

Perception of Family Caregivers Regarding Care for the Elderly

Percepção de Cuidadores Familiares em Relação ao Cuidado à Pessoa Idosa

Percepción de los Cuidadores Familiares en Relación Con el Cuidado de las Personas Mayores

RESUMO

Objetivo: Descrever a percepção de cuidadores familiares acerca do cuidado à pessoa idosa. **Método:** Estudo qualitativo com nove cuidadores familiares de pessoas idosas residentes no município da fronteira oeste do Rio Grande do Sul. Os dados foram analisados conforme Bardin. **Resultado:** Houve prevalência do sexo feminino e do estado civil solteiro. Emergiram duas categorias: Dificuldade e cansaço diante da responsabilidade e rotina diária e Cuidado em meio a empatia e gratidão. **Conclusão:** O cuidador familiar tem um papel fundamental para a pessoa idosa, sendo necessário dar apoio e suporte para o enfrentamento dos sentimentos que geram uma experiência de sobrecarga e estresse. **DESCRIPTORIOS:** Idoso; Cuidadores; Atenção Primária à Saúde; Enfermagem

ABSTRACT

Objective: To describe family caregivers' perceptions of caring for older adults. **Method:** Qualitative study with nine family caregivers of older adults residing in the western border municipality of Rio Grande do Sul. Data were analyzed according to Bardin. **Result:** There was a prevalence of females and single marital status. Two categories emerged: Difficulty and fatigue in the face of responsibility and daily routine, and Care amid empathy and gratitude. **Conclusion:** Family caregivers play a fundamental role for the elderly, and it is necessary to provide support to help them cope with the feelings that generate an experience of overload and stress.

DESCRIPTORS: Elderly; Caregivers; Primary Health Care; Nursing

RESUMEN

Objetivo: Describir la percepción de los cuidadores familiares sobre el cuidado de las personas mayores. **Método:** Estudio cualitativo con nueve cuidadores familiares de personas mayores residentes en el municipio fronterizo occidental de Rio Grande do Sul. Los datos se analizaron según Bardin. **Resultado:** Hubo una prevalencia del sexo femenino y del estado civil soltero. Surgieron dos categorías: Dificultad y cansancio ante la responsabilidad y la rutina diaria y Cuidado en medio de la empatía y la gratitud. **Conclusión:** El cuidador familiar tiene un papel fundamental para la persona mayor, siendo necesario brindar apoyo y respaldo para enfrentar los sentimientos que generan una experiencia de sobrecarga y estrés.

DESCRIPTORIOS: Anciano; Cuidadores; Atención Primaria de Salud; Enfermería

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INTRODUCTION

The number of older adults with chronic noncommunicable diseases has increased as the global population ages¹, requiring more complex care². Chronic noncommunicable diseases are characterized by specificities such as exacerbation of the disease with the need for hospitalization, sometimes prolonged, requiring a multidisciplinary approach until the end of life³.

Individuals with limitations live in chronic care-dependent processes, most often requiring continuous home care. It should be noted that care for dependent elderly people is usually provided by a family member, who is responsible for continuing treatment at home, assisting the elderly person with necessary demands, as well as with basic and instrumental activities of daily living⁴.

Family caregivers are, almost without exception, informal caregivers. They provide care and assistance without remuneration and, moreover, are not healthcare professionals⁵. They play a fundamental role in providing physical, emotional, and social support to older adults⁶. It is also mentioned that providing this care is a challenge that involves emotional,

physical, and financial aspects that tend to impact the ability to provide ideal care, especially due to the lack of information and training for family caregivers. Another barrier is linked to social isolation and community support.⁷

Given this context, the following research question was formulated: What is the perception of family caregivers regarding care for the elderly? Thus, the research aimed to describe the perception of family caregivers regarding care for the elderly.

METHOD

Qualitative study guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.¹¹ Data were collected in December 2022 and January 2023 in the homes of elderly people living in a municipality on the western border of Rio Grande do Sul, belonging to the territory of two Family Health Strategy units. The interviews were conducted after prior training by four interviewers, students in the bachelor's degree program in nursing. All were female and had no prior contact with the participants.

