

Epidemiological and psychosocial profile of informal caregivers of patients with chronic pain

Perfil epidemiológico e psicossocial dos cuidadores informais de pacientes portadores de dor crônica

Flávia Yumi Ataka¹, Raquel Lie Okoshi¹, Yuri Louro Bruno de Abreu²

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ABSTRACT

BACKGROUND AND OBJECTIVES: The importance to evaluate the informal caregiver profile is usually neglected in the face of the complaint of the patient with chronic pain, and because there is no data on informal caregivers in the Brazilian literature. The objective of this study was to elaborate the epidemiological and psychosocial description of caregivers of patients at the State Hospital Mário Covas in Santo André, SP.

METHODS: Application of the general epidemiological profile questionnaire and WHOQOL-BREF translated, by telephone, to 33 informal caregivers of patients treated at the Outpatient Clinic of Chronic Pain at the State Hospital Mário Covas.

RESULTS: The general evaluation of the quality of life of the studied population was from average to good (score of 64.01 - being zero = the worst quality of life and the 100 the best). With values above 60 for the physical domain (68.07), psychological (67.04), social relations (67.42) and environment (64.58). Care lasting on average for more than 5 years, with more than 8 hours per day and mostly by women, spouses, Catholic, aged between 30 and 60 years. Approximately 88% do not want another person to perform their activity.

CONCLUSION: Caregivers have a quality of life from average to good. Informal care is mostly performed by women.

Keywords: Chronic pain, Epidemiology, Informal caregivers, Psychosocial profile.

RESUMO

JUSTIFICATIVA E OBJETIVOS: A importância de avaliar o perfil do cuidador informal, comumente negligenciado diante da queixa do paciente com dor crônica, e por não haver dados sobre cuidadores informais na literatura brasileira. O objetivo

deste estudo foi realizar descrição epidemiológica e psicossocial dos cuidadores dos pacientes do Hospital Estadual Mário Covas, Santo André, SP.

MÉTODOS: Aplicação de questionário de perfil epidemiológico geral e o WHOQOL-BREF traduzido, via telefone, para 33 cuidadores informais de pacientes atendidos no Ambulatório de Dor Crônica do Hospital Estadual Mário Covas.

RESULTADOS: Avaliação geral da qualidade de vida na população estudada foi de média para boa (pontuação de 64,01 - sendo zero = pior qualidade de vida e 100 a melhor). Com valores acima de 60 para os domínios físico (68,07), psicológico (67,04), relações sociais (67,42) e meio ambiente (64,58). Cuidados realizados em média por mais de 5 anos, por mais de 8 horas diárias e na grande maioria por mulheres, cônjuges do paciente, católicas, com idade entre 30 e 60 anos. Aproximadamente 88% não deseja que outra pessoa exerça sua atividade.

CONCLUSÃO: Os cuidadores apresentam qualidade de vida de média para boa. O cuidado informal é realizado, em sua maioria, por mulheres.

Descritores: Cuidadores informais, Dor crônica, Epidemiologia, Perfil psicossocial.

INTRODUCTION

In Brazil, a study conducted with patients with chronic pain showed that 94.9% of the patients interviewed have their professional activity compromised^{1,2}.

In more serious cases, the patients have their mobility impaired and need a caregiver, responsible for the continuous care and aid in their daily activities. The informal caregiver is usually a family member, being responsible for assisting the patient in daily activities. Informal caregivers are family members, friends, neighbors, members of religious groups and other people in the community. They are volunteers who are willing to provide care but do not have the specific professional training³.

Several reasons lead to the delegation to the informal caregiver, such as the degree of kinship, emotional relationship, the proximity of the environment where the patient is, lack of other possibilities, self-delegation, etc⁴.

The focus of attention of the professional practice, most of the time, is the sick individual, and the caregiver is set apart from the events. Even today, family caregivers are perceived as a resource for the benefit of the individual, but not as a target of attention from the health team. They are individuals labeled to help in this process of care. It is expected that they provide care "naturally" without receiving the appropriate help and support⁵.

1. Faculdade de Medicina do ABC, Hospital Estadual Mário Covas, Santo André, SP, Brasil.
2. Faculdade de Medicina do ABC, Hospital Estadual Mário Covas, Departamento de Dor e Cuidados Paliativos, Santo André, SP, Brasil.

