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Aging and dependence in Brazil: sociodemographic and care characteristics of older adults and caregivers

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Abstract *This paper aims to identify sociodemographic and care characteristics of dependent older adults, formal and family caregivers in municipalities from different Brazilian regions. A cross-sectional study was carried out with a sample of 175 people, of whom 64 were older adults, 27 formal caregivers, and 84 family caregivers. Semi-structured interviews were conducted with specific questions for each group on the theme of care and dependence. Most older adults were female, aged 80 years or older, with low education and have been dependent for four years or more. Older adults reported feelings of loneliness, pointed out difficulties in medical care, and 29% had only access to Primary Health Care actions. Inequalities, burden, illnesses, and social problems were found among family caregivers. Black females with no formal employment, little or no training for the function, and low remuneration predominated among formal caregivers, and care was associated with domestic chores. We can conclude that gender and race inequalities persist in the care of dependent older adults, and we observed that the rigid social roles assigned to men and women in Brazil persist in the family and work dynamics in caring for the dependent older adults.*
Key words *Aging, Frail older adult, Caregivers, Elderly health*

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Introduction

In recent decades, population aging has been marked by increased life expectancy and reduced birth and death rates in most countries in the world. An increased number of older adults aged 80 and over has been observed, which is a vulnerable stage from the social and physical and mental health standpoint, and loss of autonomy and increased dependence are common[1].

Dependence is the functional incapacity of older adults to perform Basic Activities of Daily Living (BADL), such as eating, dressing, and bathing[2], or the impossibility of performing Instrumental Activities of Daily Living (IADL), such as going to the bank, take the bus, and communicate[3]. In this case, older adults require assistance to carry out these tasks and manage their lives[4].

In Latin America, 40% of older adults require long-term care, and this number will triple in the next thirty years[5]. In 2050, Brazil will have about 77 million care-dependent people, including older adults and children[6], and only 30% of the municipalities had long-term care institutions in 2009, and most were in the southeastern region of the country[7]. Simultaneously, the long-lived and dependent population increases, a shortage of caregivers, professionals, and health services prepared to assist them is observed[8].

In Brazil, most caregivers are relatives, women (spouses or daughters) aged 50 or over, and with physical and emotional proximity to older adults. Work is often uninterrupted and solitary, without the support of public protection services and policies for developing this function. They suffer restrictions in their personal lives, generating overload, illness, unemployment, and withdrawal from the social and affective network[9,10].

In 2002, the caregiver's role was recognized as an occupation by the Ministry of Labor and Income in Brazil. "Caregiver" was the individual who assisted and promoted well-being, health, food, hygiene, education, culture, and leisure for the dependent person. However, the profession is marked by unstable employment relationships, lack of specific preparation, low wages, and long working hours[11].

Despite the elderly social protection policies implemented in the country in recent decades, the State's provision of services is restricted to specific and one-off healthcare actions and assigns to the family the commitment to home long-term care. No specific policy determining the roles of the family and the public service network[12] is available, making both older adults and caregivers vulnerable.

The concept of vulnerability contributes to understanding the situation of older adults and their caregivers, as it refers to the guarantee of citizenship of politically frail people from the perspective of human rights, resulting from the combination of individual, social, and pragmatic domains. Individual vulnerability comprises biological, emotional, cognitive, and attitudinal aspects. Social vulnerability is characterized by cultural, social, and economic aspects that determine opportunities for access to goods and services. The programmatic vulnerability refers to the social resources required to protect individuals from risks to their integrity and physical, psychological, and social well-being[13].

In this study, a group of people involved in the context of dependence and care for older adults was interviewed to understand *first-hand* their situation and vulnerabilities. Thus, this study aims to identify the sociodemographic and care characteristics of dependent older adults, family caregivers, and formal caregivers in eight municipalities from different Brazilian regions.

Methods

Study type

This is a cross-sectional, descriptive study carried out in 2019 in eight municipalities located in the five Brazilian regions: Araranguá (SC), Brasília (DF), Fortaleza (CE), Manaus (AM), Porto Alegre (RS), Recife (PE), Rio de Janeiro (RJ), and Teresina (PI). It is nested in a multicenter research that studied the situation of older adults with physical, mental/emotional, cognitive, or social dependence, and focused on supporting the development of a public policy that serves dependent older adults and their caregivers, which was coordinated by the Oswaldo Cruz Foundation in partnership with Brazilian educational institutions[14].

