

Caring for those who care for dependent older adults: for a necessary and urgent policy

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Abstract *The situation of caregivers and family caregivers of dependent older adults is presented and discussed, highlighting their dedication, problems, and possible recommendations to value them. The task of caring is known to be eminently feminine, invisible, unpaid, but affects society as a whole. Policies of some European countries, Canada, and the United States in favor of male and female caregivers are described. However, most existing support models have gaps. The laws and regulations enacted have been poorly comprehensive, inorganic, and the family remains responsible for long-lived relatives who have lost their autonomy. In many countries, besides other measures, the tendency is to integrate the family care as the first PHC level, universalizing support to caregivers. One must not be forgotten that the tendency to keep dependent older adults at home is acquiescence to their desire, but it also hides the delegation of responsibility from the State to families through dehospitalization and deinstitutionalization policies. In Brazil, the issue has not yet entered the public policy radar, although it is urgent because of the accelerated increase of the elderly population, particularly those aged 80 and over.*

Key words *Health policies, Social policies, Dependent elderly, Informal caregivers*

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Introduction

This reflective essay aims to discuss the informal work of mostly female caregivers of dependent older adults and propose supporting evidence for a policy that values them¹. The period covered by the reflection dates back from post-World War II when European countries created and institutionalized their social welfare systems. These countries introduced care for dependent people and family caregivers into the State's social action agenda.

Fifty years ago, 'family care', also called 'informal care', was unknown as an expression or concept. This began to change when feminist and academic activists in developed countries in the 1970s drew the attention of governments and society to the fact that women were doing unpaid work in most families. The term "informal" was criticized for its social and economic veiling nature. At the same time, this awareness was concomitant with the movement towards the dehospitalization and provision of health services close to the community and within the family²⁻⁴. Thus, in the 1980s and 1990s, informal or family care became a widely recognized term and acquired a position on the health and social assistance policy agenda.

The governments of many countries, particularly those in Europe³⁻⁶, currently consider family care as relevant, not only because it is the most desired by older adults who suffer some or multiple dependences but also because it reduces hospitalization expenses. For this reason, several societies already see it as the last frontier of primary care⁷. Thus, dependence and family care provided, above all, by women, previously restricted to the private sphere, has been gaining importance and is the subject of a vast bibliography, considering that the number of older adults across the planet (less in some African countries) is the one growing the most, both in quantity and longevity⁸.

In places where aging has occurred slowly and persistently, such as the European Union and the countries members of the Organization for Development Cooperation, informal care has been on the agenda since 1996. In 2020, however, for the first time, it gained visibility at a world-class event, the World Economic Forum in Davos, the "richest men's club" in the world. Oxfam⁹ spearheaded the event with the document "Time to Care"⁹, which opened informal care as an issue of assisting older adults and serving the universe of people who could not survive if women did

not support them. This document addressed, in particular, the cultural issue and the exploitation of unpaid female labor.

Here is a summary of what was said. In 2019, 2,153 global billionaires held more wealth than 65% of the global population, 4.6 billion people out of more than seven billion. One of the reasons for this widening gap is the sexist global system that values the wealth of the privileged few at the expense of billions of unpaid, exclusive hours, particularly by women globally, to provide care to people in the invisible homes. Oxfam points out that women and girls around the world devote 12.5 billion hours every day to unpaid care, a contribution of at least US\$ 10.8 trillion a year to the global economy.

Governments worldwide must act to build a human economy [...] that values what matters to society, instead of promoting an endless search for profit and wealth. Investing in national care systems to address the issue of disproportionate responsibility assumed by the work of women and girls, adopting a progressive tax system, with taxes on wealth, and legislating on behalf of those who care, are possible and crucial steps to be taken towards change⁹.

Oxfam⁹ points out that if care continues to be women's natural obligation, they will remain out of the job market, as today, 42% of them of working age are outside the so-called productive sector, while the percentage of men is only 6%, according to data supported by the Research Group of the Credit Suisse Bank¹⁰. These women's invisible activities guarantee the functioning of society and the economy, while their obscurity and lack of recognition perpetuate gender and economic inequality⁹.

