Making the invisible visible: a characterization of bedridden and caregivers assigned to a Basic Health Unit

Visibilizando invisíveis: caracterização de acamados e cuidadores adscritos à uma Unidade Básica de Saúde

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ABSTRACT

Identify and characterize bedridden users who live at home in the community and assess caregiver's burden. Cross-sectional observational study. It was applied: a sociodemographic and health profile questionnaire; Katz index; Coelho and Savassi Family Risk Scale; ABEP socioeconomic classification scale; and reduced Zarit Scale. Descriptive analysis with categorical data expressed as frequency and percentage, and continuous data, as mean and standard deviation, with the confidence interval. A total of 23 bedridden patients were evaluated, most of them elderly males, with some reported family dysfunction and who lived in masonry houses without accessibility or adequate adaptations. The 27 caregivers were mostly informal, almost all female family members, with care overload considered severe. These issues must be faced by health professionals, so can offer adequate responses to the needs of this population, which is still very neglected and unassisted. To make the invisible visible is to humanize care and provide access to health.

Keywords: Bedridden Persons. Family Health Strategy. Primary Health Care. Public Health. Public Health Surveillance.

RESUMO

Identificar e caracterizar o perfil de usuários acamados que vivem em domicílio na comunidade e a sobrecarga de cuidadores. Estudo observacional transversal. Aplicou-se: questionário perfil sociodemográfico e saúde; Índice Katz; Escala de Risco Familiar Coelho Savassi; Escala de classificação socioeconômica ABEP; e Escala Zarit reduzida. Análise descritiva com dados categóricos expressos por frequência e porcentagem, e dados contínuos, por média e desvio padrão, com intervalo de confiança. Foram avaliados 23 acamados: maioria idosos do sexo masculino, com alguma disfunção familiar relatada e que viviam em moradias de alvenaria sem acessibilidade ou adaptações adequadas. Os 27 cuidadores eram em sua maioria informais, quase todos familiares do sexo feminino, com sobrecarga de cuidado considerada grave. O enfrentamento dessas questões pelos profissionais da saúde pode oferecer respostas adequadas às necessidades desta população, ainda muito negligenciada e desassistida. Visibilizar invisíveis é humanizar o cuidado e proporcionar o acesso à saúde.

Palavras-chave: Atenção Primária à Saúde. Estratégia Saúde da Família. Pessoas acamadas. Saúde Coletiva. Vigilância em Saúde.

INTRODUCTION

Home Health Care (HHC) is one of the modalities that is part of the Health Care Network. It involves the promotion, prevention and rehabilitation of health, and the treatment of illnesses through actions at home within the scope of public health policies. Although HHC is on the rise in health practices, it is not yet fully integrated into care systems and the training of specialized professionals [1].

The home context must be understood from a comprehensive perspective that goes beyond physical space, considering this environment as a set of objects, events and human beings correlated with each other. Each of these represents a particular character, interfering mutually and simultaneously in the home context. In this case, priority is given to a multidimensional diagnosis that is easily correlated with what is predicted by the reasoning proposed by the International Classification of Functioning, Disability and Health (ICF), which broadens the vision of health professionals, encouraged to act in the context of individuals, the community and the environment in which they are inserted [2,3], providing continuity of care.

From this perspective, the user who is bedridden for a long time, with little physical mobility, is often susceptible to a long context of vulnerability. Immobility Syndrome contributes to progressive functional decline and loss of ability to perform activities of daily living [4].

Periodic updating of family registration and reliable feeding of Primary Health Care (PHC) information systems are fundamental elements for monitoring bedridden people and developing follow-up strategies by local health teams and municipal managers [1,4].

In this context, caregivers, figures who often do not receive the support they need as they are also subject to care and suffer signs of exhaustion, also deserve recognition. Within the scope of HCC, it is also the responsibility of the teams to ensure that these subjects are looked after [3,4].

Given the spontaneous and scheduled demands at the Basic Health Unit (BHU), home visits end up being the least prioritized, however, the importance of this type of personalized care that is more accessible to bedridden people can strengthen the bond between health professionals and patients and families, providing a more familiar environment and care centered on the individual.

The present study aimed to identify and characterize the profile of bedridden users who live at home in the community and the burden on caregivers. Its secondary objectives are to track, within a specific territory, the sociodemographic and health profile, as well as classify functional dependence, stratify family risk and identify socioeconomic status.

