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ARTICLE

Formal caregivers of dependent elderly people in the home: challenges experienced

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Abstract *Objective: To analyze the characteristics and challenges experienced by formal caregivers of dependent elderly at home. Methods: Multicenter qualitative study, conducted in six Brazilian cities, with formal caregivers of dependent elderly people. The interviews were conducted using a semi-structured guide, at their homes, from May to August 2019, lasting an average of 60 minutes. Results: Participants were 27 formal caregivers with a mean age of 46 years, predominantly female, with mean care time for the elderly of two years and six months, without professional training of caregivers. The analysis and interpretation of the statements led to the formulation of three thematic categories: Working and health conditions of the formal caregiver; Profile and ways of caring; and Care challenges. Final thoughts: There is need to know the characteristics and demands of formal caregivers of dependent elderly people domiciled for the development of public policies and effective interventions, taking into account the needs presented by these professionals.*

Key words *Formal caregiver, Dependent elderly, Elderly health, Residence, Qualitative research*

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Introduction

In recent decades, there has been an accelerated process of population aging in most countries of the world, determined by the increased life expectancy and reduced birth rate. The growth in the number of the elderly in old age, therefore, maximized the proportion of the elderly with chronic diseases, physical and cognitive limitations[1]. According to national data, the Brazilian population exceeded the mark of 30.2 million elderly people, showing an increase of 18% in the past five years, with 4.8 million new elderly people[2].

The increased life expectancy is reflected in health conditions, morbidity and functional limitations, increasing the incidence of diseases and disabilities, with possible changes in physical, cognitive and emotional dependence, which generates the need for permanent care[3]. In this case, dependent elderly people need the presence of another person to assist them in performing daily activities, when they cannot make decisions and manage their own lives[4].

In recent years, the family structure has changed with the insertion of women in the labor market and reduced number of children, in addition to the decreased number of family members available to be caregivers, evidencing that the problem of the elderly's dependence has become relevant due to the reduced family support[5,6].

Thus, there emerges the need to hire formal caregivers, who should mostly have qualification and professional training to perform the permanent care of frail elderly people[7,8]. However, they are people who, in addition to the domestic work performed in the homes, care for dependent elderly, assisting them in their Basic Activities of Daily Living (BADL) and even in the administration of medications and specific nursing care, without having any qualification or preparation for this. Only those families with greater purchasing power, with private health insurance, guarantee professional care with Home Care teams, whose formal caregivers are health professionals, especially nursing technicians[9,10].

In view of the significant demand for care for Brazilian elderly populations, the need for the caregiver gains strength, which constituted a new political actor and, consequently, the object of actions and governmental and legislative interventions for their execution. Thus transforming the activity of caring for the elderly into a job and, consequently, a profession that needs to be regulated. In this arena of conflicts, since November 2012, Bill n. 4,702, which aims to regulate the profession of caregiver, has been under process[11].

In developing countries, people with low schooling and professional qualification are usually the elderly's caregivers. However, this reality differs in countries such as Japan, where caregivers (homehelpers) are divided into categories according to vocational training; and in France, which has already established scientific improvement recognized by the Ministry of Labor[12].

Therefore, in view of this reality, this article aims to analyze the characteristics of formal caregivers and the challenges they experience in the care of dependent elderly people at home. The study is justified by the evident gap in the health information system capable of characterizing the difficulties and needs of dependent elderly people, as well as on the qualification, activities, living and working conditions of formal caregivers.

Method

This research aims to deepen the understanding of the characteristics and challenges experienced by formal caregivers of dependent elderly people. The focus is on their working and health conditions; sociodemographic profile, care ways, challenges and obstacles faced by formal caregivers.

The study is part of a multicenter research macroproject[13], developed on the situation of dependent elderly people living with their families and their caregivers, aiming to support future proposals for a "Policy on Dependence" in Brazil, which was approved by the Research Ethics Committee of the Oswaldo Cruz Foundation.