The dependent caregiver/elderly dyad issue is an urgent topic for the world and Latin America. According to the Pan American Health Organization (PAHO)¹¹, the number of people in need of long-term care will more than triple in the region in the next three decades. It will rise from the current eight million to 27-30 million by 2050. PAHO¹¹ draws attention to the fact that, while an increase in the longer-lived and dependent population is noted, a vital shortage of formal and informal caregivers and professionals specially prepared health services is observed.

In Brazil, studies based on the National Household Sample Survey^{12,13} anticipated what was discussed at the Davos Forum, saying that if informal care, performed mainly by women, were paid, it would increase the National GDP by 10.3%. Vasconcelos¹⁴ and Küchemann¹⁵ con-

sider that women's responsibility for informal care contributes to foster the understanding that social reproduction is their responsibility and not that of society. Besides undermining an equitable division of responsibilities between men and women, it also influences the absence of priorities in public policies, resulting in the State's silence, the deficit of public services addressed to cover these tasks, and, consequently, increased inequality and poverty. Even when remunerated, care is usually provided by social groups that receive low wages, such as domestic workers in Brazil and undocumented immigrant women in Europe and other countries^{2,5,15,16}.

The issue of informal care exercised by women has a much broader spectrum than the care for older adults: responsibility for children, the home, domestic chores, which, in general, burdens them with a double or triple working day. However, in this paper, the theme is restricted to informal care for dependent older adults, considering that the population over 60 years of age grows the most^{17,18}, with emphasis on the increase of those who reached 80 years or more, stage of life that is more vulnerable from a social and health viewpoint¹⁹. According to IBGE estimates, in 2050, Brazil will have around 77 million care-dependent people (just over a third of the estimated population) among older adults and children²⁰.

Understanding the social relevance and for the health system of the topic at hand, we propose to define the situation of female caregivers and dependent older adults, showing briefly what is being done by some countries to provide support, protection, and dignity to this dyad so fundamental to the present and future society. The choice of countries is justified because they have specific policies to protect all caregivers of dependent people. This paper is a tribute to female caregivers!

The situation of female caregivers and dependent older adults

Female caregivers – Caring stems from social expectations about the family's cultural concept and remains part of women's obligations. No profound cultural changes of the male ethos or significant reforms by the National States alleviate the weight of these so-called obligations²¹ in the vein of global transformations and gender discussions. It usually so happens that, in families, women are chosen as caregivers by the

person receiving care, self-chosen, or even perform this role because there is no other option. In Brazil, their age spectrum ranges from 26 to 86 years¹⁵. These are women who give up their personal, professional, social, and emotional lives. Furthermore, even when her work is bathed in love and recognition, she is impoverished from an economic and social viewpoint and has since then had a restricted and confined existence, solely dedicated to the dependent relative. Those that are supported by some type of income consider this contribution insufficient, and those living on a low income reduce support options in light of the burden of needs. Most say they receive no help from anyone and no economic reward for their dedication²²⁻²⁴.

Caring always affects the caregiver's life. In studies that compare them with the general population, they are represented with worse physical health, more frequent use of medications, high rates of depression and anxiety, stress, distress, dissatisfaction with life, and feeling of overload. Evidence has shown that cognitive impairment and mental illness in older adults are costlier for those caring for them than physical problems^{22,22-25}. The mental health aggravations of people accompanying older adults often exacerbate with care time^{6,22}. Furthermore, caregivers experience an increased expenditure on electricity bills, geriatric and medical supplies, transportation, and home adjustments. As the Spanish Ministry of Health mentions in *Libro Blanco de la Dependencia* ("White Book of Dependence")¹⁶, this reality "places women in a discriminatory situation before protection systems, since they are the ones that benefit from social life the least while producing well-being the most"¹⁶.

Dependent older adults – The World Health Organization²⁶ considers that vulnerable older adults have the following characteristics: age over 80 years; living alone; single women or widows; LTCF residents; socially isolated; without children; with severe limitations or physical, motor, psychological and neurological disabilities; couples over 65 when one of the spouses is disabled or ill, and those living with scant resources. In the several dependence policies in place today, older adults are classified by the severity of their autonomy loss. The most vulnerable are usually those affected by mental illnesses such as depression, Alzheimer's, senile dementia, movement loss, urinary incontinence, insomnia, and are in a terminal state or a condition of social or freedom deprivation^{27,28}.

