

Between State, society and family: the care of female caregivers

Entre o Estado, a sociedade e a família: o care das mulheres cuidadoras
Entre el Estado, la sociedad y la familia: el care de las mujeres cuidadoras

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ABSTRACT

Objective: to investigate the care provided by family female caregivers of elderly dependents who have been monitored by public home care and its social repercussions, discussing the facets between State, society and families. **Method:** descriptive cross-sectional study, with 45 caregivers of elderly patients accompanied by Home Care Services. Data were collected by means of a structured script. The discussion was elaborated in light of the works "*Cuidado e cuidadoras: as várias faces do trabalho do 'care'*" (Care and female caregivers: the several faces of the care work) and "*Gênero e trabalho na França e no Brasil*" (Gender and work in France and Brazil). **Results:** Most caregivers were women (95%) who performed home care at several places and incorporated hospital equipment into everyday life. They have been caregivers for four and a half years, working 18 hours a day on average; they presented average age of 55 years; 82% were ill, and 43% had no income. **Conclusion:** the study demonstrated the relevance of the care of female caregivers to society as well as their invisibility to public health and social policies.

Descriptors: Caregivers; Women; Frail Elderly; Home Care Services; Public Policies.

RESUMO

Objetivo: investigar o care realizado por cuidadoras familiares de idosos dependentes que estão em acompanhamento pela atenção domiciliar pública e suas repercussões sociais, discutindo as facetas entre Estado, sociedade e famílias. **Método:** pesquisa transversal e descritiva, com 45 cuidadoras de idosos acompanhados em Serviços de Assistência Domiciliar. Dados coletados por meio de roteiro estruturado. A discussão foi elaborada à luz das obras, *Cuidado e cuidadoras: as várias faces do trabalho do care* e *Gênero e trabalho na França e no Brasil*. **Resultados:** Majoritariamente, as cuidadoras eram mulheres (95%), realizavam diversos cuidados domiciliares e incorporaram equipamentos hospitalares ao cotidiano. Dedicavam-se, em média, 18 horas por dia; cuidavam, em média, há quatro anos e meio; possuíam idade média de 55 anos; 82% estavam adoecidas; e 43% não possuíam renda. **Conclusão:** demonstrou-se a relevância do care das mulheres cuidadoras para a sociedade, bem como sua invisibilidade perante políticas públicas sociais e de saúde.

Descritores: Cuidadores; Mulheres; Idoso Fragilizado; Serviços de Assistência Domiciliar; Políticas Públicas.

RESUMEN

Objetivo: investigar el care realizado por cuidadoras familiares de ancianos dependientes que están en seguimiento por la atención domiciliar pública y sus repercusiones sociales, discutiendo las facetas entre Estado, sociedad y familias. **Método:** investigación transversal y descriptiva, con 45 cuidadoras de ancianos acompañados en Servicios de Asistencia Domiciliar. Datos recogidos a través de un guión estructurado. La discusión fue elaborada a la luz de las obras "*Cuidado e cuidadoras: as várias faces do trabalho do care*" y "*Gênero e trabalho na França e no Brasil*". **Resultados:** La mayoría de las cuidadoras eran mujeres (95%), realizaban diversos cuidados domiciliarios e incorporaron equipos hospitalarios al cotidiano. Se dedicaban en promedio 18 horas al día, cuidaban había cuatro años y medio, tenían edad media de 55 años, el 82% estaba enferma, y el 43% no tenía ingresos. **Conclusión:** se demostró la relevancia del cuidado de las mujeres cuidadoras para la sociedad así como su invisibilidad ante políticas públicas sociales y de salud.

Descritores: Cuidadores; Mujeres; Anciano Frágil; Servicios de Atención de Salud a Domicilio; Políticas Públicas.