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Correspondence to:

R. Dr. Henrique Calderazzo, 321 – Paraíso
Santo André, SP, Brasil.
E-mail: ayflavia@hotmail.com

In this area of study about caregivers, there is a significant number of papers related to the deterioration of the health of the caregiver, both physical and psychological, with a bigger load of stress, less satisfaction with life, job loss, ruptures of bonds, isolation and reduction of social participation and loss of the purchasing power for the family over time⁶⁻⁹.

In relation to the psychosocial issues in the life of the caregiver, several studies identified cases of depression, sleep disorders, fear, greater use of psychotropics, rupture of bonds, isolation, solitude, social withdrawal, loss of social support and little life satisfaction^{9,10}.

The lack of Brazilian studies about informal caregivers and more specifically, the quality of life (QoL) of that group, justify the relevance of this study.

The objective of this study was to elaborate an epidemiological description of informal caregivers of patients treated at the Outpatient Symptoms Control Clinic of the State Hospital Mario Covas.

METHODS

The survey was conducted with 33 informal caregivers of patients treated at the Chronic Pain Clinic of the State Hospital Mário Covas (Santo André, SP), responsible for taking care of any complaint related to pain of difficult treatment. The selection criteria of the group chosen for the study was to be a caregiver who monitors chronic pain, regardless of being a member of the family or not, with the possibility of having more than one caregiver interviewed per patient. The number of invited participants was of convenience and considered the number of patients treated at the outpatient clinic with informal caregivers.

The inclusion criteria were individuals who performed the role of informal caregiver of a patient treated at the outpatient clinic after being acquainted with the objectives of the study.

All the participants in the study received information about the study, objectives, methods, risks, and benefits, as well as the secrecy of the data obtained in this study. Voluntary participation was formalized by signing the Free and Informed Consent Term (FICT) before scheduling the interview by phone.

The inclusion of more than one informal caregiver of the same patient was accepted, with no obligatorily family relation between caregiver and patient. Five interviews failed due to an error in the patient's record (wrong phone number or death of the patient in question before the date of the interview). This is an observational cross-section study, in which previously scheduled telephone interviews were conducted, 20 minutes on average, applying two research instruments. One of them has been specifically developed for this study, with questions that address sociodemographic aspects related to the caregiver's characteristics (gender, age, marital status, religion, work time, income). The other instrument was used to assess the QoL of the caregivers and, for this purpose, we chose the WHOQOL-BREF¹¹, instrument elaborated by the World Health Organization (WHO), validated for the Portuguese language¹². This questionnaire has access the QV of the interviewed ones in last the 15 days.

The WHOQOL-BREF has 26 questions. The two first ones on the general QoL and the other 24 questions composes 4 do-

main: Physical, Psychological, Social Relationships and Environment. The answers follow the Likert scale (ranging from 1 to 5, the higher the score, the better QoL). The answers of the scale vary in intensity (nothing - extremely), capacity (nothing-completely), frequency (never-always) and assessment (very dissatisfied - very satisfied, and very bad - very good). From the values found for each of the 24 facets that make up the domains, we obtained the median of responses, that is, the value that separates 50% of the responses when they are sorted.

The values establish 1 as the worse response and 5 as the best, which made it possible to see what facets received a positive or negative evaluation. For the purpose of uniformity and to allow comparison, the medians presented in facets related to pain and discomfort, drug addiction or treatment dependency, and negative feelings were inversely analyzed according to the WHO guidelines¹³.

The calculation of the QoL assessment scores was done separately in each of the four domains. The raw score was transformed into a scale from zero to 100 (score transformed according to the syntax for SPSS, proposed by the WHO). Thus, the minimum value of the scores for each domain is zero, and the maximum is 100, and the higher the score, more positive is the evaluation of the domain.

The project was submitted to the evaluation of the Committee of Ethics in Research of the School of Medicine of the ABC, CAAE: 51237315.9.0000.0082.

Statistical analysis

Data analysis was performed using IBM SPSS 30.0 (Statistical Package for the Social Sciences) and included descriptive statistics analysis of frequency, central tendency and dispersion, and inferential analysis for comparison among domains. Category variables were expressed as frequency and percentage. Numerical variables were presented with average, median and standard deviation.

