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Quality of Life of Family Caregivers in Home Care: Challenges and Perspectives During COVID-19

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Quality of Life of Family Caregivers in Home Care: Challenges and Perspectives During COVID-19

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Abstract

Home Care (HC) has expanded globally, offering individualized care and reducing hospital demand, but the role of the family caregiver imposes significant physical and emotional burden, particularly during health crises like COVID-19. This study aimed to analyze the performance and quality of life perspectives of family caregivers during the pandemic. Methods: A cross-sectional, descriptive and quantitative study was conducted with 101 family caregivers from the Better at Home Program in Santo André, Brazil, between February and March 2021. The WHOQOL-BREF instrument was used to assess quality of life, and the Barthel Index to evaluate the degree of patient dependence. Results: The sample showed a predominance of elderly women (mean age 56 years, 44.7% between 60-84 years), with low education and family income up to two minimum wages. Most caregivers were fully dedicated to patients with high dependence (89.1% in total or severe dependence, mainly due to neurological disorders). Overall quality of life was classified as "needing to improve" or "regular" in 61.4% of cases, with the pandemic intensifying perceived difficulties and negatively impacting all quality of life domains. High prevalence of untreated chronic diseases and low COVID-19 vaccination rates were concerning findings. Conclusions: Family caregivers represent a vulnerable population requiring public policies and integrated support strategies, including quality of life assessment, psychological support, financial assistance, and respite care to ensure continuity of humanized, quality care.

Keywords: family caregivers; quality of life; COVID-19; home care; caregiver burden; pandemic impact; healthcare policy

1. Introduction

Home Care (HC) is a modality that offers individualized care based on the specific needs of each patient. Characterized by interdisciplinary action, it has expanded globally as a strategy to reduce hospital demand, reduce hospital stay and minimize associated complications, resulting in significant cost reduction ([1–3].

HC is categorized into three levels of complexity: HC1, aimed at less complex patients with less demand for multiprofessional visits; HC2, focused on reducing period of hospitalization for patients with acute or chronic diseases; and HC3, which encompasses HC2 with more regular visits by the multidisciplinary team. Functionally, it is divided into preventive, therapeutic and palliative [2,4,5].

In the Brazilian healthcare system, specific regulations establish HC as an integral component of the Health Care Networks, defining the Multiprofessional Home Care Teams (MHCT) and Support Teams (MHST). Home care, often exercised by family members, represents a multidimensional phenomenon that covers biopsychosocial issues, and may cause physical and emotional burden in caregivers [3,5,6].

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The current global epidemiological scenario, characterized by an aging population and an increase in chronic non-communicable diseases, intensifies the demand for HC. The COVID-19 pandemic has further highlighted the importance of this care modality in reducing hospital congestion and in the continuity of care. Recognizing the reality of family caregivers becomes fundamental to promote comprehensive and problem-solving health practices [7–9].

Considering the complexity of home care and the challenges imposed by the COVID-19 pandemic, this study aims to analyze the performance and perspectives on the quality of life of family caregivers of individuals with healthcare issues in times of COVID-19. Specifically, we seek to characterize the sociodemographic profile of caregivers, evaluate their quality of life through the WHOQOL-BREF, determine the degree of dependence through the Barthel Index and verify the relationships between performance and quality of life of the family caregiver. This research will contribute to the development of more effective support strategies and targeted public policies aimed at strenghtening home care.

2. Materials and Methods

2.1. Study Design

Cross-sectional, descriptive study with a quantitative approach, conducted between February and March 2021.

2.2. Location and Population

The study was conducted with participants of the Better at Home Program in the city of Santo André, Brazil, a home care initiative of the Brazilian Unified Health System that offers multiprofessional care at home through teams composed of doctors, nurses, nursing technicians, physiotherapists and social workers. The program serves people with temporary or definitive difficulties in accessing health units, patients in situations where home care is more indicated for treatment, and cases that require weekly or more frequent monitoring [10]. The sample consisted of 101 family caregivers, randomly selected on a non-probabilistic basis from a total population of 408 individuals, including family members of both sexes, aged over 18, who agreed to participate voluntarily in the study.

