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Family caregivers in home care: sociodemographic, clinical and anxiety aspects

Cuidadores familiares na atenção domiciliar: aspectos sociodemográficos, clínicos e de ansiedade

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ABSTRACT

Objective: To analyze family caregivers' sociodemographic profile, clinical profile, and anxiety levels in in-home care. **Method:** This is a quantitative, descriptive study whose data collection occurred from May to July 2021, with 30 main family caregivers of patients in home care. The data were obtained using a structured form and the State-Trait Anxiety Inventory (IDATE) and analyzed using descriptive statistics. **Results:** The family caregivers were mostly women, with an average age of 45, single, with a complete high school education and low income, dedicated full-time to care, and had comorbidities, particularly systemic arterial hypertension. As for the anxiety levels of the caregivers, it was observed that the majority had a medium level of state anxiety (IDATE-E) and a high level of trait anxiety (IDATE-T). **Conclusions:** The complexity of the demands faced by family caregivers includes socioeconomic and health challenges, both physical and mental, with an emphasis on anxiety. It is crucial to implement support interventions and public policies that ensure the health and well-being of this population.

***Descriptors*:** Family Caregiver; Home Care; Anxiety; Mental Health; Nursing.

RESUMO

Objetivo: analisar o perfil sociodemográfico, o perfil clínico e os níveis de ansiedade de cuidadores familiares na atenção domiciliar. **Método:** estudo quantitativo, descritivo, cuja coleta dos dados ocorreu de maio a julho de 2021, com 30 cuidadores familiares principais de pacientes em atenção domiciliar. Os dados foram obtidos por meio de formulário estruturado e pelo Inventário de Ansiedade Traço-Estado (IDATE), sendo analisados por meio de estatística descritiva. **Resultados:** Os cuidadores familiares eram majoritariamente mulheres, com idade média de 45 anos, solteiras, com ensino médio completo e baixa renda, dedicavam-se em tempo integral ao cuidado e apresentavam comorbidades, destacando-se a hipertensão arterial sistêmica. Quanto aos níveis de ansiedade dos cuidadores, observou-se que a maioria apresentava nível médio de ansiedade estado (IDATE-E) e nível alto de ansiedade traço (IDATE-T). **Conclusões:** A complexidade das demandas enfrentadas pelos cuidadores familiares inclui desafios socioeconômicos e de saúde, tanto física quanto mental, com ênfase na ansiedade. É crucial implementar intervenções de suporte e políticas públicas que assegurem a saúde e o bem-estar dessa população.

***Descritores*:** Cuidador Familiar; Assistência Domiciliar; Ansiedade; Saúde mental; Enfermagem.

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INTRODUCTION

Caring for a sick family member at home has become increasingly common today, impacting both the health of caregivers and family dynamics since this action can impose a substantial burden on the caregiver.[1]

The caregiver is responsible for providing care according to the needs of the individual being cared for, performing this activity regularly or continuously. Their duties range from support in basic activities such as feeding, hygiene, and locomotion to emotional support.[2] The caregiver can be classified as formal, i.e., someone who has specific training and is paid for their service, or informal, someone who has no training or pay and is usually a family member, which is the object of this study.[3]

Caring for a family member can be a rewarding experience. Still, it can also cause physical, emotional, and psychological difficulties for the caregiver since this role goes beyond helping with basic activities, as it takes on a complex range of responsibilities that impact their time, resources, and well-being. In this way, the responsibility for care and the changes in their daily lives are factors that can negatively affect the health and well-being of those who take on this role.[2,4]

Among the negative consequences of this role is anxiety, which can arise because of the overload of responsibilities, lack of support, prolonged stress, and the uncertainties associated with both the family member's state of health and the care being provided. In addition to hurting the caregiver's quality of life, this can compromise their ability to provide adequate care for the dependent person.[5,6]

Therefore, it is essential to expand our knowledge of the aspects that permeate the daily lives of family caregivers and the implications for their health. This also reinforces the importance of studies on this population's sociodemographic, clinical, and psychosocial characteristics to understand caregivers' reality and guide effective interventions. Therefore, a comprehensive overview of these aspects will make it possible to develop targeted and efficient support strategies aimed at the well-being of caregivers and the quality of care provided.