METHODOLOGY

The present work consists of an observational, cross-sectional study. The research universe was made up of users from a community in the city of São Leopoldo, Rio Grande do Sul (RS), served by a BHU that comprises three (3) Family Health teams (FHT), serving the population of an area distributed across 24 micro areas of activity.

The sample was intentional. The study included users of both sexes, of all age groups, who lived in the area where the FHT operates, were restricted to bed and had a responsible caregiver. Users who passed away before the evaluation and those who no longer lived at the monitored address were excluded.

Of a universe of 60 individuals registered in the FHT home visit spreadsheets, 41 were domiciled and 19 were bedridden, according to data previously reported by the local health team through monitoring and registrations by Community Health Agents (CHA). Pre-monitored users who were restricted to bed (n=19) were considered eligible for the study. Bedridden

users who lived in the assigned territory but were not yet registered (n=9) were also included in the research. According to exclusion criteria, five (5) users were removed from the study. The final sample consisted of 23 individuals restricted to bed. The collection was carried out between June and August 2022.

The selection process began with contact with the CHA in the territory, who indicated and scheduled visits and assessments to users in their homes. Before starting the evaluation, the procedure was explained and the Informed Consent Form was delivered and signed. The variables of the present research considered as the primary outcome the sociodemographic profile and health status of bedridden users cared for by the aforementioned FHT, and as secondary outcomes the functionality, family risk, socioeconomic status and burden on caregivers.

Five instruments were applied to collect data based on the evaluation of the HCC material in Primary Health Care proposed by the Ministry of Health [4]: a) sociodemographic and health questionnaire; b) Katz Index [5]; c) Family Risk Scale (Coelho and Savassi) [6]; d) Socioeconomic Classification Scale (ABEP) [7]; e e) Reduced Zarit Scale [4].

In order to contextualize the sample studied, the sociodemographic and health questionnaire prepared by the researchers was applied, which includes three dimensions: a) identification data; b) risk factors; and c) socio-environmental aspects.

To assess functionality, Katz's Index of Basic Activities of Daily Living (ADL) was applied, one of the most used instruments to assess independence in the performance of six functions: bathing, dressing, going to the bathroom, transfer, continence and feeding; classifying users from A to G, as independent (A) or dependent (G), based on a standard questionnaire [5].

With the purpose of determine the risk of illness of the familiar group the Family Risk Scale by Coelho-Savassi [6] was applied, which allows a

final classification from Usual Vulnerability (V0) to Maximum Vulnerability (V3). The Brazil 2021 Economic Classification Criteria was also used, by the Brazilian Association of Business and Research (ABEP) [7], which stratifies social classes in Brazil from A (R$ 21,826.74) to DE (R$ 900.60).

Finally, the reduced Zarit Scale was also used, which aims to assess caregiver burden. Care was taken to ensure that this scale was not carried out in the presence of the bedridden user. For each statement, the caregiver should indicate how often and what they feel some about what was asked (never, rarely, sometimes, often or always). Caregivers' stress is indicated by high scores, with a final classification as mild (14 points), moderate (15 to 21 points) or severe (≥22 points) overload [4].

A descriptive analysis of the data was carried out, with categorical data expressed as frequency and percentage, and the continuous data by mean and standard deviation, with the presentation of the confidence interval. This work was submitted and approved by the Research Ethics Committee of the University of Vale do Rio dos Sinos under opinion no. 5,452,878.

