrees of kinship. A study of 86 caregivers of the elderly with a mean age of 56.5 years old showed that 55.8% received help from a relative⁽⁵⁾. It is important to note that, in this research, the family member's sensitivity to contribute to the daily tasks demanded by the dependent person impacted on the improvement of the quality of the responsible caregiver, favoring the reduction of their physical and mental overload, as expressed in the statements.

A positive result of the collaboration of family members in improving the quality of life of the caregivers was reported in a survey conducted in Vietnam where, at the end of interventions through a focus group, with the participation of 21 stakeholders, including family caregivers, professionals and community leaders, stressed the need for other family members to share the responsibilities of caring for their loved ones⁽¹¹⁾.

Despite this support, other research points to the difficulty of support in some families who reported domestic conflicts and distancing of members during care, the responsibility of caring falling only on one family member⁽¹²⁾. This scenario signals the need for professional actions, whether in the community, in home visits, in the institution, working with the family or in forming caregiver support networks, showing the need

for the shared responsibility of a family, as well as the creation of conflict resolution strategies that harmonize the family relationship for the care of the dependent person.

It is noteworthy that, of the six female caregivers interviewed, half could count on the help of men, including spouses. A study conducted in Mexico with male family caregivers, aged between 29 and 86 years old, showed their understanding that it is not only the woman's obligation to provide care to the family member, much less alone. This research focuses on male commitment to their wives, as they demonstrate partnership in delicate moments⁽¹³⁾, a situation also experienced by two female caregivers interviewed.

The care provided to the dependent people, or not, leads to a reflection on the social constructions anchored in gender inequalities, in which such role is understood as inherent to the female figure, not being a habitual conduct in the male universe, as confirmed by a research developed with ten spouses of family caregivers who admit not to participate in the division of responsibilities and/or caregiving tasks⁽¹⁴⁾. In line with this result, a survey conducted with 14 men reveals that, although they claim to help with childcare tasks, they understand that this is a role of the female figure, as opposed to providing for the family, which is their responsibility⁽¹⁵⁾.

This gender social education, responsible for the asymmetry between men and women, supports and contributes to the hegemony of women by assuming the role of responsible caregivers, while men, when present, are responsible for financial support. In this research, this reality is experienced, for example, by Tulip, whose support from her brother was limited to providing financial resources, without which she would not be able to afford the services of a formal caregiver. Of the six female caregivers interviewed, half do not have the resources to hire a formal caregiver, a fact that is also confirmed in another study⁽¹⁰⁾. Thus, financial resources can contribute to relieve physical overload, but they not always reduce emotional burden.

A national research conducted with 33 caregivers of patients with chronic pain revealed that only 3% were paid, which confirms the financial difficulty of the responsible family member to have the support of a formal caregiver⁽¹⁶⁾. The importance of this professional to help in the specific demands of care is to be noted, which was also pointed out in a study conducted with 33 caregivers in São Paulo, of which 16 were formal, who assumed, among other activities, preparation of medications, punctures, exam collections and verification of vital signs⁽¹⁷⁾.

It is noteworthy that the activities of formal caregivers are not limited to technical skills, as the study revealed an affective bond with the dependent person. This broad perspective considers that the caregiver's work encompasses the interfaces of affect, intelligence and subjectivity⁽¹⁸⁾. This favors that the responsible elderly woman has more confidence in the worker and, consequently, can be less present in the process of caring for the entity.

The tranquility experienced by the female caregiver responsible for being able to trust in the formal caregiver tends to be perceived also in the presence of domestic workers, a reality of three interviewees. In this case, the workload is reduced thanks to the support of the maids who assume the housekeeping chores like washing, ironing, cooking, cleaning, and sometimes helping to care for the dependent person. A study on the interactions between employees and employers corroborates this result; it pointed out the role of these employees as contributing so that the family members could perform functions outside the housekeeping activities⁽¹⁹⁾.

However, this shared care with a paid professional is a distant reality in the care relationships with low-income elderly, according to a study conducted in Bahia. It was evidenced that this caregiver task is isolated, and that socioeconomic difficulties make it difficult to hire a specialized professional to assist in care. However, the home care program is a support available to all the female caregivers. One of the

relevant points of this service is the supply of materials at no extra cost, which does not create a burden for the family, who often deals with difficulties in acquiring these inputs⁽¹⁰⁾.