The nine family caregivers participating in the study were selected by

intentional sampling. The inclusion criteria were: the person whom the elderly considered to be family, aged 18 years or older, who were in full possession of their mental faculties and able to express themselves verbally. This study used the concept that family is who its members say they are, since family is understood as a group of people united by strong emotional bonds, with a sense of belonging and a tendency to participate in each other's lives⁹.

Formal caregivers or those who received some form of remuneration for providing care were excluded, as were caregivers who had speech disorders such as aphasia and dyslalia, preventing them from expressing themselves verbally, and those who had some cognitive deficit as measured by the Mini Mental State Examination with cut-off points of^{23/24}.

The data collection instrument was developed by the researchers and used in the interviews. These were also recorded in audio format and, after completion, the recordings were transcribed. The interviews were interrupted upon data saturation.

To characterize the sample, a sociodemographic questionnaire was used, consisting of objective questions directed at the elderly person and the

family caregiver (gender, age, race/color, marital status, education, income, profession, and length of time providing care). A script of open-ended questions was used to assess family caregivers' perceptions of the care provided: "How has caring for the elderly person been?"; "Tell me about your daily life as a caregiver"; "Do you have help from anyone else in caring for the elderly person?"; and "How do you feel about caring for the elderly person?"

The interviews lasted between eight and eighteen minutes. No field notes were taken, no pilot test was conducted, and the interviews were not returned to the participants. The recordings were transcribed in full and analyzed according to the content analysis proposed by Bardin¹¹. The steps described as pre-analysis, analytical description, and inferential interpretation of the content obtained were followed. In the first stage, an exploratory reading was performed by relating the answers to the theme under which each question was developed. Next, in the analytical description phase, the data were organized and systematized by categories and subcategories of analysis, and finally, the significant units were identified from the reports categorized according to what was identified in the interviews. For the discussion and presentation of the results, the statements were numbered from 1 to 9, and the letter "C" was used to represent "caregiver." However, there was no feedback to the participants.

This study complied with the ethical aspects in accordance with number 5,698,799 of the approval opinion of the Research Ethics Committee (CEP) under CAAE: 62731522.60000.5323.

RESULTS

Based on the categorization of the participants' reports, following the

order of recording, transcription, and content analysis, two categories were listed: "Difficulty and fatigue in the face of responsibility and daily routine" and "Care amid empathy and gratitude."

From this perspective, of the nine family caregivers, seven were female, aged between 20 and 60. In terms of marital status, five were single, three were married, and one was widowed. In terms of race, they were predominantly white. Of the nine interviewees, two had incomplete high school education, four had completed high school (one of whom had completed a technical course), one had completed elementary school, one had incomplete elementary school education, and one had completed higher education. Monthly income ranged from one minimum wage to three minimum wages. In terms of profession, three were unemployed, two were retired, and four did not mention their profession.

In terms of their relationship to the elderly person, five said they were children, two were spouses, one was a granddaughter, and one did not say. The length of time they had been providing care ranged from six months to 15 years. Finally, of the nine caregivers interviewed, only two had help in caring for the elderly person, and they were the residents of the home themselves or close family members.

Difficulty and fatigue in the face of responsibility and daily routine

Dedication to care and changes in routine were reported, in addition to interruptions in professional careers. *It has changed a lot, hasn't it... Yes... it has changed a lot. I walk around, she depends on me more, right? I live here with her... it's a routine now, tiring, right... I've always lived with her, but over the years, she has become more difficult, weaker, and then I had to take care of her (C1).*

It's just us here at home. Me, my father, and my mother. She has another daughter, but she doesn't... she doesn't participate (C3).

Look, with illness it's really difficult. It's just those at home, and even then... (C4).

I'm not working right now. I stopped working so I could take care of him... (C9).

Amidst the difficulties, stress and fatigue stood out in the act of caring. *Ah, a little, I feel a little like that... Specially a little restricted, right?! (C2).*

It's not easy not to take care of her, it's a little difficult (C3).