The study sought support in the theoretical-methodological framework of dialectical hermeneutics, because it is more appropriate to guide the interviews conducted with the formal caregivers of dependent elderly people, starting from the multidimensionality of the care of the frail elderly person, aiming to know their characteristics, experiences, difficulties faced, demands and needs to improve their situation as caregiver[14].

From the analytical point of view, this reference allows perceiving and problematizing the convergences and divergences of meanings present in the reports of the various participants, opening new interpretative vertices for their expressions, always overflowing with multiple meanings seen in their social-historical context of production. Data processing takes place through three methodological movements: contextualization, understanding and empathic and critical interpretation/analysis of the symbolic

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character of common experiences and singular experiences[15].

The scenario of the study involved cities in the Northeast (Teresina and Fortaleza), North (Manaus), Southeast (Rio de Janeiro) and South (Porto Alegre and Araranguá). The inclusion criteria were: be a formal caregiver of dependent elderly people and receive remuneration to perform care.

The interviewees were 27 formal caregivers responsible for the care of the dependent elderly, of whom 25 were women and 02, men, distributed as follows: 06 in Aranguá (RS), 05 in Fortaleza (CE), 05 in Manaus (AM), 04 in Porto Alegre (RS), 02 in Rio de Janeiro (RJ), and 05 in Teresina (PI). The strategies for selecting participants were surveys of the registration and indication of the Family Health Strategy (FHS) Teams, especially through information from Community Health Workers (CHW). After locating the dependent elderly, those who had formal caregivers with a profile established in the inclusion criteria were selected, followed by their contact and invitation to participate in the research.

The interviews were previously scheduled at home, from May to August 2019, by the study researchers and/or graduate students linked to research groups in each municipality. The interviews took place in a reserved place, lasting an average of 60 minutes. Initially, the Informed Consent Form was read and signed and authorization was requested to record the conversations.

Initially, the interviewees were asked about their sociodemographic characteristics, qualification and professional training, and subsequently about the clinical characteristics of the elderly care, with emphasis on their dependencies and needs; finally, the perceptions of the formal caregiver about the elderly and about themselves were questioned. Content saturation was used as a criterion for the closure of data collection, which were organized with emphasis on the most relevant topics from the interviewees' perspective. The analytical corpus was organized with the pre-analysis, articulating the objective of the study with the participants' reports.

In this logic, comprehensive and interpretative inferences led to the formulation of three thematic categories: Working and health conditions of the formal caregiver; Profile and ways of caring; and Care challenges. The findings were discussed using the national and international literature. To preserve confidentiality, the excerpts of the interviewees' reports are presented accompanied by the initials of the designation of formal caregiver and the sequential number of interviews.

Results

The formal caregivers interviewed were in the age range from 31 to 64 years, with mean age of 46 years. Of the total, 25 are female (92.6%) and 13 self-reported as brown (48.1%). Regarding work, the average time dedicated to the elderly assisted is 2 years and 6 months, the average remuneration, 1,394.00 BRL; 18 (66,6%) stated having no training as caregiver and 20 (74%) had no labor relationship with a registration in their working book.

Regarding the activities performed, 17 (62.9%) caregivers stated performing other tasks in the house, such as doing the laundry, general cleaning and cooking, as they expressed "doing everything". Three (11.1%) caregivers, in addition to caring for the elderly, help in some domestic activity. It is noteworthy that the action of caring for an elderly person is eminently feminine and domestic, because the two men who acted as formal caregivers were exclusively concerned with the care of the elderly.

Working and health conditions of the formal caregiver

In this thematic category, the working and health conditions expressed by formal caregivers were exposed. The precariousness of the labor and professional relationships of the caregivers participating in the study was evidenced, considering that 17 (62.9%) cared for the dependent elderly and performed other domestic activities. Moreover, 03 (11.1%) helped in some household activities related to the elderly person, and only 07 (26%) formal caregivers devoted themselves exclusively to caring for the elderly.