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INTRODUCTION

Demographic and epidemiological transitions, characterized by increased life expectancy, increased morbidity and mortality due to chronic diseases, in addition to falling fertility and birth rates, result in a change in the age structure in Brazil⁽¹⁾ and in the world⁽²⁾. Aging and chronic illness culminate in the functional incapacity of the elderly and, consequently, in the dependence on a caregiver⁽³⁾. Global aging has and will have wide-ranging effects on social, economic and health systems⁽⁴⁾, posing a challenge for social security, economic growth and health actions financing, especially in developing countries, due to socio-economic conditions⁽²⁾.

In 2003, the Senior Citizen Statute⁽⁵⁾ established as elderly the person who are 60 years old or older, and it was considered a socio-legal advance in defense of rights of the elderly, especially in the sense of social policies for their inclusion⁽⁶⁾. It has been established that it is:

Obligation of the family, community, society and Government to assure the elderly, with absolute priority, of exercising the right to life, health, food, education, culture, sports, leisure, work, citizenship, freedom, dignity, respect, and family and community coexistence⁽⁵⁾.

However, no priorities have been established for the implementation of the rights, nor have there been sources for their financing. Thus, the costs of the proposed measures are shared with society, especially by making families responsible, a fact that may threaten intergenerational solidarity⁽⁶⁾, that is, the way that different generations reciprocally support and relate to each other throughout lifetime. The interest of this study in deepening into this subject lies in the fact that it is closely related to the devaluation of the care⁽⁷⁾.

This caregiving is called 'care' in Helena Hirata's work⁽⁸⁾. The adoption of this designation was due to the polysemy of the term and its limitation of meaning when translated in a therapeutic connotation, or even in political denotation. By preserving the term 'care,' the author seeks to keep its synonyms, such as caregiving, concern, attention to the other, caring for the other and worrying, including any type of personal attention, constant and/or intense, which seeks to improve the well-being of the one who is its object⁽⁸⁾.

In recent years, the expansion of professional activities related to care has been occurring⁽⁹⁾ internationally. In 2011, in Brazil, it became possible to establish exclusive services and teams for Home Health Care (AD) within the Unified Health System, due to the possibility of financing through the *Programa Melhor em Casa* (Better at Home Program). AD is the modality of health care that assures the continuity of care at home, developing health promotion, prevention and treatment of diseases, besides rehabilitation and palliation⁽¹⁰⁾.

Home Care Services (SADs) give assistance by means of domiciliary visits, with minimum frequency of one visit per week⁽¹⁰⁾, acting especially in orienting caregivers⁽¹¹⁾. The majority of the population served is the elderly with health fragility, and the presence of a caregiver is essential⁽¹¹⁾. Thus, it is the family that is responsible for the continuity of the care of elderly dependents at home⁽¹²⁾. This caregiver may be a member of the family or neighbor, who, even without being related, takes care of the person voluntarily⁽¹³⁾.

It is observed that female caregivers are predominant^(3,7-8,12-13), what reinforces women's culturally attributed social role related

to household tasks and health care of family members⁽¹²⁾. From this point, it is pertinent, in consonance with Helena Hirata and Nadya Guimarães' reflections⁽⁸⁾, to adopt the term "female caregivers," employing the female sex whenever there is mention to the caregivers of this research as a whole.

The AD is also highlighted as an important point of the health care network for users and caregivers⁽¹¹⁾, and it has been implemented as an abbreviation or replacement for hospital internment, aiming at reducing costs⁽¹⁴⁾. It is also an alternative to reorganize the techno-care model, it becoming a space to manage new ways of caring⁽¹⁴⁾ and a more humanitarian alternative⁽¹⁵⁾ to asylum institutionalization.

OBJECTIVE

To investigate the care provided by family female caregivers of elderly dependents who have been monitored by public home care and its social repercussions, discussing the facets between State, society and families.

METHOD

Ethical Aspects

The development of the study complied with national and international standards of research ethics involving human subjects, and was approved by the Research Ethics Committee. At the time of the data collection, the objectives of the study and the Informed Consent Form were presented to the participants.