RESULTS

In total, 23 bedridden people and 27 caregivers participated in the study, who received a home visit from the evaluator and the CHA corresponding to the micro-area in which they belonged. The entire sample recruitment process can be seen in the flowchart below. (Figure 1).
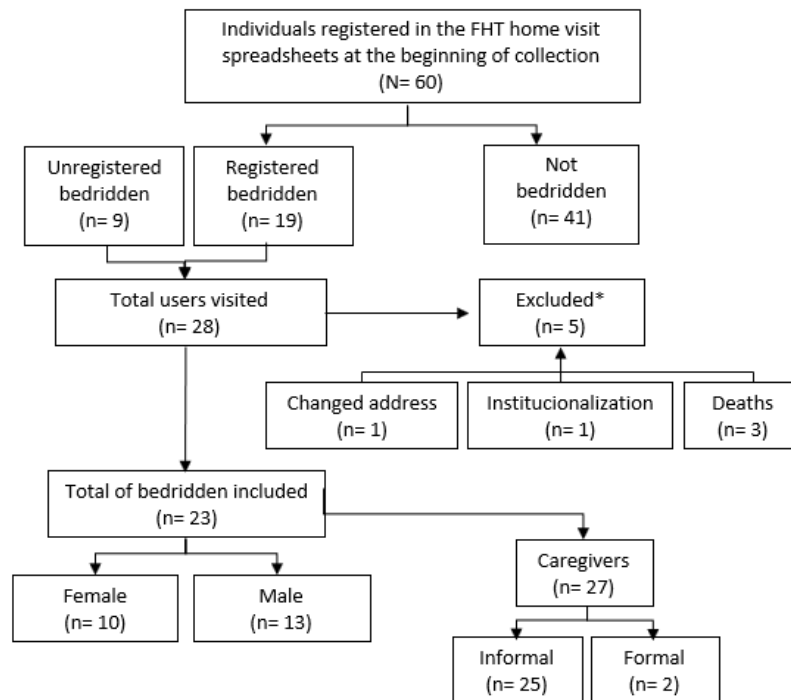
Figure 1. Eligible sample flowchart

Legend: FHT = Family Health Team, * = according to inclusion criteria

There was a predominance of male participants (56.5%), elderly (60.9%) and with an average age of 57 ± 20.99 years (95%CI 48.31-66.46). The sample consisted of a majority of self-declared white people (82.6%), who attended school until the initial years – 1 to 4 years of studies (52.2%) and only use the Unified Health System (SUS) as their access to health (82.6%). Of the study participants, 56.5% receive visits only from family members as social interaction, with 78.3% having no external contact. The majority live with some reported family dysfunction (52.2%) and 69.6% of the families interviewed are at maximum vulnerability. (Table 1).

Regarding the family income characteristics of the households visited, the majority are classified as social class *C2* (60.9%), with an estimated average family income of R$1,965.87. In this sample, five users (21.7%) still did not have access to social benefits. Regarding housing, the majority (60.9%) live in houses made of masonry material (78.3%), owned by family members (73.9%). However, 73.9% of these homes do not have accessibility or adequate adaptation for the bedridden condition, such as wheelchairs and support bars, for example (Table 2).

The majority of the sample consisted of patients who require home care in the AD1 modality (78.3%), classified as those who are physically unable to travel to a BHU for care under the responsibility of the FHT, while others have the right and should receive support from a Home Care Service (HCS) team. (Table 2).

Table 1. Sociodemographic characterization of bedridden users in the sample. 2022. (n=23)

Variable	n	%
Sex		
Male	13	56,5
Female	10	43,5
Age *(in bands)*		
0 I------10	1	4,3
10 I------20	0	0,0
20 I-----30	2	8,7
30 I------40	3	13,1
40 I-----50	2	8,7
50 I-----60	1	4,3
60 I-----70	8	34,8
70 I-----80	2	8,7
80 or more	4	17,4
Marital status		
Single	10	43,5
Widower	7	30,4
Married	4	17,4
Divorced	2	8,7
Self-declared skin color		
White	19	82,6
Black	2	8,7
Brown	2	8,7
Education		
Illiterate	5	21,7
1 to 4 years	12	52,2
5 to 8 years	3	13,1
9 to 11 years	2	8,7
More than 11 years	1	4,3
Occupation		
General services	5	21,7
Construction	5	21,7
Industry	4	17,4
Kitchen	2	8,7
Others	2	8,7
Never worked	5	21,7
Health services used		
SUS	19	82,6
SUS/Agreement	4	17,4
Social interaction		
Family only	13	56,5
Receives visitors	10	43,5
Has external contact		
Yes	5	21,7
No	18	78,3
Reported family dysfunction		
Yes	12	52,2
No	11	47,8
Family Risk *(Coelho-Savassi)*		
V0 – Usual vulnerability	0	0,0
V1 – Minor vulnerability	1	4,3
V2 – Medium vulnerability	6	26,1
V3 – Maximum vulnerability	16	69,6

Source: Prepared by the authors, based on Savassi, Lage and Coelho [6]

Legend: n = number of respondents, % = relative frequency, SUS = Unified Health System, Coelho-Savassi = Family Risk Scale