Another point identified is the low schooling and specific professional qualification registered among 20 (74%) formal caregivers, which corresponds, in addition to the precariousness in the professionalization of these caregivers, to the fragility of the formal bond, because 18 (66.6%) participants were remunerated without a labor relationship, without registration in the working book, with the obvious absence of social security rights and guarantees of the caregivers.

The following statements confirm this reality of precarious working conditions, labor guarantees, low schooling and poor qualification.

I have been taking care of the old lady for four years and three months all day, but I do everything in the house for everyone, I have no registered working book, I have never attended any elder care course. She depends on me for everything, the daughter takes care of her mother at night (FC21).

I am 42 years old, I have been taking care of an elderly man for 5 years, and his stuff, such as cooking, laundry, room and bathroom cleaning, but he is a huge work as he is unable to do anything on his own, I have no registered working book, he attended a 1-month course at the church he usually goes to (FC15).

This same thematic category also evidenced the health conditions of caregivers, with emphasis on wear of the daily activity of caring for the dependent elderly, in addition to other household tasks. The reports mention, primarily, mood changes, depression and exhaustion. According to the statements described below, this long-term care, without the necessary rest, in addition to the exhaustive actions of caring for the elderly and executing other household activities, negatively affect the physical, mental and emotional health of formal caregivers.

Sometimes I get angry [...] *sometimes I say to him "I cannot take this anymore"* (FC5).

It is an overburdening job, because we have to work hard with our heads (FC6).

Sometimes I feel tired, I get impatient [...] *it is no easy. It is hard* (FC11).

Sometimes comes the depression, I feel sad. It is a good thing I take fluoxetine, which calms me down (FC18).

I have already cried with her, seeing her in that situation (FC15).

I just have mood swings (FC24).

Although the previous reports indicate negative feelings, some interviewees evaluate their situation positively, in a resilient way, upon expressing the need to be patient and accept the situation as a mission.

It was a mission I had. [...]. *I accept this situation very well* (FC2).

I am patient, I have a lot of patience, but sometimes we lose it for the stubbornness. (FC7)

I am very relaxed, calm. I do not get involved with the patient's emotional complications. I help him balance himself, but I do not get emotionally involved. (FC8)

Profile and ways of caring

Although the research participants have low schooling and poor specific qualification for care, some ways of caring overcome these difficulties and are done with skill, balance and stability, with feelings of patience, love, affection and dialogue, behaviors and attitudes necessary for the continuous care of the elderly.

I try to be patient, you know? (FC1).

With affection and love, if there were no love, it would not be like that [...] (FC10).

I believe that love first, patience, humility. No matter what you have gone through out there, do not take to your work. Always try to have dialogue, always show joy [...] (FC13).

Love and good mood always. I am playful because my problems are not their business [...]. *If you are here, you have to do your best* (FC23).

Another point highlighted as a strategy by caregivers refers to the help and support of other people, usually family members, in carrying out the activities, as shown in the following statements.

My husband helps. He is a trained nurse [...] *He always helps. Helps put her go to bed, get out of bed and put in the chair* (FC4).

If I am feeding him and she is home, then I ask her to stay in the room with him. I have that support (FC5).

Thank God everyone here helps, it is not something we do alone, nobody does it alone, that is a very important thing, the family being together [...] *helping* (FC17).

So much support from her brothers. Her brother always comes at bath time to help, there is always someone to put her in the chair, get off of the chair and put on the bed (CF24).

Regarding care management, some caregivers reported using creativity in communication and time organization as a way to enable and contribute to daily tasks related to the elderly.

Il do everything early before she wakes up! (laughing) *I already know the time she gets out of bed. So, by the time she gets up, I everything is almost done. The house is already clean.* [...] *every week I take out a thing not to get too accumulated!* (FC14).