Considering the above, the aim is to analyze family caregivers' sociodemographic profile, clinical profile, and anxiety levels in home care.

METHOD

This is a quantitative, descriptive study. Thirty primary family caregivers assisted by a Home Care Service (SAD) at a university hospital in the interior of Rio Grande do Sul took part in the study. The sample corresponds to the total number of patients cared for by the

service during the data collection period. The selection criteria for the participants were as follows: being the primary family caregiver, aged 18 or over. The exclusion criterion was defined as caregivers who, although family members, were paid. However, no caregiver was excluded for this reason.

The data were collected in a hybrid way: in person at the homes of family caregivers or patients and virtually, by video call, depending on the participant's choice. This method was adopted as this stage took place during the COVID-19 pandemic, so the face-to-face collections were carried out following all biosafety recommendations.

The initial procedure for identifying family caregivers occurred during team meetings, and the SAD nurse provided information. Telephone contact was then made. During this first contact, the caregivers were informed of the purpose of the call and invited to participate in the study voluntarily, guaranteeing confidentiality, anonymity, and the right to refuse. Once they had accepted, they explained how the interview would take place and agreed on the best time and place for its realization.

Data was collected from May to July 2021 using the following instruments: Sociodemographic and clinical characterization form of the patient, containing variables such as name, marital status, ethnicity, gender, age, address, telephone number, occupation before illness, cause of hospitalization and time of the cause that led to hospitalization in the SAD; Sociodemographic characterization form of family caregivers and questions related to the performance of care, addressing the following sections: identification data, socioeconomic data, general personal background, family background, physical activity and activities performed as a caregiver; and the State-Trait Anxiety Inventory (STAI), to obtain anxiety levels.

The State-Trait Anxiety Inventory (STAI) was validated and adapted into Portuguese by Angela Biaggio,[7]and is a self-reported Likert-type instrument divided into two distinct sub-scales. The S-STAI subscale, used to assess the state of anxiety, comprises 20 questions evaluating how the person feels when answering, 10 of which are positive and 10 negative. The T-STAI subscale, which evaluates trait anxiety, is also made up of 20 questions, seven of which are positive and 13 of which are harmful, allowing us to assess how the individual feels in general. The total score is obtained by adding up the answers. It can vary from 20 to 80 points for each scale, with 20 to 34 being equivalent to a low level of anxiety, 35 to 49 a medium level of anxiety, 50 to 64 a high level of anxiety, and 65 to 80 a very high level of anxiety.

It should be noted that the state of anxiety corresponds to a temporary emotional condition related to unpleasant feelings such as tension, apprehension, and nervousness

/worry, which are referred to in acute and specific situations perceived at a given moment. The anxiety trait, on the other hand, is a personality characteristic of the individual throughout life, with the tendency to sense and react to situations perceived as threatening, being relatively more stable. It is usually observed indirectly if the individual is not faced with stressful situations.

The data obtained was stored and organized in an Excel for Windows spreadsheet, with independent double typing. Subsequently, the data was analyzed using descriptive statistics and the software above with simple (n) and relative (%) frequency analysis. They were also expressed as measures of central tendency (mean and median) and dispersion (standard deviation and maximum and minimum values). Caregiver anxiety was assessed using the scores obtained on the STAI, according to the categorization provided by the test.

The Ethics Committee approved the study for Research with Human Beings of the Educational Institution under report number 4.646.937.

RESULTS

The sociodemographic characteristics of the family caregivers participating in this study were predominantly female (76.7%), aged between 30 and 44 (43.3%), with an average age of 45 (σ14.42), single (50%), and having completed high school (33.3%). Regarding relationships, children were prevalent (50%), and spouses were prevalent (23.3%).

Regarding the professional situation of family caregivers, various jobs were identified (n=14), with the majority being housewives (20%), retired (16.7%) and unemployed (16.7%). *Per-capita* family income ranged from <1 to >2 minimum wages, the majority being <1 minimum wage (53.4%). It is worth noting that one of the participants only had an income from the emergency aid provided by the government, with a *per-capita* family income of R$74,00.