Table 2. Income and household profile of bedridden users in the sample. (n=23)

Variable	n	%
Social class *(ABEP scale)*		
A	0	0,0
B1	0	0,0
B2	2	8,7
C1	5	21,7
C2	14	60,9
D-E	2	8,7
Social benefits		
Continuous Cash Benefit	6	26,1
Retirement for time of service	6	26,1
Retirement by age	2	8,7
By disability retirement	2	8,7
Death pension	2	8,7
None	5	21,7
Housing situation		
User's own	5	21,7
Family member's own	17	73,9
Leased/Assigned	1	4,3
Feature of the property		
Home	14	60,9
Apartment	9	39,1
Type of construction		
Masonry	18	78,3
Wood	1	4,3
Mixed	4	17,4
Home accessibility/adaptability		
Yes	6	26,1
No	17	73,9
Home care classification		
AD1	18	78,3
AD2/AD3	5	21,7

Source: Prepared by the authors, based on the Brazilian Association of Business and Research [7]

Legend: n = number of respondents, % = relative frequency, ABEP = Socioeconomic Classification Scale, AD = Home Health Care (types according to classification by the Ministry of Health).

Among the underlying diseases that led to the interviewees' bedriddenness, those that affect the Nervous System stand out, such as Stroke (34.8%), Cerebral Palsy (CP) (17.4%) and Traumatic Brain Injury (TBI) (13.1%). Among the comorbidities, Systemic Arterial Hypertension (SAH) was the most prevalent, identified in 47.8% of cases. Only two patients used continuous oxygen therapy (8.7%), and 26.1% used other accesses or probes. The use of diapers was observed in 82.6% of cases.

Of the users, 82.6% were polymedicated, with the antihypertensive class (19.1%) being the most cited and used. Regarding lifestyle habits, caregivers reported that some participants had a history of smoking (39.1%), others had a history of alcohol consumption (26.1%) and the majority had maintained sedentary habits before total bed restriction (60.9%).

Table 3. Health conditions of bedridden users in the sample. 2022 (n=23)

Variable	n	%
Basic disease		
Stroke	8	34,8
CP	4	17,4
TBI	3	13,1
PO due to fracture/amputation	2	8,7
Alzheimer's	1	4,3
DVT	1	4,3
Post-COVID	1	4,3
Angelman syndrome	1	4,3
Toxoplasmosis meningocephalitis	1	4,3
Still no diagnosis	1	4,3
Comorbidities ** (n=90)		
SAH	11	12,2
Pneumonia/COPD/Tuberculosis	9	10,0
Alzheimer's/stroke/Parkinson's	8	8,8
Multiple disabilities	7	7,7
Malnutrition	7	7,7
DM	6	6,6
Osteoarthritis/Osteoporosis	6	6,6
Dyslipidemia	6	6,6
Depression	5	5,5
Fracture	5	5,5
Renal insufficiency	4	4,4
Cardiac arrhythmia/AMI	3	3,3
STI (HIV/Syphilis)	3	3.3
Others	10	11,1
Use of accesses/probes		
Yes	6	26,1
No	17	73,9
Use diapers		
Yes	19	82,6
No	4	17,4
Polypharmacy		
Yes	19	82,6
No	4	17,4
Therapeutic classes used ** (n=94)		
Antihypertensives	18	19,1
Anticonvulsants	10	10,6
Diuretics	9	9,6
Anticoagulants	8	8,5
Antidepressants	7	7,4
Antipsychotics	6	6,4
Antidyslipidemics	5	5,3
Painkillers	5	5,3
Antidiabetics	4	4,3
Benzodiazepines	3	3,2
Antiarrhythmics	2	2,1
Antibiotics	2	2,1
Other classes	15	15,9

Legend: n = number of respondents, % = relative frequency, CP = Cerebral Palsy, TBI = Traumatic Brain Injury, PO = Postoperative, DVT = Deep Vein Thrombosis, SAH = Systemic Arterial Hypertension, COPD = Chronic Obstructive Pulmonary Disease, DM = Diabetes Mellitus, AMI = Acute Myocardial Infarction, STI = Sexually Transmitted Infections, HIV = human immunodeficiency virus, Polypharmacy = uses 4 or more continuous medications, ** = the interviewee could name more than one response, percentage calculated on the number of respondents.