Study design, place and period

This is a descriptive cross-sectional study. Data collection has been performed at home, between March 2016 and January 2017, from female caregivers of elderly dependents monitored by three SADs in the city of Juiz de Fora, located in the countryside of the State of Minas Gerais. The city has a population of 516,247 inhabitants, and the elderly represent 13.6% population⁽¹⁾.

Sample and inclusion and exclusion criteria

The selection of the participants was based on SAD database, and the following inclusion criteria were need of being the main family caregiver of the dependent elderly (aged 60 or above), registered on SAD database, for more than one month; 105 dyads were found with the search. Thirty-four caregivers were excluded after application of the exclusion criteria, namely: 18 years old or below (n - 01); presence of caregiver (s) contracted in the 24 hours attending the elderly at home (n - 06); unsuccessful contacts after three attempts on different days and shifts (morning, afternoon and night), or nonexistent phones and/or wrong address (n - 15); caregivers of hospitalized elderly (n - 08), and those who refused to participate (n - 04). The remaining 71 elderly patients were assessed through the Barthel scale for dependence, and 26 were excluded from the study because they were classified as independent (n - 26). Thus, 45 caregivers of elderly dependents participated in this study.

Study protocol

Data collection was performed through a structured script containing information on caregivers' role and

socioeconomic-demographic conditions. The variables of interest were: 1) sociodemographic characteristics: sex (elderly and caregiver); age (elderly and caregiver); degree of education (caregiver); relationship between the caregiver and the elderly; work status (caregiver); caregiver income in relation to total family income; 2) Illnesses of the caregiver and of the elderly; 3) Support to the caregiver: taking care of more than one person (children or other dependent); care activities; equipment incorporated into home; time as caregiver (months); daily care time; housework tasks, and change of occupation to take care of someone.

Barthel scale was applied to verify the functional dependence of each elderly, and the information needed was given by the caregivers. Bartel scale it is an international scale that has been validated for the Brazilian context, and evaluates the functional dependence in daily living activities. Each item is scored according to the person's ability to perform basic activities of daily living: feeding, bathing, personal hygiene, clothing, urinary and bowel elimination, toilet use, passage from bed to chair, ambulation (using the wheelchair if it has to be used) and go up and/or down stairs. In each item, the patient is assigned a score of 0, 5, 10 or 15, depending on the time used to perform the task or need for help, and the range varies from 0 (completely dependence) to 100 (completely independence)⁽¹⁶⁾. From scoring, the following classification was used: independence (100 points), mild dependence (60 to 95 points), moderate dependence (40 to 55 points), severe dependence (20 to 35 points) or total dependence (< 20 points)⁽¹⁷⁾. The elderly classified according to Barthel index as having mild, moderate, severe and total dependence were considered functionally incapable, and those without functional disability were classified as independent.

Analysis of results and statistics

Descriptive data analysis and characterization of the female caregivers' profiles were performed with SSSP (*Statistical Package for the Social Sciences*) software. Numerical variables (elderly age; caregiver age; daily care time, and time as caregiver) were described by mean and standard deviation, median and amplitude. Categorical variables (characterization) were described and arranged in frequency tables, with absolute frequency (n) and percentage (%) values. The discussion was elaborated in light of the works "*Cuidado e cuidadoras: as várias facetas do trabalho do 'care' (8)*" and "*Gênero e trabalho na França e no Brasil (18)*".

RESULTS

The elderly had a mean age of 80.45 years (SD of 9.73); 36 were female (80%), and the mean disability measured by the Barthel scale was 18.44 (SD of 25.95), minimum of zero and maximum of 80 points, and 23 elderly patients (51%) presented total dependence (zero points) (Table 1). The predominant disabling diseases were: stroke (16 elderly patients or 35.6%) and dementia (nine elderly patients or 20%).

Regarding the 45 caregivers, 43 were women (95%) and only two men, son and husband, assumed the role of caregivers; the other female caregivers were: two granddaughters, two friends, one mother, one sister, one daughter-in-law, one ex-wife and one niece.