The European Council, a body of the European Union²⁹, defines dependents as people who, for reasons associated with the reduction or even the lack of some capacity, need to be assisted or helped to carry out daily activities, implying the presence of at least another person for support. Such activities are divided into two categories: basic and instrumental. The first concerns self-care tasks, such as dressing up, eating, doing personal hygiene, and getting around. The second designates activities necessary for personal and social development and favor the integration and participation of the individual in their surroundings, such as shopping, paying bills, maintaining social commitments, using means of transport, cooking, communicating, taking care of their health, and preserving their integrity and security. In Brazil, this same classification is defined in the National Policy for Older Adults³⁰ and the National Health Surveillance Agency (Anvisa)³¹.

Finally, it is essential to note that in Brazil, older adults and their caregivers go through several problems simultaneously, and both are often violated in their rights. Social inequalities create enormous challenges for the provision of services. Many live in inadequate housing and living conditions, and those receiving the minimum wage – today an essential and indispensable benefit – are unable to cover their basic needs for food, medicine, supplies, and transportation. There is also a shortage of health and social service professionals prepared to provide care to the dependent person and support the caregiver, and a lack of technological resources to integrate care, offer adequate information, facilitate tasks, and help in emergencies³².

Policies to support caregivers and informal caregivers

The discussion on the role of the State in supporting caregivers and family caregivers will be seen here at several levels: from the viewpoint of political action, of those who provide care and at the macro-social level. Some countries that have institutionalized or are institutionalizing support for caregivers and family caregivers in their Social Security Systems will be mentioned^{33,34}.

Political action initiatives – The European Union Bloc stands out in addressing aging, treating it not as a problem but as a challenging social phenomenon for its societies. Policymakers in these countries (EU, 2003)²⁹ and those part of the OECD⁸ have been adapting a series of measures to support family caregivers, such as cash bene-

fits, tax exemptions, and forms of legal protection for male and female workers who need flexible hours or ways of working because they are caregivers; integration of social and health services in hospitals, primary care teams, long-term care providers, and professional associations. A growing investment in policies for the innovative use of technologies to improve competence and care is observed.

All the countries of the Bloc are equipped with laws regulating actions whose costs are shared by local administrations, which, in turn, provide the services. For this very reason, operational effectiveness differs widely between and within countries. In general, there is a combination and sharing of social and health care in different policy models^{29,33,34}.

Actions in some selected countries are described here: Scandinavians, because they offer the most universal and inclusive policies; Germany, because it represents a group of conservative states with corporate systems; Spain, as it is culturally closer to Brazil. Then, we comment on the current movements of Canada and the U.S., which are in the process of institutionalizing³⁵ their models.

Scandinavian countries' protection system is the most universal and organized. The State, through the work of social and health services, is responsible for dependent older adults in their homes or other institutions, allowing relatives, if they so wish, to remain active in the labor market. In comparative terms, these countries are, among Europeans, those that offer the highest proportion of home help. Local authorities have broad responsibility for financing, planning, providing services, and providing financial contributions to relatives. Nobody is left without care, but there is ample freedom to accept or not the support of the public service. Currently, according to Johansson and Sundström³⁶ and Larsson et al.³⁷, although it remains solidly anchored in the public service, the combination of family care, governmental organizations, and, more recently, the private initiative in the provision of care is observed. However, the State's responsibility is firm and definitive.

Germany stands out among those that offer a conservative-corporate model³³. In that country, recognizing the individual right to protect dependence predominates, without looking at the beneficiary's financial condition. However, support services for caregivers are provided mainly by private, non-profit institutions. Public administrations only intervene when there is no

provision from these associations. Families can choose to receive support services at home or cash grants, and the latter option prevails. Grants' value varies according to the intensity of the officially recognized dependence. Caregivers are also allowed to take vacations, receiving incentives to do so. All inputs to older adults and caregivers stem from Social Security contributions or public subsidies³⁸⁻⁴⁰.