In the context of the participants' health aspects, 43.3% of family caregivers reported comorbidities, with systemic arterial hypertension (SAH) standing out (30%), followed by diabetes mellitus (DM) (16.7%), respiratory diseases (13.3%) and anxiety (10%). In addition, the continuous use of medication was recorded, including antihypertensives (20%), hypoglycemic agents (20%), statins (20%) and antidepressants (20%). Caregivers were predominantly non-smokers (80%) and those who did not drink alcohol (100%).

Regarding physical activity, the majority (73.3%) claimed not to exercise, mainly due to lack of time (43.3%), lack of will (30%), and the COVID-19 pandemic (10%). Among those who practiced some activity (26.7%), walking was predominant (16.7%).

Regarding aspects of care, it was found that the time dedicated to the family member varied from less than a month to 38 years, with a predominance of two months (33.3%). As for the time spent caring daily, most caregivers said they were involved full-time, in other words, 24 hours a day (70%). The remaining caregivers mentioned periods ranging from 9 to 18 hours daily (26.7%). However, there was one exception: a caregiver dedicated 12 hours every two days of the week and 12 hours every two Sundays.

When asked if they received help with their care, 86.7% of the participants said that they received it mainly daily (73.4%), most of which was provided by family members (83.3%), including children, partners, siblings, nephews, parents, brothers-in-law, daughters-in-law, grandchildren and aunts. This support came in various forms, from frequent or sporadic assistance with care to help with transportation, financial support, and household chores. I want to let you know that some participants mentioned receiving help from more than one group.

Regarding the types of care provided, all the caregivers mentioned assistance care (100%), which included procedures such as dressings, administering medication, checking vital signs, tracheostomy suctioning, capillary blood glucose control, changing the collection bag (colostomy), installing and controlling oxygen, and stoma care In addition, the majority were involved in caring for food and hydration (90%), hygiene (90%), comfort (76.7%) and locomotion (66.7%). Other tasks concomitant with care were reported by 96.7% of the participants, including household chores (86.7%), work (30%), and caring for other family members (26.7%), such as children, partners, and parents.

The distribution of caregivers' anxiety levels, as assessed by the STAI, was observed that 43.3% had a medium level of state anxiety (S-STAI), followed by low 30%, high 20%, and very high 6.7%. Concerning the level of trait anxiety (T-STAI), there was a predominance of high levels (36.7%), followed by low levels (33.3%) and medium levels (30%).

By relating the distribution of the levels obtained on the S-STAI to the respective levels on the T-STAI, it was observed that of the 36.7% of caregivers who had a high level of trait anxiety, 13.3% had a medium level of state anxiety, followed by high 10%, very high 6.7% and low 6.7%. A low level of trait anxiety was identified in 33.3% of the participants. In comparison, the same level of state anxiety predominated in 20%, followed by a medium level of 10% and a high level of 3.3%. Finally, of the caregivers who had an average level of

trait anxiety (30%), 20% had an average level, 6.7% had a high level, and 3.3% had a low level of state anxiety, as Table 1 shows.

Table 1. Distribution of family caregivers of home care patients according to anxiety levels on the T-STAI (trait) and S-STAI (state). Santa Maria (RS), Brazil, 2021.

Anxiety level T-STAI	n(%)	Anxiety level S-STAI	n(%)
Low	10 (33.3)	Low	6 (20.0)
		Medium	3 (10.0)
		High	1 (3.3)
Medium	9 (30.0)	Low	1 (3.3)
		Medium	6 (20.0)
		High	2 (6.7)
High	11(36.7)	Low	2 (6.7)
		Medium	4 (13.3)
		High	3 (10.0)
		Very high	2 (6.7)
TOTAL	30(100.0)	TOTAL	30(100.0)

It should be noted that some family caregivers who had lower levels of state anxiety (S) than trait anxiety (T) were being monitored by mental health professionals and/or were taking medication such as antidepressants and anxiolytics. They also reported having a more robust support network and engaging in various physical activities.

DISCUSSION

When analyzing the characteristics of family caregivers, we found a predominantly female profile, with an average age of 45, concentrated in the 30-44 age group. These findings align with various national and international studies that identify women as the primary workforce in informal care, with ages ranging from 18 to 85, and more than half of informal care is provided by this population.[8-10] This data shows the persistence of moral values historically built up in society, which naturalize women as caregivers.