Table 1 – Classification in relation to the degree of dependence of the functionally dependent elderly assisted by public Home Care Services, Juiz de Fora, Minas Gerais, Brazil, 2016-2017 (N = 45)

Variable	n	%
Mild dependence	6	13.33
Moderate dependence	5	11.11
Severe dependence	4	8.89
Total dependence	30	66.67
Total	45	100.00

Note: Classification according to Loredó-Figueroa; et al, 2016.

Table 2 – Characteristics of the elderly, family caregivers, and characteristics of the role of female caregivers of the functionally dependent elderly assisted by the public Home Care Services, Juiz de Fora, Minas Gerais, Brazil, 2016-2017 (N = 45)

Variable	n	Mean	SD	Min.	Med.	Max.
Elderly						
Age (years)	44	80.45	9.73	61.00	81.00	98.00
Caregiver						
Age (years)	45	54.84	12.54	32.00	54.00	87.00
Time as caregiver	45	54.47	118.44	1.00	24.00	792.00
Care weekly hours	44	125.86	49.49	10.00	146.00	168.00

Note: SD: Standard deviation; Min.: Minimum; Med.: Median; Max.: Maximum.

Female caregivers had a mean age of 54.84 years (SD of 12.54); 24% were elderly; five were in the age group of 60 to 69 years (11%), four in the group between 70 and 79 years (9%), and two were 80 years or above (4%). They have been working as caregivers for four years and a half on average, ranging from one month to 66 years. The female caregiver who has played this role for 66 years is the mother of two elderly women who were born with special needs, remaining completely dependent throughout their lives. An average of 125.86 hours per week has been devoted to caregiving, corresponding to approximately 18 hours of daily dedication. Almost half of them were caregivers for 24 hours a day. Only five female caregivers worked for a period inferior to eight hours a day (Table 2).

Only two female caregivers who worked had a formal labor bond (4.44%). Female caregivers who did not work and had income through social security benefits were retirees, pensioners, or received disability insurance. The 23 female caregivers classified as unemployed (37.78%) were those who had no income and were solely dedicated to caregiving. Previous to the work of taking care of the elderly, six female caregivers had no income and dedicated themselves to household tasks, and another 11 interrupted their work activities according as started

caregiving (24.44%). However, the report of the change in the labor status in order for the caregiver to start taking care of someone occurred 23 times (51.11% of the cases). In addition to the 11 female caregivers who had stopped working, 12 female caregivers have reduced workloads and, consequently, income (they have chosen to leave a work bond or change from formal work to informal work, or, if they already worked informally, to reduce the workload). Moreover, 19 female caregivers took care of someone else in addition to the elderly dependents (Table 3).

Table 3 – Socioeconomic-demographic characteristics of the functionally dependent elderly and family caregivers, and characteristics of the role of female caregivers of the functionally dependent elderly assisted by public Home Care Services, Juiz de Fora, Minas Gerais, Brazil, 2016-2017 (N = 45)

Variable	n	%
Elderly		
Sex		
Female	36	80.00
Male	9	20.00
Age group		
60-69	8	17.78
70-79	9	20.00
80+.	28	62.22
Caregiver		
Sex		
Feminino	43	95.56
Masculino	2	4.44
Age group		
< 50	15	33.33
50-59	19	42.22
60+.	11	24.44
Kinship (caregiver in relation to the elderly)		
Son/daughter	30	66.67
Spouse/ partner	6	13.33
Other female caregivers	9	20.00
Schooling		
0 to 5	12	26.67
6 to 11	23	51.11
12+.	10	22.22
Paid work		
Yes	10	22.22
Unemployed	17	37.78
Social Security benefits	18	40.00
Income in relation to total family income*		
No income	17	43.59
50% or less	17	43.59
51% to 99%	4	10.26
100%	1	2.56
Change of occupation to take care of someone	23	51.11
Caregiver takes care of someone else	19	42.22
Illness report	37	82.22

Note: *n = 39 (six female caregivers were not considered)

As for family income, three elderly patients had no income (6.67%); in six families the elderly were the only source of income (13.33%); income of five elderly patients was not reported. Another three elderly patients (6.67%) benefited from the continuous provision set forth in the Organic Law of Social Assistance. In relation to female caregivers, 17 had no income (43.59%), and one was the only responsible for family support (2.56%) (Table 3).