In the beginning, it was even simpler, right... but it's always a rush... Tiring, but you also get a few hours of rest (C4). Tiredness, exhaustion, stress... not having time for anything... Ah, it's difficult. (C6)

Like, I can't go out, I can't travel... I have a son too, and I switched because he's also a son, right... (C9).

It was identified that sharing daily care activities among family members directly impacts the quality of care, as it reduces the burden on those involved.

There are three of us daughters taking care of him here, right! Yeah, in this case, it's one day for each daughter, and we take care of him with love, right! (C5).

Care amid empathy and gratitude:

Positive feelings related to gratitude and empathy were also mentioned by family caregivers.

It's been really good taking care of him (C5).

Because you put yourself in the other person's shoes, right? You're not free, you're not old enough to have these problems, right? (C1).

I learned to put myself in the other person's shoes, so I say this: I take care of my husband the way I would like to be

treated, the way I would like to be cared for (C4).

Caring for her is not tiring. For me, it is rewarding to be able to care for her (C3).

DISCUSSION

The predominance of female family caregivers has been identified in other locations¹². Furthermore, 73.07% of caregivers were children, and in this study, of the nine interviewees, five were children. In line with this, other studies show that, globally, family caregivers of older adults are female, mostly daughters and spouses¹²⁻¹⁴.

A study conducted in Itajubá, in southern Minas Gerais, also supports this finding, as it is understood that when one is unemployed, it is impossible to work and perform the role of caregiver, given that older adults require care for their basic and specific needs¹⁵. Of the caregivers interviewed, three were unemployed and justified their unemployment as a result of a change in routine.

The impact of overload on informal caregivers of older adults, education is an important aspect. This can hinder or prevent the understanding of professional information about older adults, creating tension in the face of the responsibility of being a caregiver. In this study, of the nine interviewees, two had incomplete high school education and one had incomplete elementary school education.

Meanwhile, the other participants, who have completed high school, report that the routine is difficult, tiring, and stressful.

According to a study conducted in two Family Health Strategies in a municipality in the mid-north region of the state of Mato Grosso, caring for a dependent elderly person has direct implications for family caregivers, as they mention changes in routine and habits. Also, caring for an elderly person involves daily care, requiring knowledge, competence, and initiative, and often family caregivers are not prepared¹⁷.

Daily care can be very exhausting, especially for family caregivers, triggering severe exhaustion related to their daily routines being different, having to give up work and leisure to care for the elderly person¹⁸. This context highlights the need for psychological, physical, and social support and information about caregiving, which, when addressed, significantly reduces the burden¹⁹.

It is also mentioned that shared care with the family, as well as education in resilience, is effective in reducing the stress of family caregivers of elderly people with chronic diseases²⁰. Regarding the positive feelings identified, empathy is a multidimensional experience and is linked to the ability to understand and share experiences for appropriate responses²¹.

The feelings of gratitude, meaning of life, and love expressed by caregiv-

ers, especially when caring for an elderly family member, strengthen the caregiver/elderly person relationship and can generate satisfaction in the form of care in return²². The experience of caregiving, when anchored in affection, solidarity, and a sense of gratification, provides caregivers with a sense of well-being⁽²³⁾. Thus, it is clear that the act of caregiving also generates positive feelings, positively impacting the daily routine of family caregivers of dependent elderly people.

CONCLUSION

This study aimed to describe family caregivers' perceptions of caring for the elderly. Family caregivers are key to effective care. The act of caring takes place amid seemingly contradictory feelings such as stress, fatigue, gratitude, and empathy, which not only coexist but are deeply interconnected.

It is necessary to empower family caregivers with information and seek alternatives to support their inherent care needs beyond personal ones. From this perspective, face-to-face and virtual health education strategies can assist in this process. Primary health care professionals are essential in identifying and implementing effective solutions. Through research, teaching, and outreach activities, universities can contribute to this process through new studies, training courses, and outreach activities focused on the specific needs of family caregivers.

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