The reliability of the instrument was analyzed to assess the coherence of the answers obtained in repeated measurements and the degree of independence among the results when applied on different occasions. The measurement reliability refers to consistent and accurate results. The method used to assess the reliability of the work was Cronbach's alpha. It allows you to assess whether each item of the scale measures, equivalently, the same concept, that is, if the items are positively related. Cronbach's alpha values range from zero to 1, being considered acceptable values between 0.70 and 0.90¹⁴.

RESULTS

Thirty-three caregivers of patients with chronic pain were interviewed. The sociodemographic profile of this population is shown in table 1.

Most caregivers were female (81.8%), with an average age of 50.3 years, being the youngest caregiver 21 years old and oldest 87 years. It was found that 66.7% of the caregivers are married and 54.5% have High school education. Most of the studied group claimed to be Catholic (45.5%), followed by Evangelicals (39.4%). As for the degree of kinship, 26 (78.8%) had some

Table 1. Demographic and socioeconomic characteristics of the caregivers interviewed

	n=33	%
Gender		
Male	6	18.2
Female	27	81.8
Age group (years)		
20 to 30	2	6.1
30 to 40	8	24.2
40 to 50	8	24.2
50 to 60	8	24.2
<60	7	21.2
Marital status		
Married	22	66.7
Divorced	1	3.0
Single	7	21.2
Widow	3	9.1
Education		
Illiterate	1	3.0
Elementary school	9	27.3
High School	18	54.5
College	5	15.2
Religion		
Catholic	15	45.5
Evangelic	13	39.4
Other	5	15.2
Kinship		
Father or mother	1	3.0
Son or daughter	10	30.3
Spouse	15	45.5
Other	6	18.2
None	1	3.0

degree of relationship with the patient, with 45.5% of the caregivers being spouses and 30.3% children of the patients. The characteristic of the caregivers' activities is described in table 2. It was noted that the caregivers have been performing this activity for several years, 42.4% of the population have been following the patient for more than 5 years (Figure 1). Moreover, almost all (97.0%) received no remuneration for this job, and the frequency dedicated, by and large, is daily (91.0%), with work load exceeding 8 hours a day for 78.7% of caregivers (Figures 2 and 3). In addition to the responsibilities of a caregiver, 36.4% had other activities in the workplace, and 42.4% of the caregivers performed other activities when required. Only 9.1% of the respondents would like to have someone else playing the caregiver role. Concerning the economic structure of the family, 57.6% considered that this parameter had been significantly impacted and 36.4% were responsible for bearing the cost of the medicine. Despite the high workload of the caregivers, and be performing this task for a long time, most of them do not want to have someone else taking over the role of caregiver.

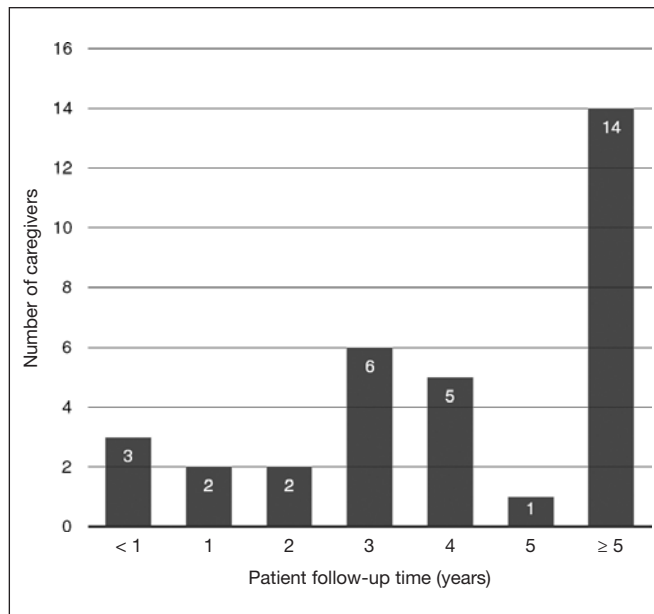


Figure 1. Distribution of caregivers regarding the time to patient care, stratified by year