Table 4. Health histories and functional classification of bedridden users in the sample. 2022 (n=23)

Variable	n	%
Smoking history		
Yes	9	39,1
No	14	60,9
History of alcoholism		
Yes	6	26,1
No	17	73,9
History of sedentary lifestyle		
Yes	14	60,9
No	9	39,1
Falls in the last 12 months		
Yes	10	43,5
No	13	56,5
Hospitalization in the last 12 months		
Yes	13	56,5
No	10	43,5
Length of stay (n=13)		
1 I------8 days	5	38,5
8 I------16 days	2	15,4
16 I------ 30 days	4	30,8
1 month or more	2	15,4
Pressure injury		
At the moment	10	43,5
Historic	5	21,7
No injury	8	34,8
H1N1 vaccination		
Yes	16	69,6
No	7	30,4
Complete COVID-19 vaccination		
Yes	13	56,5
No (missing some reinforcements)	8	34,8
No dose	2	8,7
Average bedding time		
0 I------ 3 months	3	13,1
3 I------ 6 months	1	4,3
6 I------ 12 months	2	8,7
1 I------ 5 years	7	30,4
5 years or more	10	43,5
Verbal communication		
Yes	11	47,8
No	12	52,2
Functional classification *(Index of Katz)*		
ABC	0	0,0
DE	0	0,0
F	2	8,7
G	21	91,3
Other	0	0,0

Source: Prepared by the authors, based on Katz *et al.* [5]

Legend: n = number of respondents, % = relative frequency, COVID-19 = coronavirus, H1N1 = influenza A virus, KATZ = index that classifies functionality in activities of daily living into categories.

Worryingly, 43.5% of participants had experienced a fall in the last 12 months. When asked about the same period, the majority would have required some hospitalization (56.5%), with the average length of stay being 13 days. 43.5% of users developed pressure injuries, while another 21.7% had a previous history.

The majority of restricted users in the surveyed territory (69.6%) had access to annual vaccination against the influenza virus (H1N1), and at least the first dose against COVID-19 (91.3%). A large part of the sample studied had been bedridden for five years or more (43.5%), with an average length of stay of 36 months. The

majority of users did not communicate verbally (52.2%), and when classifying the function using the Katz Index, 91.3% fell into category G (dependence for all activities of daily living assessed). These and other characteristics of the health conditions of the study participants are expressed in tables 3 and 4.

Table 5. Characterization of caregivers of bedridden users in the sample. 2022. (n=27)

Variable	n	%
Caregiver sex		
Female	26	96,3
Male	1	3,7
Caregiver age		
30 I------40	3	11,1
40 I------50	7	25,9
50 I------60	7	25,9
60 I------70	7	25,9
70 or more	3	11,1
Characteristics of the caregiver		
Family	25	92,6
Formal	2	7,4
Relationship of the family caregiver (n=25)		
Mother	8	32,0
Daughter	5	20,0
Wife	4	16,0
Sister	3	12,0
Grand daugther	1	4,0
Cousin	1	4,0
Sister-in-law	1	4,0
Daughter-in-law	1	4,0
Son-in-law	1	4,0
Overload level *(Zarit Scale)*		
Light	8	29,6
Moderate	6	22,2
Serious	13	48,2

Source: Prepared by the authors, based in Brazil [4].

Legend: n = number of respondents, % = relative frequency, Zarit Scale = Caregiver Burden Scale

Table 5 presents data characterizing the caregivers of the users evaluated in this study, with a predominance of women (96.3%) as the main people responsible for care and an average age of 55 ± 12.24 years (95%CI 50. 41-60,10). Most of the sample was made up of informal caregivers (92.6%) family members: mothers, daughters, wives, sisters, among others, the majority (48.2%) with a level of overload categorized as severe.