Sample

An intentional sample of 175 people participated in this study, consisting of 64 dependent older adults, 27 formal caregivers, and 84 family caregivers (Table 1). A "dependent older adult" was considered to be someone aged 60 years or more who, due to the reduced or lack of physical or cognitive capacity, required help in performing BADL or IADL, implying the presence of at least one more person for the provision of care[15].

Physical dependence was considered func-

Table 1. Number of dependent older adults, family caregivers, and formal caregivers interviewed in the survey. Municipalities in different Brazilian regions, 2019.

Municipality/State	Dependent older adults		Family caregivers		Formal caregivers	
	n	%	n	%	n	%
Araranguá (SC)	12	18.8	13	15.5	6	22.2
Belo Horizonte (BH)	7	10.9	11	13.1	0	0.0
Brasília (DF)	10	15.6	10	11.9	0	0.0
Fortaleza (CE)	10	15.6	11	13.1	5	18.5
Manaus (AM)	5	7.8	10	11.9	5	18.5
Porto Alegre (RS)	11	17.2	11	13.1	4	14.8
Rio de Janeiro (RJ)	3	4.7	7	8.3	2	7.5
Teresina (PI)	6	9.4	11	13.1	5	18.5
Total	64	100	84	100	27	100

tional, practical, or motor incapacity to perform BADL or IADL, and cognitive dependence was the complete or partial loss of orientation in time, memory, attention, calculation, language, and visual capacity[16]. Caregivers were understood as formal (hired) or family members, considered as those who provide assistance or care to older adults in the performance of their daily activities[17]. Older adults in Long Term Care Institutions (LTCI) or living alone were excluded because this study aimed to understand the dependent older adult-family caregiver dyad's situation.

Data collection

For data collection, participants were identified through the Municipal Health Secretariats and the Primary Health Care (PHC) services of each municipality included in the study. Then, the contact and scheduling of interviews with respondents were carried out, and all participants were interviewed in their homes by previously trained professionals.

The data were collected through semi-structured interviews, with items that considered obtaining quantitative and qualitative data, using a script constructed and agreed by a group of researchers from different Brazilian universities. Specific questions were used for each group interviewed and involved the perception of topics related to care and dependence.

The interviews were audio-recorded (with the respondents' permission) and transcribed. It is noteworthy that the quantitative variables selected for this study were collected from the textual corpus generated by the transcripts performed by the researchers, containing sociodemographic and care information related to care practices and aspects of the world of work.

Variables

The variables were grouped according to each group of research participants:

Dependent older adults:

Sociodemographic characteristics: gender, ethnicity, marital status, age group, number of children and grandchildren, religion, education, with whom they lived, residence adapted to needs, cognition (preserved or impaired capacity to orient in time, memory, attention, calculations, language, and visual capacity), and social interaction (emotional contact with family, friends, neighbors, or others).

Care characteristics: time requiring care, professional caregiver, and monitoring doctor.

Family caregivers:

Sociodemographic characteristics: gender, ethnicity/skin color, and age group;

Care characteristics: the degree of kinship, the reason to be a caregiver, time in the job, alternating care, self-perception about one's health, and emotional problems (Sadness, stress, tiredness, overload, insomnia, and irritation).

Formal caregivers:

Sociodemographic characteristics: gender, ethnicity/skin color, and age group;

Care and professional characteristics: employment contract, training course, remuneration, length of experience, carrying out other activities in the home where they are working,

difficulties experienced at work, feeling for older adults and emotional (Sadness, depression, fatigue, overload, and anxiety) and social (Lack of recognition, freedom and social relationships) problems.

Statistical analysis

The variables were entered and categorized in a database in the Excel software, and coded. Subsequently, the Statistical Package for the Social Sciences (SPSS) program, version 20.0, was used for the statistical analysis, and the variables were presented employing crude and relative frequency.

Research ethics

The Research Ethics Committee of the Oswaldo Cruz Foundation approved the project. All participants signed the Informed Consent Form.

Results

In total, 64 dependent older adults, 84 family caregivers, and 27 formal caregivers in different Brazilian cities were interviewed, establishing a sample of 175 people. Most older adults were women (64.1%), white (56.3%), with low schooling (15.6% were illiterate and 40.6% had incomplete elementary school), and Catholic (71.9%). Most older adults were over 80 years old (54.7%), lived without a partner (68.7%), had children (87.6%), and grandchildren (75%). Of the total, 37.5% lived with their daughter, 31.3% with a partner, and 70.3% in a home adapted to their needs (Table 2).