2.3. Collection Procedures

After approval by the Research Ethics Committee (CEP-FMABC No. 4.471.622) and institutional authorization, the coordination of the Program was communicated and provided the registration of the families. The first contact was made by telephone to explain the objectives of the study and request authorization for an interview. After acceptance, home visits were scheduled with 3 to 12 daily visits from Monday to Saturday, except Wednesdays, prioritizing nearby territories on the same date to optimize time. The collection included sociodemographic data, past and current health history, and application of two instruments validated during structured interviews. All participants signed a Free and Informed Consent Form.

2.4. Instruments

The WHOQOL-BREF [11], a reduced version translated into Portuguese [12], composed of 26 questions distributed in four domains (physical, psychological, social relationship and environment), evaluated on a Likert scale of 1 to 5 points, where higher scores indicate better quality of life. The Barthel Index [13] assessed functional independence in activities of daily living, mobility and eliminations, with scores from 0 to 100 points in intervals of five, where higher scores indicate greater functional independence.

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2.5. Statistical Analysis

Descriptive analysis of the data was performed, with categorical variables presented as absolute and relative frequencies. Quantitative variables were presented as mean, median, and standard deviation, following normality testing using the Shapiro-Wilk test. For comparison between the WHOQOL-BREF and the Barthel Index (severe vs. mild/moderate dependence), the Student's t-test was used. The significance level adopted was 5% for hypothesis testing, and the statistical software used was Stata version 14.0.

3. Results

Data collection for this study was performed between February and March 2021, a period in which the COVID-19 pandemic posed significant challenges. The sample comprised 101 participants, reaching the proposed goal and covering all regions registered in the Better at Home Program.

3.1. Sociodemographic and Health Characterization of Caregivers and Patients

The analysis of the sociodemographic characteristics of caregivers revealed a female predominance (89.1%), with a mean age of 56 years (standard deviation, SD=12.541), ranging from 20 to 84 years. It is evidenced that 44.7% of caregivers were in the 60-84 age group. Regarding family income, 54.5% received between 0 and 2 minimum wages, and the median number of residents per household was 3 people. Education showed that 29.7% had from 0 to 7 years of study. The majority (79.2%) had children (median of 2 children), while 20.8% had none. The most common relationship with the patient was daughter (46.5%), followed by partner (22.7%). The vast majority of caregivers (85.2%) lived with the patient, as detailed in Table *1*.

Table 1. Biological and socioeconomic characterization of caregivers registered in the Better at Home Program of the Municipality of Santo André. Santo André, 2021.

Variable		n	%	Mean	±
Sex	Male	11	10,9	---	---
	Female	90	89,1	---	---
Marital status	With partner	69	68,3	---	---
	Without Partner	32	31,7	---	---
Lives with patient	No	15	14,9	---	---
	Yes	86	85,2	---	---
Caregiver's relationship with patient	Daughter	47	46,5	---	---
	Son	7	6,9	---	---
	Mother	6	5,9	---	---
	Sister	4	3,9	---	---
	Brother	1	0,9	---	---
	Partner	23	22,7	---	---
	Others*	13	12,8	---	---
Age (years)	20 to 40	14	13,9	56	12,541
	43 to 59	41	41,4		
	60 to 84	46	44,7		
Family income (minimum wage)	0 to 2	55	54,5	2,6	1,623
	3 to 12	46	45,5		

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Education (years)	0 to 7	30	29,7	10,8	4,448
	8 to 18	71	70,3		
Living children	0 a 2	76	75,3	1,8	1,489
	3 a 7	25	24,7		
Number of residents	1 a 3	65	64,4	3,3	1,324
	4 a 8	37	35,6		
Total		101	100		

*mother-in-law; friend; contacted caregiver; granddaughter; daughter-in-law, nephew, sister-in-law and stepdaughter.