The 23 homes visited by the researchers, accompanied by the CHA, intentionally and indiscriminately incorporated micro-areas of the three local FHT. The map below represents in orange, symbolically, the signs of people and families who participated in the research and are part of a population that is often invisible. (Figure 2).
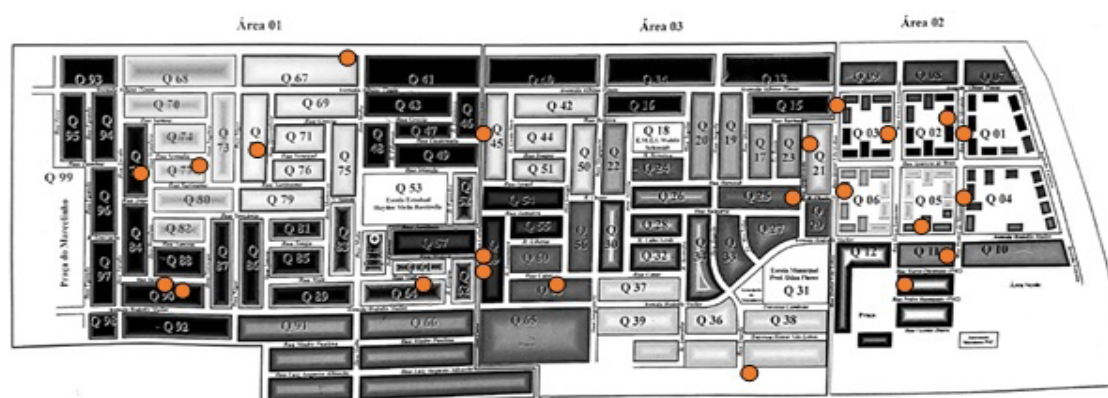
Figura 2 – Território com marcações dos 23 domicílios visitados

Figure 2. Territory with markings of the 23 homes visited

DISCUSSION

This study identified the sociodemographic and health profile of bedridden users who live at home, as well as functional dependence, family risk and the burden on caregivers involved in this process.

Elderly males and self-declared whites were the majority of this sample. Elderly men are more likely to become bedridden, as a result of less demand for health services, lack of preventive care and greater exposure to risk factors throughout life [9,10,11].

The low level of education of the participants in this study may be associated with limited access to health information, leading to the development of more serious illnesses. Added to this is the overlap between illiteracy and less care, less search for health services and the consequent occurrence of late diagnoses [9,11].

Among the individuals surveyed, there was unanimous recognition of the importance of the SUS and its use as a facilitator of health care, whether for the acquisition of supplies such as diapers and dressing materials, for the collection of medications, carrying out exams or access to consultations with health professionals, frequently reported in previous studies [12,13,14].

In this research, the sample consisted of a population with low acquisitiveness. The most common family income range (60.9%) was just over one minimum wage (class C2), well above the national percentages (26.4%) and for the south of the country (26.7%) of people who are in the same economic class [7].

The financial situation directly impacts the care received by users and even the burden perceived by caregivers. Difficulties in accessing the hiring of a formal caregiver and access to materials needed to carry out home care are examples of barriers [12,13,14].

Low social contact, in turn, outside their homes or through visits can generate a state of loneliness, isolation or devaluation towards the bedridden person. Many times, the self-perception of their life as a burden for the family member or caregiver also arises [9]. Self-perceiving as dependent contributes to greater functional decline and the emergence of new complications such as hospitalizations, depression and even death [15].

In this study, more than half of the bedridden people evaluated did not present verbal communication, a reason that in itself neglects a series of stimuli. Various barriers, whether structural, urban, technological, communication, transport or attitudinal (ableism) reinforce exclusion, often even among family members themselves. Therefore, receiving external visits is seen as a protective factor against family dysfunctions [16].

Several family dysfunctions were found in the sample studied. It is more common for

women, with a history of being mothers and caregivers, to receive better family support and to experience family dysfunction less frequently than men when it comes to older individuals. In this case, with the family being the main means of care throughout life, it is also up to the health professional to be attentive to the cultivation of healthy relationships, both for those who care and for those who are cared for [16].

Regarding access to benefits, restricted mobility incapacitates the user from working, and government investments in retirement payments, benefits, pensions and aid are necessary. Social assistance is a citizen's right to ensure that basic needs are met, as provided for and ensured by the Organic Social Assistance Law since 1993 [1].

What is worrying, in the case of the sample studied, is the identification of users who, despite being potential beneficiaries, still do not receive any type of social benefit. This situation can be justified, if nothing else, by the barrier to access to information by family members and even health professionals.

Vaitsman and Lobato [17] highlight the importance of empowering these families and greater coordination and cooperation between the social assistance, health and pension sectors to expand the protection network for users. Unfortunately, this is a reality that reflects several gaps in the different institutions that, normally, depend on informal links and relationships: characteristic of horizontal and diffuse forms of management.