Of the older adults, 23.1% had been requiring care for four years or more, 87.7% had no professional caregiver, and the PHC doctor monitored 29.2%. Most reported feeling uneasy about their situation, had a preserved cognition, but did not have social relationships (Table 3).

Table 4 shows that most family caregivers were female (84.5%), white (40.5%), and were between 40 and 59 years of age (52.4%). Those who provided care to older adults were most often the "daughters", who reported being in this role precisely because they were "daughters" or because "they did not have anyone else to provide care". Most caregivers have provided care to older adults for over two years and did not share their work with other people. Most reported that they have been experiencing illness (60.7%), emotional

Table 2. Sociodemographic characteristics of dependent older adults of municipalities from different Brazilian regions, 2019.

Variable	n (64)	%
Gender		
Female	41	64.1
Male	23	35.9
Ethnicity*		
White	36	56.3
Black (brown and black)	20	31.2
Marital status		
With a partner	24	37.5
Without a partner	40	62.5
Age group (years)		
60 – 69	6	9.4
70 – 79	23	35.9
≥ 80	35	54.7
Children**		
None	2	3.1
1 – 3	28	43.8
4 – 7	17	26.6
≥ 8	11	17.2
Grandchildren***		
None	5	7.8
1 – 3	23	36.0
4 – 7	10	15.6
≥ 8	15	23.4
Religion****		
Catholic	46	71.9
Evangelical	7	10.9
Other	6	9.4
Schooling*****		
Illiterate	10	15.6
Incomplete Elementary School	26	40.6
Complete Elementary School	11	17.2
Secondary School	8	12.5
Higher Education	5	7.8
Living with		
Partner	20	31.3
Daughter	24	37.5
Son	12	18.8
Alone	4	6.2
Other relatives	4	6.2
Home adapted to needs******		
No	12	29.7
Yes	45	70.3
Social interaction*******		
No social relationships	34	53.2
With social relationships	22	34.3

Source: Field research data. Did not answer: *8(12.5%); **6(9.4%); ***11(17.2%); ****5 (7.8%); *****4(6.3%); ******7(10.8%); *******8(12.5%).

problems (75.0%), social problems (75.0%), and reported that the family is the leading support network that helps in caring for older adults (48.8%) in the exercise of this activity.

Table 5 shows the characteristics of formal caregivers. Most were women (92.6%), black (63.0%), were between 40 and 59 years old (74.1%), did not have an employment contract (74.1%), never took a training course for the function (77.8%), received approximately one minimum wage (≤ R$ 1,000.00), and had been in the job for less than one year (59.3%). In this population, 74.1% performed other activities at the older adult's residence, and 55.6% faced difficulties at work. Most said they liked what they did, did not suffer from emotional problems, and were supported by relatives of older adults and other caregivers.

Discussion

This study identified sociodemographic and care characteristics that indicate vulnerabilities in dependent older adults, family, and formal caregivers. We observed that the respondents are affected by individual, social and programmatic vulnerabilities[13], involving aspects that suggest poor living and health conditions.

Table 3. Care characteristics of dependent older adults in municipalities from different Brazilian regions, 2019.

Variables	n (64)	%
Time under care (years)*		
< 1	9	14.1
1 - 3	9	14.1
≥ 4	15	23.4
Professional caregiver		
No	57	89.1
Yes	7	10.9
Monitoring doctor**		
PHC	19	29.7
Specialist	12	18.7
None	11	17.2
Other	13	20.3
Self-perception***		
Well-being	18	28.1
Discomfort	39	61.0
Cognition		
Impaired	23	35.9
Preserved	41	64.1

*Did not answer: *31(48.4%); **9(14.1%); ***7(10.9%).

Table 4. Sociodemographic and care characteristics of family caregivers in municipalities from different Brazilian regions, 2019.