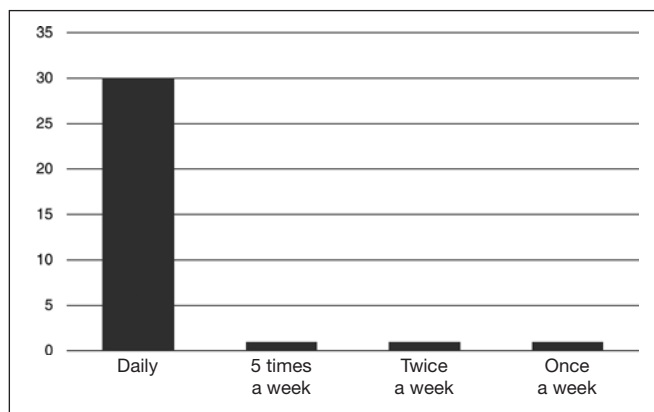


Figure 2. Distribution of caregivers regarding the time devoted to patient care, stratified by frequency per week

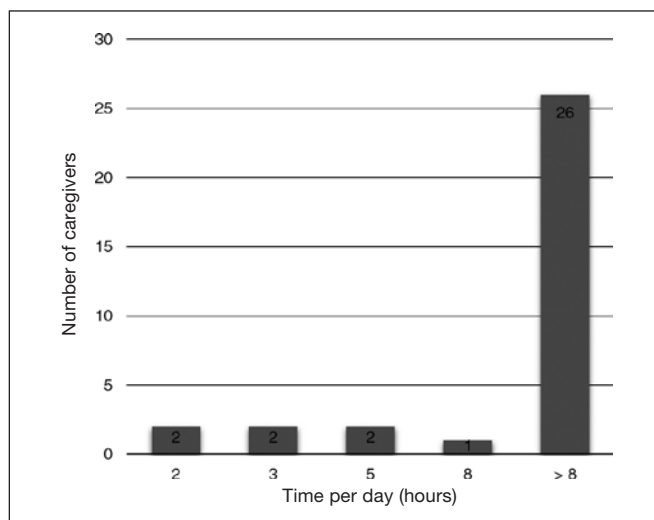


Figure 3. Distribution of caregivers regarding the time devoted to patient care, stratified by frequency per hours per day

Table 2. Characteristics of the caregiver activity

Overall evaluation	n	%
Etiology of patient's chronic pain		
Neuropathic	13	39.4
Cancer	8	24.2
Fibromyalgia	3	9.1
Others	9	27.3
How long have you been assisting the patient? (years)		
<1	3	9.1
1	2	6.1
2	2	6.1
3	6	18.2
4	5	15.2
5	1	3.0
>5	14	42.4
Are you paid for this activity?		
No	30	91.0
Yes	3	9
What is the frequency of this remuneration?		
Per hour	2	6.0
Not established	1	3.0
What is your time availability to provide care?		
Daily	30	91.0
5 times a week	1	3.0
Twice a week	1	3.0
Once a week	1	3.0
How many hours of your day are dedicated to caring?		
2	2	6.0
3	2	6.0
5	2	6.0
8	1	3.0
>;8	26	79.0
Do you share this activity with someone else?		
No	15	45.5
Yes	14	42.4
Sometimes	4	12.1
Do other family members help you?		
No	9	27.3
Yes	18	54.5
Sometimes	6	18.2
Would you like someone else taking over your role as caregiver?		
No	29	87.9
Yes	3	9.1
Sometimes	1	3.0
Why?		
No answer	29	87.9
I have other activities	1	3.0
I have long been a caregiver	1	3.0
I don't have time.	0	0.0
Other reason	2	6.1

Continue...

Table 2. Characteristics of the caregiver activity – continuation

Overall evaluation	n	%
Did the patient's disease significantly affect the economic structure of the family?		
No	8	24.2
Yes	19	57.6
Sometimes	6	18.2
In the case of a family member, are you responsible for paying the medicine?		
No	5	15.1
Yes	12	36.4
Sometimes	9	27.3
Besides being a caregiver, do you have another activity in the same place?		
No answer	5	15.2
No	2	6.1
Yes	12	36.3
Sometimes	14	42.4

The WHOQOL-BREF questionnaire had satisfactory reliability by Cronbach's alpha test result of 0.797.