Regarding accessibility, most homes did not have infrastructure for users to move around their own homes, such as grab bars or ramps. It is known that the ambiance and organization are extremely important for safety and autonomy [1].

In this context, the large percentage of falls self-reported by users or their caregivers in the last 12 months was worrying, considering that few had any degree of mobility. These falls may be related to the lack of adaptations at home, but it is understood that the acquisition of most of these materials is difficult to access, as well as the availability of people to carry out these adaptations.

Another factor that may be related to falls is the use of polypharmacy, the combination of which can trigger sensory changes in the individual. Polymedicated patients, in general, are at high risk for problems linked to pharmacotherapy. They are the biggest consumers of health resources, as they suffer a greater number of hospitalizations/ year and, generally, are in a situation of fragile care [8].

In this sense, it is valid to combat the care model focused exclusively on the treatment of diseases and medication prescriptions, like models that consider the integrality and context of subjects and families [18]. However, there is a great challenge in guaranteeing this comprehensive care, which needs to enable a balance between individual approaches in a timely manner and community approaches to value social determinants [3].

Primary Health Care is responsible for type 1 home care patients (AD1), who are in a controlled state of health, but unable to travel to a BHU [4]. Type 2 (AD2) and type 3 (AD3) home care modalities are considered the responsibility of HCS, through the Multidisciplinary Home Care Team. In these cases, the PHS remains a reference for these users [4,19].

In the present study, users who had an AD2 profile were identified, however, they were monitored as AD1. In these cases, it was possible to instruct the teams responsible for the appropriate referral to evaluate criteria and include care in the ideal modality [19]. On the other hand, some homes were not visited by the FHT, nor by the specialized HCS team. It is a gap that was also noted in a previous study [14], in which 45% of bedridden or homebound users were not assisted. Fortunately, there were some isolated situations, but they justify the theme of this work, the idea of which was to make these bedridden people and their caregivers visible, including them in the care processes.

As expected, when assessing family risk, it was found that the homes visited should be priorities in the scheduled follow-up of the FHT, since all of them presented some degree of family risk, with almost 70% of families being at the highest level of vulnerability (V3), according to the instrument applied [6].

All patients in the study had underlying diseases and comorbidities. The most common underlying disease was stroke, a pathology that is responsible for a large number of deaths and permanent disabilities in the population and is a frequent finding in the literature [9,12,14,20]. Early management of stroke can reduce costs associated with hospital admission and the continued care through home care provides chances of better functional recovery [14].

The most prevalent comorbidity was SAH, in line with what other authors found, a national and global public health problem and an important risk factor for other cardiovascular conditions [11,12,14,20,21]. Physical inactivity on the part of bedridden people can be a predictive factor for increased blood pressure since there is an increase in peripheral vascular resistance [9]. The possibility of underreporting of Diabetes Mellitus (DM) cases in this population is also considered, as a large part is unaware of the diagnosis and does not undergo follow-up until signs of complications appear [11].

The greater the number of Chronic Noncommunicable Diseases (NCD), the greater the chance of incapacity for that individual, since the bedridden condition weakens the functioning of the body, and the problems are also associated with the time the individual is in this condition [11,22].

A prolonged period in bed facilitates the emergence of diseases such as Deep Vein Thrombosis (DVT), urinary tract infections and pneumonia [9]. The complications resulting from diseases such as hypertension and DM compromise tissue perfusion, favoring the development of pressure injuries, combined with a decrease in functional capacity [20].

The bedridden person, with little physical mobility for a prolonged period, is often susceptible to a long context of vulnerability. Immobility Syndrome contributes to progressive functional decline and loss of ability to perform activities of daily living [4,23]. Specifically regarding muscular atrophy, only seven days of bed rest are necessary for a 30% reduction in muscle strength and losses of 20% for each additional week [11].

In this research, it was found that the users investigated needed family care and frequent interventions by health professionals, due to their functional dependencies. Even the young bedridden population has similar important characteristics of dependence and care needs when compared to elderly bedridden people [12]. A previous study showed that 94% of those interviewed were dependent or semi-dependent on caregivers, requiring assistance during ADLs [4].

The percentage of sedentary lifestyle before bed is highlighted, since physical inactivity is an important risk factor for NCD or restriction to bed with progressive functional decline [9,10,21]. In this sense, knowing the users' past history when carrying out the assessment is essential, since past lifestyle habits are conditioning factors for bed-sitting [11]. Furthermore, it is up to health professionals to take advantage of the possibilities in PHC to provide health education on the adoption of healthier lifestyles to control NCD [24].