Table 4 – Hospital equipment incorporated into the home of family caregivers of elderly dependents assisted by the Home Care Services, Juiz de Fora, Minas Gerais, Brazil, 2016-2017 (N = 45)

Variable	n	%
Diapers	36	80.00
Bath chair	31	68.89
Special mattress	30	66.67
Wheelchair	29	64.44
Hospital bed	27	60.00
Nebulizer	22	48.89
Oxygen	12	26.67
Crutch/walker/cane	9	20.00
Enteral catheter	7	15.56
Gastrostomy	7	15.56
Suction pump	4	8.89
Indwelling catheter	2	4.44
Tracheotomy	1	2.22
Other pieces of equipment	16	36.36

Table 5 – Care activities of family caregivers of elderly dependents assisted by the Home Care Services, Juiz de Fora, Minas Gerais, Brazil, 2016-2017 (N = 45)

Variable	n	%
Housework (who does it)		
You	33	73.33
Spouse or partner	1	2.22
Daughter	2	4.44
Sister	1	2.22
Another female relative	4	8.89
Housekeeper	4	8.89
Bath on the bed	15	33.33
Bath on the chair	26	57.78
Assistance when bathing	10	22.22
Oral hygiene	32	71.11
Intimate hygiene and/or diaper change	37	82.22
Oral feeding	13	28.89
Catheter feeding	14	31.11
Bandage	20	44.44
Oral or catheter medication	37	82.22
Injectable medication	3	6.67
Oral/nasal secretions aspirations	4	8.89
Tracheotomy secretions aspirations	1	2.22

With regard to illness, 37 female caregivers reported illnesses (82.22%), mostly chronic, and only one reported an acute illness (dengue). The most prevalent illnesses were: systemic arterial hypertension (28 female caregivers or 62.22%); mood disorders

(14 female caregivers or 31.11%); use of antidepressants or anxiolytics (reported by 18 female caregivers or 40%); diabetes mellitus (eight female caregivers or 17.78%), dyslipidemia (seven female caregivers or 15.56%) and dorsopathy (six female caregivers or 13.33%). We can highlight the presence of two or more diseases in 23 of the 37 female caregivers (86.48%), two female caregivers with neoplasia, besides the presence of complications such as vascular accident, acute myocardial infarction, congestive heart failure, chronic kidney disease, and diabetic neuropathy. As for hospital medical equipment, it was found that all households had one or more than one type of equipment or medical procedure incorporated (Table 4).

Other pieces of equipment/procedure mentioned were: glycosometer, industrialized enteral diet, digital sphygmomanometer, stethoscope, oxygen concentrator, oxygen cylinder, pulse oximeter, infusion pump and bed rails. Female caregivers took care of people through several activities, listed in Table 5 below. In addition to these activities, they performed control of vital signs, saturation and capillary glycemia, and preparation of homemade diets for tube feeding.

DISCUSSION

Care activities are mostly performed by women within families or in public or private institutions, either by nursing professionals or by family female caregivers. This is due to the fact that these "qualities" are socially attributed to the feminine sex as "innate" or "natural," developed in the domestic sphere, as opposed to the masculine qualifications learned and exercised in public spaces⁽⁸⁾. The characteristics of the above-mentioned care work, and the relationship between the womankind and care, show the complexity of the care work and the difficulty in understanding the boundaries between their different dimensions: love, affection, emotions are not in the exclusive domain of families; and caregiving, doing, and techniques do not seem to be in the exclusive domain of care female workers⁽¹⁹⁾.