Although there has been a gradual increase in male participation in caregiving, this presence is still small, possibly due to the predominance of a patriarchal culture in which men are tasked with the role of financial provider in the home.[8,11] However, when men take on the role of caregiver for a family member, they realize the difficulties and lack of skills and give new meaning to the situation, adopting attitudes compatible with the reality in which they find themselves. As caregivers, men change their habits and priorities to include themselves and adjust to the new role because, for them, caring is a choice that symbolizes affection, care, and love.[12]

In this study, there was a predominance of single marital status, which differs from studies carried out with family caregivers,[13,14] in which the majority were married. In addition, family caregivers were children caring for their parents, possibly related to increased life expectancy. This greater longevity, when accompanied by functional /cognitive losses, generates the need for continuous care, often taken on by children.[15]

Corroborating an international study,[16] results show that most family caregivers have completed high school. However, other studies found low levels of education among caregivers.[8,17] This divergence may be related to the specific characteristics of the sample and the different socioeconomic contexts in which the studies were carried out. Research conducted with family caregivers of CVA victims states that those with a higher level of education may have a more significant emotional burden due to a better understanding of their family member's health condition. On the other hand, those with a lower level of education sometimes find it more challenging to understand their family member's health situation and, consequently, have less emotional distress.[8]

Analysis of the socioeconomic aspects of family caregivers revealed a prevalence of per capita income of less than one minimum wage, confirming other studies[18,19], highlighting the social disparity that affects a large part of Brazilian society and directly impacts the lives of thousands of families. This precarious financial situation can be directly related to the need or choice to take time off work to dedicate themselves, often completely, to the family member who needs care.[5,18]

In this sense, it was found that family caregivers dedicate themselves entirely to care, with care time ranging from less than a month to 456 months (38 years). This period corroborates the findings of national and international studies with family caregivers,[6,20,21] which show the variability of care time, proving that home care can last for days, months, years, or even be permanent, depending on the degree of dependence on the family member, whether partial or total. It can, therefore, be inferred that if the individual does not regain their independence, the presence of a caregiver will be necessary.

Considering this, further studies suggest that caregivers who carry out their responsibilities for long periods and dedicate a more intense workload to care face psychological challenges, especially in their social interactions, highlighting the adverse impacts that the care routine can have on the mental health of the family caregiver.[8,18]

Regarding the activities carried out as a family caregiver, authors highlight the following as the main ones: attending appointments, helping with eating, getting around and taking medication. In addition, they point out that the caregiver's reality goes beyond direct care for the dependent family member, as they also must reconcile this demand with

domestic activities and, often, professional work.[3,10,20,22] This overload of responsibilities can lead to social isolation, physical and emotional exhaustion, and a decline in the caregiver's health and well-being.

The evidence presented shows the need for continuous care for the sick family member, exposing the family caregiver to an overload of responsibilities and increased levels of anxiety, causing economic and personal consequences and challenges, as well as interfering with their work activities and health. It should be noted that this situation has direct repercussions on their physical and emotional well-being since family caregivers are more susceptible to developing mental and physical health problems and facing an unexpected adaptation to the new dynamics of life.[14,18,22]

In this context, we can see the importance of the presence of a secondary caregiver in helping with care and reducing the anxiety and burden on the main caregiver, as observed in this and other studies.[18,23,24] The presence of a secondary caregiver can play a crucial role in distributing care responsibilities, providing moments of relief and rest for the main caregiver, and contributing to promoting the health and well-being of this individual. The support of family members, friends, or health professionals is fundamental to relieving the burden of daily care activities, as it allows the main caregiver to devote time to their own needs and reduces the adverse effects of physical and emotional overload. Thus, the presence of a secondary caregiver and social support are essential strategies for relieving anxiety, preserving the health and well-being of the primary caregiver, ensuring a better quality of life, and the ability to cope with the challenges inherent in the context of family care.[17,18,23]

Concerning the health history of the family caregivers in this study, SAH and DM emerged as the most prevalent diseases, requiring continuous medication use. This evidence is in line with the findings in literature since a similar study showed that most caregivers had some chronic non-communicable disease.[18,25] The results of this study about physical activity agree with another study highlighting low adherence, which can increase the risk of chronic non-communicable diseases and other health conditions, such as anxiety or depressive symptoms.[23,26]

Polypharmacy was also common, mainly to manage symptoms such as anxiety and muscle tension. Studies[18,27] indicate caregivers who use a lot of medication tend to be more physically and mentally overburdened, as it is understood that the presence of illnesses may be related to the role played by the caregiver, with a possible association with mental exhaustion, such as anxiety and depression. The use of a significant number of medicines, often due to self-medication, can also lead to a worsening of physical and mental overload.