Variables	n (84)	%
Gender		
Female	71	84.5
Male	13	15.5
Ethnicity*		
White	34	40.5
Black (brown and black)	32	38.1
Age group (years)		
20 – 39	7	8.3
40 – 59	44	52.4
60 – 79	12	14.3
≥ 80	21	25.0
Degree of kinship		
Partner	20	23.8
Daughter	39	46.4
Other relatives	25	29.8
Reason for being the caregiver		
No one else is available	31	36.9
For being the wife	6	7.1
For being the daughter	23	27.4
Other reason	24	28.6
Length of service (years)**		
≤ 1	8	9.5
2 – 5	41	48.8
6 – 9	8	9.5
≥ 10	22	26.2
Alternate care with other people		
No	46	54.8
Yes	38	45.2
Illness (self-reported)		
No	33	39.3
Yes	51	60.7
Emotional problems (self-reported)		
No	21	25.0
Yes	63	75.0
Social problems		
No	21	25.0
Yes	63	75.0
Support network		
PHC	13	15.5
Family	41	48.8
Neighbors/friends	6	7.1
No support	24	28.6

*Did not answer: *18(21.4%); **5(5.9%).

Table 5. Sociodemographic, work, psychological, and care characteristics of formal caregivers in municipalities from different Brazilian regions, 2019.

Variables	n (27)	%
Gender		
Female	25	92.6
Male	2	7.4
Ethnicity		
White	10	37.0
Black (brown or black)	17	63.0
Age group (years)		
30 – 39	6	22.2
40 – 59	20	74.1
> 60	1	3.7
Work contract		
No	20	74.1
Yes	7	25.9
Caregiver course		
No	21	77.8
Yes	6	22.2
Salary (R$) *		
≤ 1.000	11	40.7
1.100 – 2.000	6	22.2
≥ 2.100	2	7.4
Length of service (years)		
≤ 1	16	59.3
1 – 3	5	18.5
≥ 4	6	22.2
Performs other activities in the house other than elderly care **		
No	4	14.8
Yes	20	74.1
Faces challenges at work***		
No	10	37.0
Yes	15	55.6
Perception of work****		
Likes what he does	17	63.0
Feels overwhelmed and undervalued	5	18.5
Emotional problems		
No	15	55.6
Yes	12	44.4
Support network*****		
Family/Others caregivers	17	63.0
No support	7	25.9

*Did not answer: *8(29.6%); **3(11.1%); ***2(7.4%); ****5(18.5%); *****3(11.1%).

Concerning individual and social vulnerabilities, most older adults are female, aged over 80 years, and with low schooling. These women have required care for a long time (four years or more) and reported depression, sadness, and loneliness. While they have children and grandchildren, they complain that many do not visit them frequently. Also, they have no professional caregiver and no regular health care.

These data corroborate Brazil's demographic projection, which points to a higher proportion of women among older adults due to the different mortality by gender, which prematurely affects the male population[18,19]. In families, besides being the group suffering the most from addiction[20-22], they are also characterized by the care they provide to other older adults[23-25]. Worth remembering is that people aged 80 and over is increasing in Brazil. It is the one that requires a higher number of caregivers[14] since it is the most vulnerable to several types of dependence.

Studies point out that the low level of education and the worst socioeconomic conditions of older adults are associated with the early loss of physical and functional capacity, as these people tend to accumulate more diseases throughout their lives, performed unhealthy work activities, have harmful lifestyle habits, and lower access to health services[26-29]. Furthermore, they face greater difficulty in receiving help and are an extremely vulnerable group[29,30].

The loneliness and isolation experienced by older adults point to losses in social and family life and, according to Santini et al.[31], can cause emotional and psychological problems, especially depression. These issues appear in the study as frequent complaints and indicate the need for mental health care to increase their social bonds and address death and terminality[32]. The social protection network consists of people who are close and can enhance or reduce vulnerabilities[9].

While older adults interviewed in this research have a high number of children, grandchildren, and can count on the presence of their spouse or caregiver, many feel alone. This paradox may result from changes and family dynamics marked by the coexistence of great-grandchildren, grandchildren, and children in the same residence, while bonds and solidarity are lost[33].

The programmatic vulnerability found in this study refers to the fact that many older adults do not have medical care, and only 29% reported access to PHC care, which reinforces the hypothesis about the need for health services to review their care practices to face the challenges of multimorbidity and the aging process needs. Strategies to promote access, reduce care fragmentation, and value and promote PHC skills to improve care

are required, and, based on that, to foster a new organization of health care networks[32,34,35]. There is no solution: the number of older adults will increase, and it is crucial to ensure adequate and qualified care for this population.