A study conducted with caregivers of dependent family members in Portugal and Brazil confirms the relevance of these programs to reduce the financial costs as they provide, in addition to equipment, assistance and guidance⁽¹²⁾. A research that defends the need for the presence of nurses in home care confirms that this service develops assistential, administrative and educational actions⁽²⁰⁾. In this sense, the findings reveal that the program avails the provision of the specialized service of the multidisciplinary team at home, as well as guidance, which facilitates care since many dependent people have important limitations, making it difficult to travel to the health service.

The importance is noteworthy of a home care program, not only for the dependent person, who will receive direct care, but also for the responsible family member, since such support exempts him from wasting time for the provision of medication and professional care in several areas, which would also require financial expenses with the acquisition of inputs and/or displacements. Linked to these aspects, the home care service still contributes to the performance of safe procedures and techniques, especially regarding mobility techniques, device handling and administration of medications that caregivers point out as the greatest difficulties in care. In these respects, they evaluate home care as satisfactory⁽²¹⁾.

A bibliographic research performed in the *National Library of Medicine National Institutes of Health* (PUBMED) database revealed that home care worldwide is more focused on palliative care patients⁽²²⁾. In Brazil, it includes activities aimed at people who present temporary or definitive difficulties at different levels, in order to provide care within the family, avoiding hospitalization and risks of infections⁽⁹⁾.

Like the assistance from the home care program, the 24-hour emergency mobile care is an important and resolute service, as expressed

by the caregivers' statements. A national study conducted with eight family members of critically ill patients who were attended by the Mobile Emergency Care Team from Parana, showed that they evaluated the team's activities in a positive way, emphasizing the agility and quality of care⁽²³⁾. Having the support of a service whose main action is to provide specialized assistance at the place of occurrence is essential for the promotion of comfort and safety to the family, especially in the face of professional preparation to deal with major issues.

Considering the overload of tasks and the responsibility of a responsible family caregiver, especially given the demands of the bedridden person, the supports presented here are essential not only for the dependent person, but also for the responsible family member. This is because care tasks encompass a range of factors, such as economic, temporal, family and personal reorganization, which directly impact the caregiver's quality of life⁽¹⁾. In Brazil, support for families caring for dependent people is urgent, as the country has a fragile organization of the health care network, with an insufficient number of professionals committed to helping the family caregiver, and low coverage when compared to the needs demanded by the dependent persons⁽²⁴⁾.

However, a study highlights the need for a support network for family caregivers to assist them in caring for the family and to provide informal and formal support, as well as providing health care and having strategies that ensure information and communication by the team⁽¹²⁾. Such support has its value in improving the caregiver's quality of life, leaving him or her freer to meet his or her personal demands, as well as reducing and/or canceling the physical and emotional illness, especially when it is an elderly person already susceptible to their own changes proper of the senescence process and, therefore, more predisposed to presenting health problems, such as chronic musculoskeletal diseases⁽²⁵⁾.

Although the study has limitations, as it does not allow identifying the quality of the relationships between the family members,

justifying the degree of support to the responsible caregiver, and considering the rare situations of family conflicts related to neglect of care, it is fundamental to foster the creation of spaces for discussion about strategies that enable support for the elderly female caregiver. It is believed that the development of interaction actions between professional and family members may favor the process of reducing their workload related to direct care with the dependent person.

Conclusion

The study showed that the elderly female caregivers had the support of family members, domestic workers and formal caregivers to exercise care. Other bases identified were the home care devices and the mobile emergency service that, through protocols and strategies previously built by public policies, allow for the reception and support of the elderly female caregivers in the demands related to the exercise of care.

Given the above, actions are needed to ensure that the dependent person, especially those whose female caregivers are elderly, has the right to access services at home, not only to meet their health needs, chronic or acute, but also the biopsychosocial demands that, when met, favor healthy aging. The importance of the multi-professional action to support the caregiver at home is to be noted, especially nursing, for more frequent and close contact, being essential for the care orientation process.

Collaborations:

1 – conception, design, analysis and interpretation of data: Nildete Pereira Gomes, Mateus Vieira Soares and Arianna Oliveira Santana Lopes;

2 – writing of the article and relevant critical review of the intellectual content: Nildete Pereira Gomes, Larissa Chaves Pedreira, Nadirlene Pereira Gomes and Tania Maria de Oliva Menezes;

3 – final approval of the version to be published: Larissa Chaves Pedreira, Nadirlene Pereira Gomes and Tania Maria de Oliva Menezes.

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