As in a recent study [14], in which the sample of individuals presents an exclusive dependence on the SUS for the assistance received, the constant presence of CHA in periodic visits stands out, denoting specific care from these important professionals for this population. The CHA helps to strengthen ties between professionals and users, expanding the possibilities of home visits, by pressuring the organization of flows [14].

Which leads us to reflect on the relevant role of this professional group in the vaccination efforts carried out for bedridden users, which have intensified in recent years due to the pandemic, ensuring broad vaccination coverage of the

sample studied. Data that cannot be celebrated as much in other regions [25,26], reinforcing the need to strengthen the link between the Family Health Strategy, responsible for information sources and community guidance, and families [10, 27].

When focusing on the caregiver, women with some degree of kinship with the bedridden person were observed: a situation frequently reported in the literature [12,13,20,26]. Culturally, there is the idea that women are responsible for care and they are the ones who usually end up assuming this demand, even when working in the job market and maintaining domestic responsibilities and caring for other family members. This configuration contributes to the emergence of biopsychosocial overload [20].

Marital status appears as a determinant in influencing who will be the main caregiver, since married users are normally assisted by their wives. Meanwhile, widowers or single people turn to their daughters or mothers for help, respectively. These, characterized as informal caregivers, do not receive remuneration and perform this role out of necessity, affection or even obligation [12].

Most family caregivers take care alone and end up deprived of their freedom, as they can hardly leave their homes, since they have no one to replace them [28].

Previous studies have indicated that caregiver overload leads to limited exercise and self-care, as well as reducing leisure time, compromising their health [4,28]. In many situations, the person providing care does not feel prepared to take on such a position, having never received any guidance.

Through health education, it is important that these families are included in the care process and trained so that they feel more confident in important decision-making, as well as receiving support, since they are also subject to care and suffer signs of exhaustion. [13].

The situations in which the burden was assessed as mild are associated with a specific degree of kinship: the mothers interviewed.

This fact is related to the cultural role and allows important reflection on maternal care and its priority for children [28].

Periodically updating family registration with appropriate completion of PHC information systems are fundamental elements for monitoring bedridden people and planning follow-up strategies by local health teams and municipal managers [4, 29]. It is essential to encourage ongoing education for multidisciplinary teams, in order to equip professionals to improve user assistance, as well as constant supervision, strengthening health surveillance [11].

Health systems are called upon to increasingly seek answers to the different demands that are emerging. In this sense, emphasis must be given to the importance of HHC in PHC, which appears as a great ally in increasing the multiple possibilities of responses from the SUS. In the case of bedridden patients, HHC is the main or only service accessed by these users [30].
HHC allows the articulation between different services, helps to optimize hospital beds and resources and expands access to services for bedridden or homebound users, in addition to representing a relevant solution to the overload of emergency doors. The impact on economics is reiterated through the reduction in public spending on health [4,30].

Finally, the need for greater coverage of areas covered by the FHT is emphasized, which is still only 27.6% in the municipality studied [31]. It is also reiterated the importance of the complete composition of minimum teams and encouraging the expansion of multidisciplinary teams to support PHC for effective and comprehensive care for the population.

CONCLUSION

This study substantiates the importance of the HCS. Even though the results of this research portray a local panorama, knowledge

of the population's reality is essential for the discussion about health care, as well as for the elaboration and implementation of public actions and policies for this specific population. This type of tracking facilitates the visualization of standardized health data of the assisted population, enabling longitudinal analysis, comparison of results with other services, as well as the assessment of the effectiveness of the home care provided.

A limitation of the study is the choice of a restricted territory in the municipality. As suggestions in future study protocols, it is possible to establish the investigation of variables such as (1) caregiver's education, (2) care guidelines for the caregiver, (3) frequency of visits and home care received and (4) perception and the users' evaluation about the assistance provided.

The scenario identified in the study expresses some vulnerabilities of HHC and PHC, still influenced by a fragmented health care model, with a strong orientation towards acute conditions. Making invisible people visible means humanizing care and providing access to health. The confrontation of these issues by health professionals can offer adequate answers to the needs of this population, which is still very neglected and unassisted.

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