The occupational situation of caregivers indicated that 91.1% were primary caregivers, with 81.2% dedicating themselves entirely to the function. The average time working as a caregiver was 5.8 years. The COVID-19 pandemic brought significant challenges, with 40.6% of caregivers reporting difficulties in their activities. Regarding the health of caregivers, 51.5% reported having pre-existing diseases. *Figure 1* details the distribution of these health problems, highlighting Arterial Hypertension and Diabetes Mellitus. Immunization against COVID-19, from February to March 2021, was incipient, with only 7.9% of caregivers vaccinated.

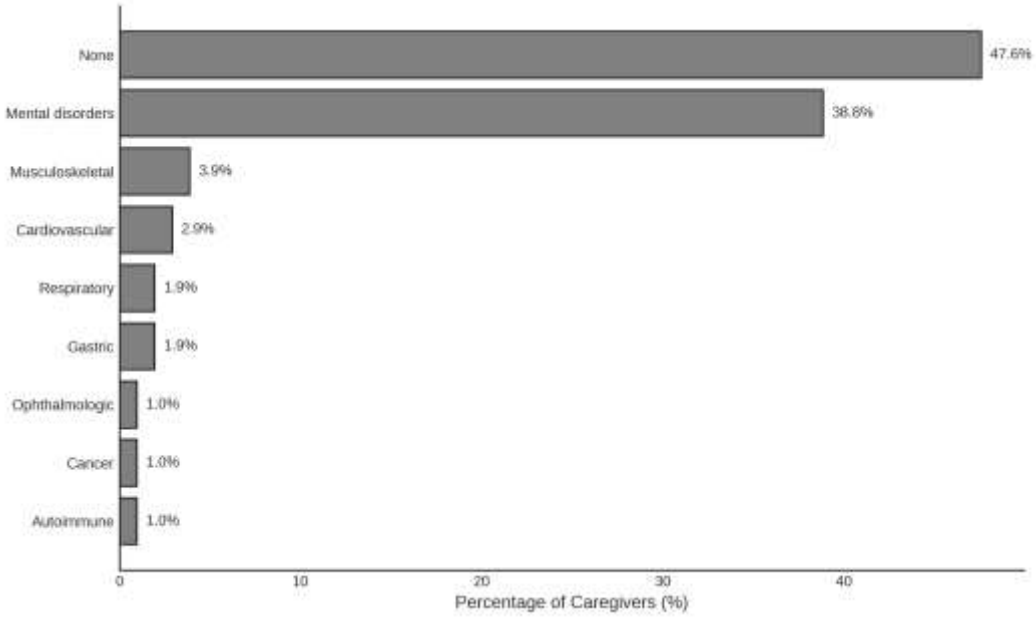

Figure 1. Distribution of health problems reported by caregivers of patients enrolled in the Better at Home Program. Santo André, 2021.

The patients treated by the program were predominantly male (56.4%), with prevalance of age between 82 and 98 years (48.5%), and mean age of 75.1 years (SD = 17.491) ranging between 18 to 98 years. The main diagnoses were mostly neurological (65.3%), with emphasis on Stroke in 29.7% and Alzheimer's Disease in 22.6% of cases.

3.2. Quality of Life of Caregivers and Level of Dependency of Patients

The assessment of the general quality of life of caregivers, using the WHOQOL-BREF questionnaire, indicated that 61.4% had a quality of life between the classifications "need to improve" and "regular". Similarly, when considering the sum of the specific domains (physical, psychological, social relationship and environment), 84.3% of caregivers fell into these categories. The medians for

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the domains were 74% (physical), 70% (psychological), 72% (social relationship) and 66% (environment), with standard deviations ranging from 11.922 to 17.825, denoting heterogeneity in perceptions. *Figure 2* illustrates the relationship between the medians of the quality of life domains of caregivers and the degree of dependence of patients.