I have placed a whistle in the bathroom for this old lady to call me whenever she needs help. With the elderly all that matters is patience, everything in life is patience (FC16).

To change decubitus, I move her gradually, then I turn one part and then the other. It is not that complicated. And I am always hydrating her a lot (FC24).

Like in the bath, sometimes she gets in the bathroom and I turn on the shower so she can hear the noise of the water, but sometimes she still has that difficulty (FC26).

Care challenges

The challenges experienced by formal caregivers of the dependent elderly are numerous, considering that care demands are permanent, repetitive, increasing and varied, resulting from the expansion of frailties and physical and emotional losses. Practically, all women (over 92% of the participants) experience exhausting working hours, which are not rewarded and remunerated by families.

The care provided to the dependent elderly requires several activities, from the simplest to the most complex, varying according to their surrounding conditions. Some interviewees reported that the elderly they care for still have a higher level of autonomy, but most report similarities in the work routine:

My routine is about hygiene, his hygiene, always controlling his temperature [...] *so, there has to be this very special care, and I do it with love. The meals are always on time, so is the medication, everything. He needs dressing in the sacral region* (FC23).

My routine with her goes from bathing, medicine schedules, her snack, lunch, I sleep here with her, stay with her until Saturday afternoon (FC27).

Most study participants reported that their daily tasks go beyond the care of dependent elderly people, being responsible for cleaning the house and cooking for the family as a whole, as observed in several reports.

I clean the house, do laundry (FC3).

Do the laundry, clean the house, cook, bath him, you know? That is all (FC5).

I have to do his laundry, iron his clothes, some of his stuff in the house need to be cleaned. Clean the apartment, get everything organized, wash the bathrooms, get everything cleaned (FC7).

I do a little bit of everything. I take care of the house, I wash, I iron, I cook, all on me! (FC14).

I have done all house chores. So I wash, iron, cook, which were not in the contract. Even only spoken, but I am doing, including cooking, everything, everything, but I do not want to (FC20).

Concerning the working hours, the statements refer to the permanent disregard for the workload established in labor laws, which exceeds the eight daily hours. Sometimes surpassing the night time, without paying overtime and additional.

Among the formal caregivers interviewed, only those linked to home care service providers have their work regulated in labor legislation. The others, hired by families as housekeepers, sometimes do not even have the guarantees currently won by the category. They accumulate care activities of the dependent elderly and house chores, like house cleaning and family feeding, tiring and repetitive tasks, combined with lack of guarantees and low wages, generating overloads, mentioned by some interviewees.

An elderly caregiver had to be just an elderly caregiver. Not involving another function (FC6).

It is just the workload that is hectic. I work Monday through Friday, seven to seventeen, so I do not have time to solve bank problems, stuff like this. But I have chosen it, so... (FC8).

I had to have someone to replace me at those times [...] *Sometimes I feel very overwhelmed by this* (FC27).

At night, we get so tired. Because we spend all night waking up (FC7)

I wanted [...] *it to be like this: I wanted to take a day off, you know? That would be a rest!* (FC5).

In leisure, the issue of holidays, which is inexistent (FC25).

The wage. The elderly's caregiver should earn the best wage. Because it is too much commitment (FC6).

Referring to the needs and aspirations they have, the caregivers pointed out the legalization of the profession and the offer of courses and training for the care of the elderly.

In the case of this upcoming legalization, we will be more valued, better seen, more recognized. It is something that is going to be well recognized and it is going to be so good. Very good indeed (FC13).

In the case of health, I wish I had [referred to a course] *specific for caregiver* (FC13).

I think I need to learn more [...] *Attend more courses... That is what I have to learn more about! So much I do not know* (FC15).

Learn to give shots because the patient may need in an emergency. [...] *Revive. So I feel like attending a course* (FC16).