Thus, not without motivation, care in society is established mainly within the family institution, in the private sphere, affirming the result of the research in which the majority of caregivers are daughters, that is, 29 of them (64.44%). These data are consonant with the results of national and international studies on female caregivers of elderly patients^(13,20-21). This finding is the repercussion of the social representation that families, as expressed in the Senior Citizen Statute, should be the main responsible for taking care of their elderly members. Although the State recognizes the importance of public policies aimed at the elderly, and the public sphere partially assumes their care, as in the AD programs, there is still the absence of the State and policies specifically aimed at female caregivers, attesting the non-recognition of this category of major relevance before population aging.

Another reinforcement of the representation of the duty of families as the main responsible for taking care of their elderly members lies in the idea that the elderly want to be taken care of by them. This means old age seen as a matter for families, which should be helped by public power in this task; thus, elderly people end up not having visibility as subjects of rights. Thus, betting that the wellbeing in old age is in home seclusion and that the family will have help from the state in this task,

so that to hire a domestic worker, for instance, is to postpone inconsequently both the reflection and the innovative practical proposals for a well succeed aging experience⁽⁸⁾.

Contrary to the designation of the national AD program – Better at Home Program –, under what perspective would it be better for the elderly people to stay at home under the sole responsibility of their relatives? Delegating responsibility only to the family is very burdensome for society, for the family, for the elderly and their caregivers. However, AD programs certainly help remedy care gaps to elderly dependents that are discharged from hospital and still need continuous care.

The female caregivers of the research had a mean age of 54.84 years, consistent with the national⁽²²⁾ and international literature⁽²⁰⁾. The reduced number of children or their absence in contemporary families, in addition to the process of population aging, prognosticate that the tendency in Brazil is the increase in the number of spouses or another elderly person assuming the role of caregiver, what progressively means the elderly taking care of the elderly⁽²³⁾. This is a worrying fact, since caregivers' advanced age and their own aging process, together with the care attributions, potentially lead to insomnia, fatigue, illness, worse performance in daily living activities, making it difficult for these caregivers to provide quality care⁽²³⁾, also compromising their own quality of life.

Regarding caregiver sex, countless researches are consensual about the predominance of the womankind in the home care^(3,7-8,12-13,24). The care work is an example of sex, class and racial inequalities, since caregivers are mostly women, poor, black, and many times, immigrants (internal or external migration)⁽²⁵⁾. Affirming these results, this research presents womankind preponderance, indicating that women have accumulated functions, or even have left their professional life to dedicate themselves exclusively to home care.

How to overcome these inequalities and change the scenario of differences related to labor sexual division existing in contemporary societies? Helena Hirata's hypothesis is that we cannot change the sexual division of professional work without changing the division of domestic work, power and knowledge in society⁽²⁶⁾. There have been changes in the distribution of domestic and care work between men and women in the domestic sphere over the last twenty years, but they seem to be much slower than in professional work⁽²⁶⁾. Women have been taking care of the elderly, children, the sick, and those physically and mentally handicapped within the domestic space, in the so-called "private" sphere, free of charge and performing the work because of love. The development of professions related to care, commodification and externalization of this work was a consequence, on the one hand, of population aging and, on the other hand, of women mass insertion into the labor market.

Womankind work does not only focus on a definition of capital, since it is no longer a simple production of objects and goods and becomes the "production of living in society." It can be said that this definition of womankind work recovers the care work dignity, even though it does not exclude the fact that it is also unqualified and unrecognized work, and that women do not usually choose to do it or not⁽¹⁸⁾. There is no justification for female dominance in this role; therefore, it is necessary to reconstruct paradigms of a society in which women no longer accept priority (or even exclusive) responsibilities over family life⁽¹⁸⁾.