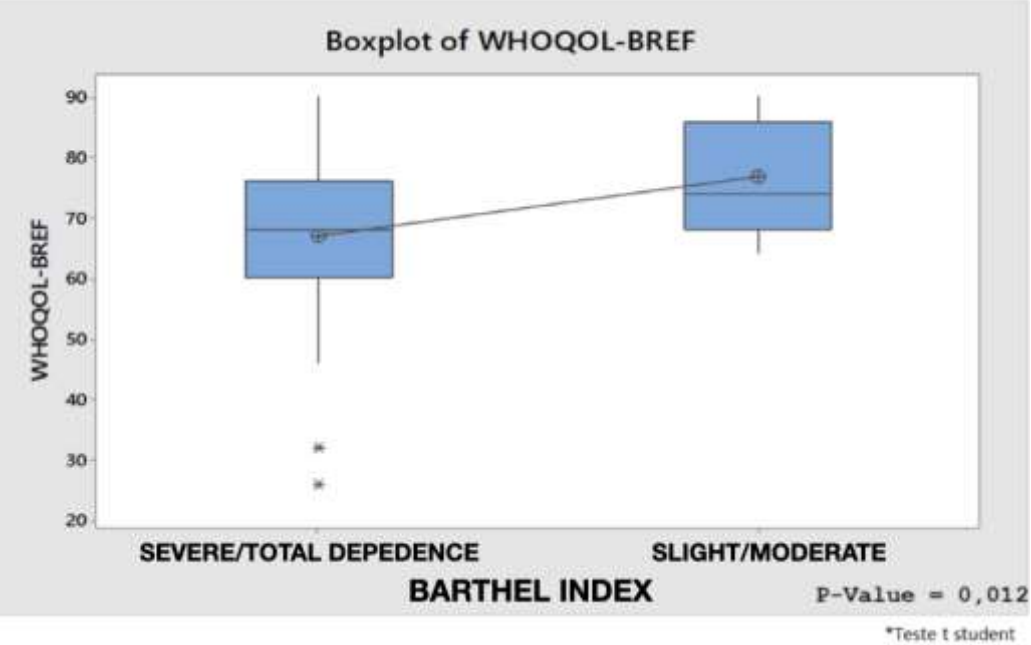

Figure 2. Comparison between the overall medians of the quality of life domains (WHOQOL-BREF) among family caregivers based on the the degree of dependence (BARTHEL INDEX) of Better at Home Program patients. Santo André, 2021.

The level of dependence of patients, assessed by the Barthel Index, revealed a condition of high dependence, with 28.7% classified as total dependence and 60.4% as severe dependence, totaling 89.1% of the sample in this condition (*Table 2*). The analysis of basic activities of daily living, such as feeding, grooming toilet use, bathing, bowel and bladder continence, dressing and undressing, transfer (bed/chair and back), going up and down stairs, mobility and wheelchair handling, showed that all these activities exhibited a predominance of total dependence, with percentage rating from 53.5% to 91.1%.

Table 2. Classification of the level of dependence by the BARTHEL INDEX of patients registered in the Better at Home Program of the Municipality of Santo André. Santo André, 2021.

Classification	n	%
Total dependency (10)	29	28,7
Severe dependence (11 a 30)	61	60,4
Moderate dependence (31 a 45)	7	6,9
Slight dependence (46 a 49)	4	4,0
Independence	0	0

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(50)		
Total	101	100

4. Discussion

The Better at Home Program registers patients with high need for home care, establishing intense links between the Home Care Service (HCS) teams and families to meet their multiple demands [3]. Inclusion in the program necessarily requires the presence of a home caregiver, predominantly a family member, as observed in this study. Family caregivers experience a complex transition in the care process, acquiring knowledge and developing skills for activities of daily living (ADL), medication administration, catheter care and prevention of pressure injuries, generating significant adaptations in their routines [14].

This study showed a mean age of 56 years, with a significant proportion of elderly (60-84 years) performing activities that require full dedication, corroborating other studies on the age profile of caregivers [15,16]. The female predominance, especially daughters as primary caregivers, reflects established cultural norms that attribute to women the matrix role of family care [17,18]. This characteristic is in line with international evidence that identifies women as the most vulnerable group during the COVID-19 pandemic, presenting higher levels of anxiety, depression and burden [19].

The predominant low level of education and the absence of employment ties reflect the high demand for care, with an average duration of 2-10 years. The family income of 0-2 minimum wages and the average of three residents per household show socioeconomic vulnerability, a pattern consistent with studies on caregiver burdens [18,20]. This unfavorable socioeconomic condition intensifies the challenges faced by caregivers, limiting access to support resources and increasing the risk of deteriorating quality of life.