Discussion

Gender specificities can be observed with the predominance of females, a fact identified in several studies involving formal caregivers in Brazil[16-18] and in other countries[19,20]. Typically, care is essentially exercised by women, and even with advances in the world labor market, the perception that they are responsible for activities related to domestic work, including care, still persists[18]. Of the study participants, only two formal caregivers are male and have a reality different from

the aforementioned one, since they do not assume other care with the house.

Being a caregiver of the elderly demands unrestricted dedication and attention. These demands can directly influence the health of the professional and, thus, the caregiver may experience exhausting sensations and emotional discomfort[21], a fact evidenced in the present study, demonstrating that the act of caring can trigger changes in mental health and negative impacts on the perceived health.

In addition to the investigation on the health of formal caregivers, a study[12] observed that 26.7% of them were diagnosed with emotional discomfort, and presented inefficient sleep, feeling stress and tiredness. Some authors relate this exhaustion to intense working hours, to the increased demand for care over time, to daily and uninterrupted coexistence associated with care provision, to the state of health, to the level of dependence of the elderly and to the unpreparedness of caregivers to cope with their activity[22-24].

About the self-perception of caregivers, among the answers were statements directed to acceptance and conformity with their situation. Resilience is a skill that leads the human being to impose him/herself before life adversities, involving overcoming and adapting. Considering that the work of the formal caregiver was his/her own choice, this can facilitate the ability to cope with the daily difficulties imposed, therefore, this acceptance ends up contributing to the better performance of caregivers in the care of the elderly even when they dedicate themselves to the care of the elderly considered difficult[25].

The work of the formal caregiver requires several strategies and methods to overcome the difficulties experienced in the routine. By analyzing the mechanisms used at work, the feelings involved in caring for the elderly, such as affection, love and zeal, enable the formation of a bond that permeates a contract of work or remuneration, facilitating the experience of care and coping with the mishaps resulting from the caregiver's work activities[26,27].

In a comparative study involving the subjectivity of formal and informal caregivers, feelings of pity, love, worship and affection stood out more in formal caregivers[28]. This datum corroborates what was found here, which unveiled that the formal caregivers, for having chosen this occupation and not being obliged, deal well with the demanding situation of the dependent elderly, resignifying - as something positive. Although most caregivers expressed positive feelings and affections in relation to care, this is not the only way to react. FC8, for example, uses the mechanism of suppression of affection to keep a professional posture. For her, being a professional requires the isolation of affections that would be incompatible with good professional practice, denoting a more defensive strategy of control.

Another point highlighted by some interviewees was the support of other people in care. Even if paid, caregivers need help to carry out some activities, and, often, depending on the occasion and availability, they turn to their own family members for cooperation in routine functions. Thus, there is FC4's, who has the effective help of the nurse husband, FC1 whose niece offers eventual help and FC2 whose husband and daughter help in heavier tasks. This division of responsibilities contributes to alleviate the physical and emotional overload, and enables coping with obstacles and challenges, which is undoubtedly reflected in the care of the dependent elderly[18,27]. Most elderly people's families are reported as a source of support and valuable help to caregivers, although many formal caregivers see them as negligent and that abandons.

Being creative, resourceful and resilient in daily challenges directly influences the care routine, and the optimization of the organization and the management of time and work can soften and improve the conditions of those who care. Actions that involve creativity in communication between those involved, such as simple gestures and codes used in the relationship between those involved are facilitating resources[29,30].

The care demands vary according to the degree of dependence of the elderly under the care. The present study showed that most of them were totally dependent on care, making the caregivers' routine similar, determined by activities of maximum need, full-time, such as bathing, going to the bathroom, performing personal hygiene, getting around and eating, in addition to IADL[31].

In a study with formal caregivers which investigated the type of care they practice, most of them stated that they performed the activities of feeding, medication control, body hygiene and oral hygiene[21], which corroborates the findings of this study. The repercussion of the elderly's disease implies consequences for the caregiver, since the impairment of cognitive and behavioral functions influence the activities of daily living and overload those who assist them[13,31].