Two explanations have been formulated in the debate concerning the devaluation of the care work: feminist theories, which analyze the continuity of the devaluation of domestic work and care within the family, executed by women free of charge; and the theory that the vulnerability and lack of citizenship of elderly dependents and handicapped patients have impact on caregivers' status⁽⁷⁾. Few researches deal with the sex dimension in the care work. However, it is clear from the examples presented that taking this issue into account is fundamental, including for training the caregivers for their competence and full qualification to perform this professional activity⁽¹⁹⁾.

The female caregivers reported mainly chronic illness (82%), with preponderance of systemic arterial hypertension, followed by mood disorders. In Brazil, the prevalence of hypertension in elderly women with low schooling is higher when compared to the general population⁽²⁷⁾; however, the percentage of hypertensive female caregivers found in this study is even higher. Regarding mental illness, the literature shows that female caregivers are more likely to develop mood disorders, especially depressive and anxious symptoms^(21,28). In this study, mood disorders were reported by 31% female caregivers.

All female caregivers interviewed incorporate medical and hospital equipment into home and care. It is considered that incorporation of equipment may be related to female caregivers' search for attending the elderly with better quality, giving them greater autonomy or even life maintenance, as, for example, the use of special mattresses preventive of injuries by pressure, walkers or feeding tubes. A study on caregivers experience in the practice of home care says that the special needs of care, such as enteral diet, diapers, mattress, hospital bed and tracheal aspirator, when not made available by the public health services, affect the family budget and the care subjects' quality of life⁽¹⁵⁾.

Female caregivers were responsible for a significant and continuous part of the care, performing complex tasks such as bandages, aspiration of oral, nasal and tracheal secretions, monitoring of vital signs, saturation and glycemia, medication administration and tube feeding, among others. These data are in line with the study that reveals that due to the complexity of care provided to the elderly and the need for continuous assistance, caregivers become exhausted and difficulties to perform the activities arise, as well as negative consequences for the care itself⁽¹⁵⁾.

In this way, caregiving has a partnership with nursing, which is established according as the caregiver continually takes care of someone. Here we mention the ethical question of the threshold between at which extent nurses are allowed to train a caregiver, and what is the exclusive responsibility of the Nurse and the Nursing team. On the other hand, if there is no professional available to perform caregiving, who will do it⁽²⁹⁾? From another perspective, the caregiver also becomes a person who demands Nursing care according as she/he needs guidance on the performance of care and, above all, on how to maintain her/his own health.

In addition to the care work, 73% female caregivers accumulated household tasks, such as cleaning the house, preparing meals and washing clothes. Another relevant social fact is that 42% female caregivers took care of someone other than the dependent elderly, namely: another elderly, adults with disabilities, or children. It is necessary to change the representation

according to which the competences mobilized in the care work are the same or a mere extension of the domestic functions socially attributed to women⁽⁸⁾. The care provided by the female caregivers in this research involved both household tasks and knowledge for the accomplishment of Nursing procedures and complex care, besides incorporation of technologies and medical-hospital equipment.

Care is definitely a question of social and academic relevance, because it is a matter of providing a decent aging to the population and, at the same time, a decent job to those who take care of someone⁽⁸⁾. Overcoming inequalities through public policies and the actions of feminist movements are two possible ways followed by a number of industrialized societies⁽²⁶⁾.

Female caregiver labor market situation is little explored in the literature. In this study, the most representative category was the female caregiver receiving Social Security benefits (40%), a percentage well above that found in a 2008 national survey. The high frequency of female caregivers who receive social benefits may be related to the fact that they become caregivers because these women would not be working and would have more time available than other family members. In this situation, home care would be performed by women, even if elderly or ill, who maintain the care work.

Next, there is the category of female caregivers unemployed and without any source of income (37%). Only ten female caregivers (22%) were paid employees, data similar to those found in another national study with female caregivers of elderly dependents⁽¹³⁾. The high unemployment rate among the female caregivers indicates that significant changes in the families' lifestyles to take care of the elderly dependents cause the female caregivers to leave formal work⁽²⁴⁾.