Concerning the levels of anxiety investigated, the data agree with the results presented in a study[28], which used the STAI to measure the level of anxiety/stress of family caregivers and found that most of them had a medium level of state anxiety (76%) followed by a low level (24%). Concerning the level of trait anxiety (STAI-T), this study showed a predominance of caregivers with a high level (36.7%), followed by low (33.3%) and medium (30%) levels, diverging from the results presented in the study above, in which there were more cases of caregivers with a medium level (90%) followed by high (6%) and low (4%) levels. In addition, no other studies were found that used the same categorization of anxiety levels as this study, applied to family caregivers.

As for the distribution of the levels of the STAI-T with the respective levels of the STAI-S of the family caregivers presented in this study, it was evident that most family caregivers had levels of state anxiety equivalent to their trait or even exceeded this limit. It is also worth noting that some family caregivers had lower levels of state anxiety than the trait, which may be related to the fact that mental health professionals and/or were monitoring them were taking medication such as antidepressants and anxiolytics. They also reported having a more extensive support network or practicing various types of physical activity. However, no studies were found that addressed the relationship between anxiety levels in this population.

However, regarding physical activity, research shows that constant practice benefits mental health and physical well-being and can reduce behavioral problems. The most prominent benefits include a reduction in depressive and anxiety symptoms, as well as a reduction in negative emotional responses to stress and the use of psychoactive substances, which promotes more effective emotional regulation.[29]

The limitation of this study is that the sample was restricted to a certain geographical region and a specific institution, which may hinder the generalization of the results to other populations or health contexts. Although this study provides essential data, it is important to recognize that it represents only part of the complex panorama of home care and the needs of patients and family caregivers. However, the information from this study enables professionals to implement more comprehensive and practical care actions, considering the specific needs of caregivers. In addition, they can direct future research by providing a broader picture of the reality of family caregivers.

CONCLUSION

The results of this study reflect the complexity and demands of family caregivers of patients in home care. The overload of tasks the caregivers face results in economic, social, and health repercussions, affecting their physical and mental well-being. The socioeconomic

analysis of this population reveals significant challenges, including financial precariousness and the prevalence of chronic diseases. In addition, family caregivers predominantly showed medium, high, and very high levels of anxiety, highlighting the importance of a comprehensive approach for this population.

Family caregivers with state anxiety levels below the trait generally sought support from mental health professionals, used medication such as antidepressants and anxiolytics, and reported having a more robust support network or being involved in various physical activities. This highlights the crucial role of support in mitigating the impacts of care on their health.

It is, therefore, necessary for nursing, as a theoretical-practical science, to consider the scientific evidence that identifies the burden of caring as a generator of anxiety to formulate interventions that offer support and strengthen the support network of caregivers at home to improve the quality of life of this population. As a possible strategy, we suggest the development of support groups and, in the academic sphere, extension projects with periodic meetings with family caregivers in primary care, creating a support network for exchanging experiences between caregivers, students, and health professionals.

In this context, more research on this topic, covering psychology and public management, is crucial. This research will help draw up public policies that offer these caregivers financial, professional, and psychosocial support and invest in health promotion, ensuring a more inclusive and sustainable care system. This approach will benefit caregivers and positively impact the quality of patient care, promoting a more harmonious and practical relationship between all those involved in the care process.

CONTRIBUTIONS

PP Paz contributed to all stages of the article's production: conception, data analysis and interpretation, writing, critical revision of the content, and final approval of the version to be published. JM Druzian and DGM Duizith contributed to the writing, critical revision, and final approval of the version to be published. K Rossato, CS Silveira, and DF Siqueira contributed to the critical revision of the content and the final approval of the published version. NMO Girardon-Perlini contributed to the conception, data analysis, writing, critical revision of the content, and final approval of the version to be published.

CONFLICT OF INTERESTS

The authors declare no conflict of interest.

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