During the pandemic, caregivers reported difficulties related to fear of contamination, although they said it did not change their care routines. However, the assessment of quality of life revealed a statistically significant association between greater pandemic difficulties and lower scores in the physical, psychological, social relations and environmental domains. These findings corroborate international evidence demonstrating deterioration in the quality of life of caregivers during COVID-19, with impacts on physical, psychological, social and financial well-being [18,21,22]. The pandemic exacerbated pre-existing problems, including social isolation, loss of support services, and intensification of 24-hour care [23,24].

The low immunization rate (7.9%) in the collection period (February-March 2021) reflects the initial moment of vaccination in Brazil. The account of caregiver - “today society is experiencing the reality of the family caregiver, not being able to leave the house and living the same routine every day” - illustrates how the pandemic temporarily universalized the experience of social isolation already experienced by caregivers, intensifying their limitations and health risks [23,25]. This perspective reveals how caregivers already faced conditions similar to those imposed by the pandemic on the general population, evidencing their chronic vulnerability.

The high prevalence of Arterial Hypertension and Diabetes Mellitus among caregivers, associated with reports of non-adherence with treatment due to lack of time and burden, represents a worrying condition. This situation reflects the internationally observed pattern of neglect of self-care among caregivers during the pandemic, with fatigue, sleep disorders and reduced self-care [19,28]. Previous studies have identified untreated morbidities among caregivers due to the prioritization of patient care [15,26]. The pandemic intensified this trend, with caregivers reporting greater difficulty in accessing health services and reducing the time dedicated to their own well-being [29].

The predominance of male patients with neurological diagnoses, especially stroke and Alzheimer’s disease, characterizes degenerative and progressive conditions that directly impact the quality of life of caregivers. The caregiver account “it hurts my mother not to recognizing me as a daughter” exemplifies the specific emotional suffering in the care of patients with dementia, a

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condition that studies identify as particularly challenging for caregivers [23,27]. Caregivers of people with cognitive and behavioral problems were identified as a high-risk group during the pandemic, presenting high levels of clinical stress and deteriorating mental health [31,37].

The Barthel Index revealed a predominance of total (28.7%) and severe (60.4%) dependence, totaling 89.1% of patients in high dependence, a pattern similar to other studies [2]. Total dependence on all activities of daily living, except partial feeding, confirms the high demand for care and justifies the need for intensive support to caregivers. This condition of high dependence correlates with greater caregiver burden and worse quality of life indicators, especially during periods of crisis such as the pandemic [30,32].

The results show that longer care time is statistically associated with a higher degree of dependence, suggesting a progressive deterioration in the physical and emotional health of caregivers. This situation is particularly worrying considering that high-intensity caregivers and co-residents were identified as groups of greater vulnerability during the pandemic [29,33]. Despite the challenges, some studies have identified aspects of resilience among caregivers, including closer relationships, sense of purpose in caregiving, and innovations in care practices [22,23].

The experience of the pandemic reinforced the need for health policies that recognize caregivers as a vulnerable population, requiring systematic assessment of quality of life, mental health support, financial support and respite options, as recommended by the international literature [35,36]. Home services should expand their scope to also meet the needs of caregivers by implementing clear communication strategies, psychological support, and health education programs that support this essential care workforce [33,34]. The pandemic demonstrated the critical importance of family caregivers in the health system and the urgency of developing comprehensive policies that protect and support this vulnerable population.

5. Conclusions

The caregivers of the Better at Home Program have high socioeconomic vulnerability: mostly elderly women, with low education and income, responsible for the comprehensive care of patients with great dependence. COVID-19 aggravated the challenges and was associated with worsening quality of life in all domains. Untreated chronic conditions, prolonged care time, and burden, especially in neurodegenerative diseases, require policies that prioritize these caregivers. Integrated strategies with systematic assessment of quality of life, psychological support, financial support, respite care services and health education are needed to sustain this workforce and ensure continuous, qualified and humanized home care.

Supplementary Materials: The following supporting information can be downloaded at the website of this paper posted on Preprints.org.

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