Spain has a strong presence of social insurance and contributory benefits proportional to the salary. However, the protection given to older adults and dependents, in general, is marked by the strong presence of the family, civil society institutions, and a free universal health system organized regionally and locally. Social care is mainly geared to people with insufficient resources, leaving out the middle class, resulting in critical regional deficits and imbalances⁴¹. At the local level, sponsored by regions or provinces, various forms of support are offered to informal caregivers: in most cases, social work provides a person to relieve the workday of those providing care; in some provinces, the government offers cash assistance to cover the extra expenses for assistance to older adults; and technological devices have been introduced, particularly for monitoring the most fragile older adults and support in emergencies; most locations offer day centers; and there are some innovative initiatives, such as the program called "food on wheels", which produces and distributes scheduled meals to those who live alone, are sick, with little autonomy, relieving them or caregivers from the task of preparing meals^{16,42}.

In *Canada*, home care for older adults is the subject of government action and activism by caregiver associations that claim tax exemptions and pension plans for those who stop working to care for dependent people. The government and society started to consider informal caregivers vital to the health system, as they provide 80% of all home care and 30% for those living in institutions⁴³⁻⁴⁶. The way to serve them is part of federal policy guidelines, but their application varies across 14 jurisdictions. Today, in ten of these provinces, those in need of care receive a living allowance and are free to choose the services and the person to assist them. However, only three of them allow caregivers to use this money to remunerate the caregiver. The Special Commission on Aging⁴⁷ emphasizes that social class is an essential factor in informal caregivers' quality of life in Canada. Those who can pay are always looking for external help, often underpaid, offered

by immigrant women^{21,47}. The estimated cost of unpaid work of informal caregivers amounts to three billion dollars/year.

The *United States* recently enacted Law N° 115-119 of 2018, known as the "RAISE Family Caregivers Act"⁴⁸, which consists of "recognizing, assisting, including, supporting and engaging family caregivers". The law mandates that the United States Department of Health and Human Services (HHS) develop and maintain a strategy that addresses the 43 million informal caregivers who help dependent people without remuneration. It also created an Advisory Board to make it possible. It includes civil servants, representation associations, dependent older adults, and caregivers. Its guidelines are: (1) comprehensive health and long-term care promotion; (2) care centered on the person and family, with a focus on the patient and those providing care, also including them in the planning and evaluation of the services provided; (3) caregiver information and education; (4) financial security of those providing care and receiving care.

According to the American Association of Retired Persons (AARP)⁴⁹, the 43 million family caregivers in the U.S. provide 34 billion hours of care/year, estimated at US\$ 470 billion dollars⁵. A strong presence of civil society organizations is observed in American society's engagement, not only in the provision of services but also in addressing the claims. The liberal state moves forward through these entities. Among other actions, an association called "National Alliance for Caregiving"⁵⁰ ranks the best and worst American states for dependent older adults, encouraging good practices. The promotion of several initiatives has been following the "Family and Medical Leave Act"⁵¹, which has been in effect since 1993 (Clinton administration), which aims to make working hours more flexible and protecting workers when their absence from work occurs for a certain period to promote care. Next are the "Family Caregiver Support Program" created in 2000⁵², which provides a support fund for caregivers, and the "Lifespan Respite Care Act"⁵³, which promotes care for the families of older adults, helping them with the services and costs of care. Currently, the civil society movement pushes the government towards a Social Security reform that benefits family caregivers who must leave their jobs to take on the responsibility of assisting older adults, losing substantial benefits and retirement pensions. It is also essential to cite innovative initiatives of family-centered care models that involve various professional services, as is the case in Minnesota⁵⁴⁻⁵⁷.

What protection and support initiatives are there for family caregivers in Brazil? Unfortunately, a total absence is observed from the viewpoint of an institutionalized public policy. The empirical work carried out by the researchers with several papers in this thematic edition found: (1) a lack of awareness of this social group that they are entitled to social and health protection, (2) no associative and claiming movement; (3) specific and intermittent support from some primary care units that go to homes, which is noted and appreciated by families; and (3) some local initiatives led by health institutions and universities that have been mobilizing themselves with specific and experimental programs to support caregivers⁵⁸. However, these proposals do not have the most resilient aspects of institutionalization: processes, structures, proposed actions with rules and routines, and guidelines for their effectiveness³⁵. Not even a movement (process) that reflects the will of caregivers, social pressure and commitment from the State has been identified.