The averages and standard deviations obtained from the scores with the raw values of each domain are shown in table 3. Table 4 shows the average of the values of each domain, on a scale from zero to 100, as for the WHO guidelines, for better visibility of the data. Therefore, we see that in the first two questions of the global QoL questionnaire, the studied population obtained an average score of 3.56 (64.01 in table 4, that is, a general QoL from average to good (or medium to good). Concerning the scores obtained for each domain, in general, the average is above score 3 and, on the scale from zero to 100, above 60%, suggesting that the QoL of these caregivers is between average and good. The domain with the best score was the Physical domain, with 3.72 in table 3, and 68.07 in table 4, and the worse was the Environment with 3.58 in table 3, and 64.58 in table 4.

Table 3. General analysis of the quality of life domains

References	Average	Standard deviation
Global evaluation	3.56	0.82
Physical domain	3.72	0.67
Psychological domain	3.68	0.65
Social relations domain	3.69	1.06
Environment domain	3.58	0.53

Table 4. Analysis of the quality of life domains, transforming scales to values from zero to 100, according to the World Health Organization guidelines

References	Average	Standard deviation
Global evaluation	64.01	20.43
Physical domain	68.07	16.74
Psychological domain	67.04	16.26
Social relations domain	67.42	26.69
Environment domain	64.58	13.23

Table 5 shows the domains regarding the perception of the QoL, and satisfaction in relation to health. Both evaluations had a median of 4, showing that at least half of the respondents are satisfied with the items analyzed.

Table 5. Analysis per quality of life domains

Global evaluation	Average	Median
Perception of quality of life	3.56	4
Satisfaction with the health	3.59	4

With regard to the results in each of the facets, we present the average, median and the standard deviation of the scores for each one, in its respective domain. Table 6 refers to the facets of the Physical Domain in which the item “energy and fatigue” presents median of 5, that is, at least half of the respondents assessed this aspect as very satisfied. The lowest median refers to every day’s activities (median=3). As for the Psychological, shown in table 7, all facets had a median of 4, showing that at least half of the caregivers are satisfied with their self-esteem, body image, and appearance, negative feelings, and spirituality. In this domain, it is worth mentioning that 82% of caregivers reported being satisfied or very satisfied with the physical appearance and self-esteem. Only 33.3% reported some concentration problem, and 30.3% of the respondents showed negative feelings (bad mood, despair, anxiety, and depression), very frequently or always.

Table 8 shows the results of the Social Relations Domain, and we see that caregivers were satisfied with their personal relations and the support received from friends. In both, the median was 4 and average of 3.91 and 3.48, respectively.

Environment, in table 9, shows the data of eight facets, and seven of them had good evaluations from the caregivers, with median score of 4: security, home environment, financial resources, availability and quality of the social and health care, opportunity for new information, opportunity for recreation/leisure, physical environment, and transportation. The only item with median 2 related to the opportunity for new information and skills. In this facet, 54.6% of caregivers considered the access to new information and skills very little or too little.

Table 6. Analysis of the physical domain

Physical Domain	Average	Standard deviation	Median
Energy and fatigue	3.91	1.33	5
Sleep and rest	3.79	0.89	4
Every day’s activities	3.03	1.40	3
Dependence on drugs, or treatments	3.94	0.61	4
Capacity to work	3.97	0.67	4

Table 7. Analysis of the psychological domain

Psychological Domain	Average	Standard deviation	Median
Self-esteem	3.12	1.41	4
Body image and appearance	4.03	0.64	4
Negative feelings	3.94	0.66	4
Spirituality, religion, personal beliefs	3.64	1.39	4

Table 8. Analysis of the social relation domain

	Average	Standard deviation	Median
Personal relations	3.91	1.40	4
Social support	3.48	1.23	4

Table 9. Analysis of the environment domain

	Average	Standard deviation	Median
Physical security and protection	3.91	0.68	4
Home environment	3.70	1.04	4
Financial resources	3.36	0.96	4
Health and social care: availability with quality	3.91	0.84	4
Opportunity to acquire new information and skills	2.67	1.43	2
Participation in recreation and leisure opportunities	3.76	0.90	4
Physical environment	3.48	0.90	4
Transportation	3.88	0.78	4

DISCUSSION

In this study, as well as in many others, the prevalence of female caregivers is higher to males¹⁵⁻²⁰. Several can be the reasons, such as filial obligation and women’s cultural condition in the society, still chauvinist¹⁵.