One point that emerged from this study was the observation that, in addition to the care provided to the elderly, the interviewees, especially

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women, stated that they also perform domestic activities in the residence where the elderly live. This reality is common in Brazil, and, despite the absence of more robust data on this, the role of domestic workers in the care of the elderly tends to be seen as a component of domestic services. On several occasions, employees are hired as caregivers, but also perform house-related functions[30].

Given the imperative need to regulate the profession of caregiver of the elderly in Brazil, there is growing criticism and fear by militants involved in the defense of this professionalization about the requirement of elementary school, because most caregivers who already work in home care have little or almost no schooling[11].

Another problem evident in the panorama of long-term care is the accumulation of tasks by a single person, which can cause problems related to the caregiver's health. Although these people often perform domestic activities as an extension or as a naturalized effect of their functions, as found in this study, in these cases, a form of exploitation is established, which goes surpasses and makes the care profession vulnerable[26,30].

This is not a reality found only at the national level, Spasova et al.[32] point out that a substantial part of the care for dependent elderly people in European households is offered by family members and complemented by formal caregivers.

With the responsibility of assisting the elderly, usually on an uninterrupted occasion, and with the addition of other functions, the workday becomes intense and exhausting, as reported by several interviewees. Thus, the support of health and social service professionals to formal caregivers is essential, also from the legal point of view, in order to enable the correct direction of their activities[16,21].

The recognition of the real function of the formal caregiver, in addition to the establishment of rights and duties, workload and wage floor, are paramount to reduce obstacles and misunderstandings that persist in this occupation until then unregulated as a profession[16]. Another challenge to be overcome by formal caregivers in the current conjuncture is to find in the law that will regulate the profession a space that clearly delimits the boundaries of this activity, in order not to confuse it with the activities of other professionals[33].

In view of the complexity involved in care, there stands out the relevance of more qualified professionals to assist the elderly, in order to provide this population with an aging with greater dignity and quality of life. The implementation of public policies aimed at these professionals should address several contexts and the planning of interventions aimed at improving their health and work conditions[18].

Although the contributions of this study are relevant for the health promotion of formal caregivers, they are limited by the reduced number of formal caregivers interviewed, which hinders data generalization. In addition to increasing the number of subjects interviewed, it would be important to deepen even more the understanding of the condition of formal caregivers by the insertion of sociocultural aspects present in the various regions investigated, which cross social practices, especially the action of caring for the elderly. Additionally, another limitation of the study is the Midwest region nor covered by the national collection, which prevented us from having a more comprehensive view of the investigated phenomenon.

Final thoughts

As proposed, the present study allowed analyzing the characteristics and challenges experienced by formal caregivers of the dependent elderly domiciled, from the perspective of the caregiver's perception, the strategies involved in care and the demands existing in this function. The data revealed that formal caregivers have unique characteristics, but similar to most other studies involving this theme, not only in the Brazilian reality but also in other countries.

The feminization of care is notorious, in addition to this, several feelings involved in the caregiver's life context directly reflect on their self-perception. Also evident was the precariousness of this occupational activity both regarding the low education of caregivers, as well as the fragility of training in the country, in addition to the small number of regular labor contracts, services are often provided without register in the working book, and when this happens, they are hired as housekeepers.

Understanding the reality of formal caregivers is necessary to know the complexity of actions, personal experiences and interrelationships that involve care. Finally, adding to the challenges and complexity of the daily life of the dependent elderly and their care, there is a need to continue multicentric studies and researches in Brazil and even comparative investigations with other international realities in order to unveil specific vari-

ables of the problem of long-term care at home and thus present to managers and legislators elements capable of influencing the elaboration of care policies for the dependent elderly and their caregivers, especially formal, who experience the informality and illegality of their work, in the exercise of an occupation, without the regulation of a profession that assists and cares for such fragile lives.