Some considerations about the analyzed literature

It should be noted that one of the main limitations of this work is the random choice of the narrated cases, which mainly observed the strategic nature of this paper that aimed to highlight the possible courses, established or under construction, in order to have an effective policy for family caregivers. In this sense, some proposals are summarized.

Rodriguez⁴¹ summarizes his vision of the support that caregivers need in three categories: emotional help that reinforces their sense of belonging and self-esteem; information to help them face difficulties; and instrumental support in the tasks they have to perform.

U.S. Lifespan Respite Task Force⁵⁶ listened to more than 150 family caregiver groups. Their demands are more or less similar: (1) to receive a monthly credit to cover expenses that increase with the maintenance of older adults and a voucher that partially rewards them for the care hours they provided; (2) to have a support program that allows them to have scheduled rest, relief from work hours, and vacation time; (3) to have a shuttle service to take their loved ones to the hospital, on a walk, or anywhere else, when necessary⁵⁷.

In Canada, studies by the Health Council⁵⁹ follow the same direction. Research by Mc-

Namara and Rosenwax⁷ and a review by Silva et al.⁶ complete this first survey: (1) to obtain accurate information about the diagnosis of the person they care for; (2) to receive training to act correctly in the provision of care; (3) to have adequate support from health and social assistance professionals, and effective communication channels with them; (4) to have legal and financial support during the time they provide care and also after the loved one dies, so that, if applicable, they can reintegrate into the world of work.

Government responses to the needs of dependent older adults in countries with protection systems are still very insufficient and have gaps. Some of the many causes are: (1) First, there is no social place for these actors, except within the family, where they confine themselves, although a current trend (which has not yet become an action) to integrate family caregivers as PHC's first level of care is observed. (2) Several analysts recognize that the development of laws, regulations, finance, organizational reforms, and the use of technologies has been poorly comprehensive, inorganic, and unsystematic. (3) Although the understanding of the family's valuable service to the dependent older adults has primarily increased, a strong cultural component assigns women the responsibility to care voluntarily and free of charge. (4) This cultural component has the aggravation of silencing and invisibility under which caregivers work. (4) Finally, from the State's viewpoint, the contemporary trend towards dehospitalization and deinstitutionalization combines a lot with older adults' desire to be cared for at home, but this burden is not credited to families. (5) For all these reasons, it is necessary to look at the problems and challenges in their micro and macro-social aspects simultaneously^{3,5,9,35}.

A fundamental step in favor of rights and justice for relatives who provide care to older adults is the development of national care systems, with civil society's full participation. In particular, the inclusion of groups and movements that advocate women's rights. Oxfam's proposal⁹ is to proceed with an integrated care work redistribution with a comprehensive approach to redistributive policies to narrow the gap between rich and poor, men and women.

Over the past few decades, feminist economists, civil society, and care advocates have proposed solutions to radically redefine the priority of this type of work, creating a transformative framework from what they called "4R": (1) *recognition* of the work of unpaid and poorly paid

care, performed mainly by women and girls, as a production with real value; (2) *reduction* in the number of hours dedicated to unpaid care tasks, through access to quality, time-saving equipment requiring less support infrastructure; (3) *redistribution* of unpaid care more fairly within the family, requiring responsibility from the State and civil society in this matter; (4) active *representation* of caregivers in the formulation and implementation of policies, services, and systems that affect their lives.

This text ends with a brief consideration on the Brazilian situation. The 1988 Constitution, the National Policy for Older Adults³¹, and the Statute of Older Adults⁶⁰ consider that family, governments, and society must support this social group. State laws and measures aim to protect older adults, provide subsidies that guarantee their community participation, defend their dignity, care for their well-being, and ensure their right to life.

However, although the State provides some essential health services, care coverage is insufficient, especially concerning informal caregivers. Due to the lack of financial resources that allow recruiting specialized people, care is usually provided by a relative, mostly women or domestic workers who add care to all other functions they perform in the home. The Brazilian State's participation concerning the dependent person is not specific and disappears amid the routine practices of social and health services. It is not comparable to the burden of care, medicines, supplies, and other expenses left to families. No specific initiative in the country benefits family caregivers, while the percentages of older adults over 80 are on the rise. There is an urgent need to promote a clear policy to protect older adults, care providers who take care of them, and value the dignity that longevity in the country requires, without discrimination of class, gender, race, color, and health conditions.

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