The general evaluation showed that about 78.8% of the caregivers have some degree of kinship with the patient, being 45.5% of them, spouse, a fact that is very frequently pointed out in the literature^{18,20}. Most caregivers assist the patient for over 5 years, and this activity is not remunerated in 97% of cases. The economic characteristic of the studied group, caregivers of patients with chronic pain treated by the public service of this hospital, can justify this fact since having a formal caregiver often means expenditure beyond the financial capacity of the family. For 91% of the respondents, patient care is daily and for more than 8 hours per day, adding up to more than 60 hours per week.

When asked about work rotation with another person, the results were very similar. Fifty-four percent of the respondents said they had the help from other family members. Caregiving is usually performed by one of the family members, with no help or recognition from the others^{23,24}, according to Pavarini et al.²⁵. Nevertheless, 87.9% said they do not want someone else taking over the role of caregiver. Despite the overload, caregivers feel satisfaction in taking care of the patient, because he/she is a member of the family and, in general, it is believed that this attitude is a moral duty and social and family responsibility^{15,26}. The fact that this questionnaire involves the ethical side of the interviewees, who may feel inhibited to show their feelings in relation to the task, should be considered a bias. Among those who would like to see someone else performing their duties, no respondent mentioned the lack of time as a reason for this desire. The reasons not mentioned could be emotional and physical fatigue, stress and motivation to perform other activities.

Significant changes in the family economic structure were pinpointed in 57.5% of the cases. The purchase of drugs was cited as one of the causes for this increase in spending since when the public health service does not provide the drug, the family has to buy it. Moreover, another factor that contributes to the change of the economic structure is the leave of absence, once the caregiver spends most of the time and day with the patient, being, in some cases, unable to perform other remunerated activities.

In the study, we saw that the work capacity item was indicated as the least affected by the caregiver function, whereas the accomplishment of the daily activities was pointed as the most harmed. This shows that caregivers maintain their capacity to work but find it difficult to perform other functions of their life. One can see the strong influence that care has in the daily life of caregivers. Many studies have shown that both caregiver and patient, live in the same place, which ultimately generates an increase in daily tasks, adding up the care to the household chores^{16,17}. In the Psychological domain, body image and appearance were pointed out as the least affected by the work of the caregiver, while self-esteem was seen as influenced by the activity. Other factors analyzed were negative feelings and spirituality, religion and personal beliefs. The lowest frequency of complaint regarding the appearance, while self-esteem was regarded as one of the most altered parameters, leads to questions about what points were considered by the respondents to characterize self-esteem. It is believed that excessive fatigue can justify this fact, because the caregiver no longer cares about the body image and starts to consider other parameters to characterize his/her self-esteem, such as confidence and competence, which are likely to be affected by the situation of stress and demand in which they find themselves.

Personal relations and social support were analyzed in the domain of Social Relations, where the great part of the interviewees is relatively satisfied with their social bonds. It was observed that going to church on the weekends is the main social interaction for most of them. Relationship with neighbors was also cited. This beneficial response on social bonds is of great importance since it is known that this contact with others helps to reduce cases of depression, for example. The participants who gave a negative response said that they do not get support from family or friends, which, on the other hand, contributes to an outcome of anxiety and negative feelings, making more difficult the task of the caregiver. It is known that anxiety can be an indication of an overload of the obligations the person needs to fulfill²². As for the Environment domain, physical security and protection were ranked as the most satisfactory, as well as health and social care, focusing on the availability and quality of these resources. As a downside, there was the opportunity to acquire new information and skills. Home environment, financial resources, participation in leisure activities and recreation, physical environment and transportation were also assessed. These points received a satisfactory answer in relation to the service provided by this hospital, which is considered of high quality in service, with competent and caring physicians. On the other hand, the complaint about the lack of opportunities to acquire new information and skills

shows that caregivers are restricted to the care routine, not having the chance to have access to other activities. It is worth pointing out that with regard to the family environment, the answer was positive, showing that even with the emotional burden of the care activity, the families maintain a healthy environment in their homes, without the relations being affected.

CONCLUSION

Contrary to what it is imagined about this stressful activity of informal caregiver, in the face of the different aspects analyzed, caregivers consider their QoL from average to good. Due to the shortage of national surveys about caregivers, as well as of innovative studies in the area, there is the need to improve policies and practices to reduce the stress and the overload perceived by this group.

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