Not working may lead to a greater burden on the female caregiver, due to financial stress⁽³⁾, loneliness and social isolation⁽³⁰⁾ caused by the exclusive dedication to home care. Another relevant point of leaving work is that female caregivers often become dependent on the benefit or retirement of the elderly⁽¹⁵⁾.

In contrast, female caregivers who keep on working have a substantial productivity loss. The US national profile of family female caregivers of the elderly with disabilities discusses the issues of absenteeism, presenteeism and productivity loss. Care activities have caused one in five caregivers to miss work at least once in a month⁽²⁰⁾. However, as a whole, the work productivity loss is related to presenteeism rather than to absenteeism, since it is associated with the reduction of productivity when working⁽²⁰⁾.

Among the female caregivers of this research, more than a half changed their work occupation, leaving work or reducing workload, and therefore, income. Previous research identified that 74.2% female caregivers reported having worked outside the home and, at that moment, were exclusively engaged in domestic activities and without remuneration⁽¹³⁾. Female caregivers were not able to maintain the labor bond, since the home care overload made it difficult to remain employed⁽³⁾.

When reflecting on labor and income data, we found that 43.5% female caregivers had no income; the elderly was the only source of income in 13.3% families; and 24.4% female caregivers left work to take care of the elderly. Then, the question arises: how will these female caregivers sustain themselves after years of exclusive dedication to care? If the role of caregiver is so

relevant socially and to the State, why could not this caregiving, from an economic point of view, be paid and has labor rights?

All these results attest the importance of strategies and policies in the workplace to support working family female caregivers, such as paid family leave⁽²⁰⁾. In addition, low employability and lack of income deserve reflection in the short and medium term, particularly in relation to social programs and social security conditions⁽²⁴⁾. Thus, it is observed that the care of this study implies in interpersonal relationships and feelings, requiring women's abdication of years of their own life planning. It is a work that has relevant social character. The remuneration for the care would be socially and morally legitimate as a social recognition of both the care and the need for female caregivers⁽⁸⁾.

However, the remuneration for the care would imply rethinking the role of the State in the construction of ways of labor regulation and professionalization of care in each case⁽⁸⁾. We can consider from the predominance of families (unpaid caregivers) to the private market (formal caregivers hired). With regard to remuneration, should caregivers receive from the State or from the private client? In relation to professionalization, how to guarantee qualified assistance to the elderly? These are still questions with answers underway, which stimulate the reflection on care not only occurring as an exclusive obligation of families and abnegation of women.

Limitations of the study

As limitation, the sample is constituted by convenience and comes from only one type of service, which limits the generalization of the results to the population of caregivers of the elderly in general. This sample size was due to the dependence on SAD database and on the inclusion criteria, although the data collection period has been extended.

The research provides recommendations for future investigations, in particular with longitudinal design and intervention studies involving caregivers.

Contributions to the areas of nursing, health or public policy

The discussion of the research contributes to the analysis of health care policies present in the collective sphere by raising the question of the need for care directed to a population in evident aging process, with chronic illnesses and the need for long-term care. Especially for nursing professionals, it gives visibility to the complex and devalued social reality of the female caregivers and their health needs, emphasizing the relevance of the women care for elderly dependents and, in particular, for society. The study extends the research conducted strictly focused on the elderly by discussing the social and health issues of family female caregivers and home care.

CONCLUSION

Despite the limited sample of the study, it provides reflections on the social issues of the care from family female caregivers to elderly dependents receiving public AD. The profile of caregivers is as follows: women (95%), daughters (66%), within the 50-year age group, with low schooling, sick (82%), who do not have paid work and dedicate themselves exclusively to caregiving.

As a conclusion, the relevance of the care work of female caregivers to society is presented, as well as their invisibility to public health and social policies. In addition, the research provides reflections that contribute to the (re) elaboration of a social pact between caregivers, society and the State, especially towards the caregiver and, therefore, towards the construction of a more equitable society "for all."

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