Regarding family caregivers, we identified characteristics that indicate individual, emotional, and social vulnerabilities. This group's living conditions denote the deficient role of caregivers, marked by inequalities, overloads, illnesses, and various problems. Most are women, mainly daughters and spouses, corroborating other Brazilian studies, according to which daughters are usually the person providing care, which affects their economic and financial life, as it impoverishes them (since it is not a paid activity), causes overload due to uninterrupted work, increases health risks, and social isolation[14,23,36]. Many are also older, long-lived women, which sets up a context for older adults taking care of their peers.

While some women interviewed affirm that they are supported by relatives in caring for their dependent relatives, another part affirms not having social networks. The network and social support are essential measures for coping with the problems of both older adults and caregivers[10].

Family care exercised mainly by women symbolizes the gender inequalities present in society, historically set by asymmetric intergender power relationships, whose activity of caring in the private sphere has been predominantly female. In this research, part of the respondents revealed that the condition of "being a daughter" was decisive for assuming the role of caregiver, which affects their personal, professional, social, and affective lives, impacting society as a whole. Despite rearranged family schemes and women's social role, the population aging process is not accompanied by changes in the gender distribution of care work, except in exceptional cases, especially in the family context[33].

In most cases, there was a lack of alternating care, as if the family once and for all provided care to a single person who, on the one hand, had the emotional comfort of assisting their loved one, but on the other, was burdened by work overload and loss of social life and, sometimes, employment[24,36]. Several scholars have shown that these people are also more susceptible to mental health problems, insofar as the time spent on elderly care is long and uninterrupted[12], they often sleep poorly and stay away from social life[37].

Caregivers' health care is crucial to reduce the risk factors that they (mostly women) incur in their activity. In this study, the presence of a professional caregiver was small and inferior compared to family caregivers. This data reinforces the extent to which family and informal care predominates with older adults, corroborating other Brazilian studies[23,24,36], and requires support from public services.

The characteristics of formal caregivers also suggest social vulnerabilities, mainly related to the world of work. Most were black females without formal employment, with little or no professional practice training, and received low pay. Besides the unstable working conditions, most formal caregivers accumulated other activities in the residence where they cared for older adults, such as cooking, cleaning the house, and taking care of other relatives.

Among the vulnerabilities of the formal caregivers participating in this study are the low-skilled, predominantly black workforce, and, in most cases, without a formal employment contract and labor guarantees. Black women's participation with low schooling in the labor market reflects the intersection between inequalities of gender, ethnicity, and social class in society. They are the most disadvantaged and vulnerable social group, since capitalist, patriarchal, and racist regimes prevent them from obtaining better incomes and jobs, and are overrepresented in less prestigious occupations[38].

In Brazil, blacks' schooling rates are low, and many hold poor, low-pay domestic jobs compared to white people[39]. The lack of a formal employment contract and training for the profession's exercise highlights the lack of public and social policies that ensure the qualification of formal caregivers[36]. This situation occurs despite government initiatives, such as the National Program for Access to Technical Education and Employment (Pronatec), which offers technical courses for older caregivers. However, if well trained, these people would demand better wages and formal employment, which, by the way, is already done in cases where caregivers are organized into cooperatives or small businesses.

Although it addresses fundamental aspects of the dependent-caregiver elderly dyad, this study has some limitations. Data collection is eminently qualitative, the sample consists of a small number of people, and there were some non-answers to the interview questions. However, the results identify situations that are corroborated by many other national and international surveys cited here.

Conclusion

The sociodemographic and care characteristics of a sample of older adults and formal and family caregivers from different Brazilian municipalities identified in this investigation represent individual, social, and programmatic vulnerabilities.

The study identified weaknesses in older adults resulting from the situation of dependence. Furthermore, gender and race inequalities were observed in care for older adults, showing the rigid social roles attributed to men and women according to their skin color in Brazilian society. In the family sphere, support networks are relevant to the topic studied, mainly to prevent emotional and social problems. As for formal caregivers, there is a need for a valuation and qualification policy, contributing to the profession's formalization.

The data shown are from a sample of older adults and caregivers, and cannot be generalized or representative of Brazilian society. However, they can contribute to the creation, development, and implementation of governmental and social strategies to improve and expand support networks and the regulation of an appropriate policy that addresses dependence and the exercise of care.

Collaborations

RF Ceccon, LJES Vieira, CC Praça Brasil, K Soares, VM Portes, CAS Garcia-Júnior, IJC Schneider, AAF Carioca equally participated in the conception, design, analysis, and interpretation of data, drafting of the paper or its critical review, and approval of the final version.

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