Collaborations

MLF Figueiredo, DMD Gutierrez and ML Carvalho were responsible for the conception, design, analysis, data interpretation and writing of the article. RF Silva and ML Carvalho were responsible for the critical review. MLF Figueiredo, JJT Darder were responsible for the final approval of the version to be published.

References

1. Camarano AA. *Estatuto do Idoso: avanços com contradições*. Rio de Janeiro: IPEA; 2013.
2. Instituto Brasileiro de Geografia e Estatística (IBGE). *Características gerais dos moradores 2012-2016*. Rio de Janeiro: IBGE; 2017.
3. Cruz RR, Beltrame V, Dallacosta FM. Envelhecimento e vulnerabilidade: análise de 1.062 idosos. *Rev. Bras. Geriatr. Gerontol.* 2017; 22(3):e180212.
4. Klompstra L, Ekdahl AW, Krevers B, Milberg A, Eckerblad J. Factors related to health-related quality of life in older people with multimorbidity and high health care consumption over a two-year period. *BMC Geriatr* 2019; 19(1):187.
5. Giacomin KC, Duarte YAO, Camarano AA, Nunes DP, Fernandes D. Cuidados e limitações funcionais em atividades cotidianas – ELSI-Brasil. *Rev Saude Publica* 2018; 52(Supl. 2):9s.
6. Tarallo RS, Neri AL, Cachioni M. Atitudes de idosos e de profissionais em relação a trocas intergeracionais. *Rev. Bras. Geriatr. Gerontol.* 2017; 20(3):421-429.
7. Minayo MCS. O imperativo de cuidar da pessoa idosa dependente. *Cien Saude Colet* 2019; 24(1):247-252.
8. Jesus ITM, Orlandi AAS, Zazzetta MS. Sobrecarga, perfil e cuidado: cuidadores de idosos em vulnerabilidade social. *Rev. Bras. Geriatr. Gerontol.* 2018; 21(2):194-204.
9. Cesari M, Prince M, Thiyagarajan JA, Carvalho IA, Bernabei R, Chan P, Gutierrez-Robledo LM, Michel JP, Morley JE, Ong P, Rodriguez Manas L, Sinclair A, Won CW, Beard J, Vellas B. Frailty: An emerging public health priority. *J Am Med Dir Assoc* 2016; 17(3):188-192.
10. Lampert CDT, Scortegagna SA, Grzybovski D. Dispositivos legais no trabalho de cuidadores: aplicação em instituições de longa permanência. *REAd* 2016; 22(3):360-380.
11. Debert GG, Oliveira AM. A construção do cuidado do idoso como profissão. *Rev Bras Cien Politica* 2015; 18:7-41.
12. Hirata H, Guimarães NA, Sugita K. Cuidado e cuidadoras: o trabalho de care no Brasil, França e Japão. *Sociologia e Antropologia* 2011; 1(1):151-180.
13. Minayo MCS, Figueiredo AEB. *Manual de pesquisa "Estudo situacional dos idosos dependentes que residem com suas famílias visando a subsidiar uma política de atenção e de apoio aos cuidadores"*. Rio de Janeiro: Fiocruz; 2018.
14. Minayo MCS. *Pesquisa social: teoria, método e criatividade*. Petrópolis: Vozes; 2016.
15. Minayo MCS. *O desafio do conhecimento. Pesquisa Qualitativa em Saúde*. 12ª ed. São Paulo: Hucitec; 2017.
16. Diniz MAA, Melo BRS, Neri KH, Casemiro FG, Figueiredo LC, Gaioli CCLO, Gratão ACM. Estudo comparativo entre cuidadores formais e informais de idosos. *Cien Saude Colet* 2018; 23(11):3789-3798.
17. Silva CF, Silva JV, Ribeiro MP. Cuidadores formais e assistência paliativa sob a ótica da bioética. Rev. Bioét. 2019; 27(3):535-541.
18. Barbosa LM, Noronha K, Spyrides MHC, Araújo CAD. Qualidade de vida relacionada à saúde dos cuidadores formais de idosos institucionalizados em Natal, Rio Grande do Norte. *Rev. Bras. de Estudos de População*. 2017; 34(2):391-414.
19. Kalanlar B, Alici KN. The effect of care burden on formal caregiver's quality of work life: a mixed-methods study. *Scand J Caring Sci* 2019; 12 [Epub ahead of print]. [cited 2020 Jun 01]. Avaliable from: https://doi.org/10.1111/scs.12808.
20. Shiba K, Kondo N, Kondo K. Informal and Formal Social Support and Caregiver Burden: The AGES Caregiver Survey. *J Epidemiol* 2016; 26(12):622-628.
21. Martins G, Corrêa L, Caparrol AJS, Santos PTA, Brugnera LM, Gratão ACM. Características sociodemográficas e de saúde de cuidadores formais e informais de idosos com Doença de Alzheimer. *Esc. Anna Nery* 2019; 23(2):e20180327.
22. Lopes RA, Coelho MAGM, Mitre NCD. Cuidadores de instituições de longa permanência para idosos: dor, ansiedade e depressão. *Fisioterapia Brasil* 2013; 14(2):117-121.
23. Terassi M, Rossetti ES, Luchesi BM, Gramani-Say K, Hortense P, Pavarini SCI. Fatores associados aos sintomas depressivos em idosos cuidadores com dor crônica. *Rev. Bras. Enferm*. 2020; 73(1):e20170782.
24. Griffiths AW, Wood AM, Tai S. The prospective role of defeat and entrapment in caregiver burden and depression amongst formal caregivers. *Personality and Individual Differences* 2018; 120(1):24-31.
25. Manzini CSS, Brigola AG, Pavarini SCI, Vale FAC. Fatores associados à resiliência de cuidador familiar de pessoa com demência: revisão sistemática. *Rev. Bras. Geriatr. Gerontol.* 2016; 19(4):703-714.
26. Hedler HC, Faleiros VP, Santos MJS, Almeida MAA. Representação social do cuidado e do cuidador familiar do idoso. *Rev. Katálysis*. 2016; 19(1):143-152.
27. Marigliano RX, Gil CA. O cuidador formal domiciliar de idosos: aspectos psicológicos e vivências emocionais. *Mais60- Estudos sobre Envelhecimento* 2018; 29(72):26-47.
28. Areosa SVC, Henz LF, Lawisch D, Areosa RC. Cuidar de si e do outro: estudo sobre os cuidadores de idosos. *Psic., Saúde & Doenças* 2014; 15(2):482-494.
29. Charles L, Brémault-Phillips S, Parmar, J, Johnson M, Sacrey LA. Understanding How to Support Family Caregivers of Seniors with Complex Needs. *Can Geriatr J* 2017; 20(2):75-84.
30. Carvalho EB, Neri AL. Padrões de uso do tempo em cuidadores familiares de idosos com demências. *Rev. Bras. Geriatr. Gerontol.* 2019; 22(1):e180143.
31. Nunes DP, Brito TRP, Corona LP, Alexandre TS, Duarte YAO. Idoso e demanda de cuidador: proposta de classificação da necessidade de cuidado. *Rev. Bras. Enferm*. 2018; 71(Supl. 2):844-850.
32. Spasova S, Baeten R, Coster S, Ghailani D, Peña-Casas R, Vanhercke B. *Challenges in long-term care in Europe, a study of national policies*. Brusssels: European Commission; 2018.

33. Debert GG; Daniliaukas M. A construção do cuidado do idoso como profissão. In: *Anais do Seminário Internacional Fazendo Gênero 11 & 13th Women's Worlds Congress*; 2017; Florianópolis. p:1-12

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