

The Experience of Family Caregivers of Elderly People in Palliative Care: Decision-Making

Vivência do Cuidador Familiar de Pessoas Idosas em Cuidados Paliativos: Tomada de Decisão

La Experiencia de los Cuidadores Familiares de Personas Mayores en Cuidados Paliativos: Toma de Decisiones

RESUMO

Objetivo: compreender a vivência do cuidador familiar no processo de tomada de decisão compartilhada em cuidados paliativos a pessoa idosa na Atenção Primária à Saúde. **Método:** Estudo qualitativo realizado entre outubro de 2022 e fevereiro de 2023 com dez cuidadoras familiares de pessoas idosas em cuidados paliativos na Atenção Primária à Saúde. Os dados foram analisados segundo Bardin. **Resultados:** Construíram-se as seguintes categorias: Informações ao cuidador familiar necessárias para a tomada de decisão; habilidades de enfrentamento do cuidador familiar para a tomada de decisão. **Conclusão:** Os recursos e habilidades de enfrentamento foram associadas ao apoio oriundo de informações sobre os cuidados ao longo do curso da doença para gerar segurança e conforto na tomada de decisão.

DESCRIPTORES: Idoso; Cuidados paliativos; Família; Tomada de decisão.

ABSTRACT

Objective: to understand the experience of family caregivers in the shared decision-making process in palliative care for older adults in primary health care. **Method:** Qualitative study conducted between October 2022 and February 2023 with ten family caregivers of older adults in palliative care in primary health care. The data were analyzed according to Bardin. **Results:** The following categories were constructed: Information needed by family caregivers for decision-making; coping skills of family caregivers for decision-making. **Conclusion:** Coping resources and skills were associated with support from information about care throughout the course of the disease to generate security and comfort in decision-making.

DESCRIPTORS: Elderly; Palliative care; Family; Decision-making.

RESUMEN

Objetivo: comprender la experiencia del cuidador familiar en el proceso de toma de decisiones compartidas en cuidados paliativos para personas mayores en la Atención Primaria de Salud. **Método:** Estudio cualitativo realizado entre octubre de 2022 y febrero de 2023 con diez cuidadoras familiares de personas mayores en cuidados paliativos en la Atención Primaria de Salud. Los datos se analizaron según Bardin. **Resultados:** Se construyeron las siguientes categorías: Información necesaria para el cuidador familiar para la toma de decisiones; habilidades de afrontamiento del cuidador familiar para la toma de decisiones. **Conclusión:** Los recursos y habilidades de afrontamiento se asociaron con el apoyo derivado de la información sobre los cuidados a lo largo del curso de la enfermedad para generar seguridad y comodidad en la toma de decisiones.

DESCRIPTORES: Ancianos; Cuidados paliativos; Familia; Toma de decisiones.

Melissa Frezero Consiglio

Nurse. Hospital at Steinenberg

ORCID: <https://orcid.org/0000-0001-5460-3841>

Cenir Gonçalves Tier

Nurse. Doctor of Nursing. Nursing professor at the Federal University of Pampa.

ORCID: <https://orcid.org/0000-0003-1539-7816>

Aline Ost dos Santos

Nurse. PhD candidate in Science. Federal University of Rio Grande

ORCID: <https://orcid.org/0000-0002-1849-9933>

Marcia Adriana Poll

Nurse. PhD in Nursing. Nursing professor at the Federal University of Pampa

ORCID: <https://orcid.org/0000-0002-9451-9991>

Silvana Bastos Cogo

Nurse. PhD in Nursing, Nursing professor at the Federal University of Santa Maria

ORCID: <https://orcid.org/0000-0002-1686-8459>

Leticia Dickow

Nursing undergraduate at the Federal University of Pampa

ORCID: <https://orcid.org/0009-0004-3479-5734>

Marina Peres Alves

Nursing undergraduate student at the Federal University of Pampa

ORCID: <https://orcid.org/0009-0002-0628-0675>

Marianna Jorge da Silva

Nursing undergraduate student at the Federal University of Pampa

ORCID: <https://orcid.org/0009-0005-6750-3782>

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INTRODUCTION

Aging is a process defined as gradual, irreversible, individual, continuous, physiological, coupled with various psychological, social, economic, and political transformations¹. Chronic noncommunicable diseases influence daily activities and autonomy, leaving sequelae and disabilities that will perpetuate until the process of death and dying².

In this context, when the disease is no longer responsive to any type of curative treatment, Palliative Care (PC)³ promotes comfort, relief from pain and suffering, and improved quality of life. PC encompasses an approach to the family during the processes of illness, death, and mourning.

Multidisciplinary actions must occur to meet the demands of patients and their families during the course and planning of care. Family caregivers take on the responsibility for care, especially when it comes to caring for dependent elderly people who require greater interventions in different aspects of their physical, emotional, social, cultural, spiritual, and ethical lives.

Throughout this journey, family caregivers tend to need to engage in shared decision-making (SDM). Given these assumptions, communication between health professionals and family caregivers can be considered the cornerstone of the SDM process.

Given the above, this study aims to understand the experience of family caregivers in the shared decision-making process in palliative care for the elderly in Primary Health Care. The guiding question is: What are the experiences of family caregivers of elderly people in palliative care in the decision-making process in Primary Health Care?

METHODOLOGY

This is an exploratory-descriptive

study with a qualitative approach guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ)⁶.

The inclusion criteria for family caregivers were: age 18 years or older, being in full possession of their mental faculties as determined by the Mini Mental State Examination, being able to express themselves verbally, and agreeing to have the interview recorded. Formal caregivers, caregivers with speech disorders such as aphasia and dyslalia, preventing them from expressing themselves verbally, and those who presented some cognitive deficit as measured by the Mini Mental State Examination with cut-off points of 23/24⁷ were excluded.

Data collection was carried out by nursing students between October 2022 and February 2023 in the homes of elderly people receiving palliative care, covering three Family Health Strategies in a municipality on the western border of Rio Grande do Sul, chosen intentionally and for convenience.

The data were collected through semi-structured interviews that addressed information about the family caregiver's experience in the shared decision-making process in palliative care. The interviews lasted an average of 30 to 40 minutes. Data analysis was performed using content analysis, which was organized into three different phases. The first phase involved a preliminary reading, followed by the establishment of meaning clusters and, finally, the processing of results and interpretation of objective data⁸.

In compliance with the ethical prerogatives of research involving human beings, the project was submitted, analyzed, and approved by the Ethics and Research Committee (CEP) in accordance with Resolution No. 466 of 2012 within the scope of the CEP, under registration CAAE: 62758122.6.0000.5323 and opinion

number: 5,799,695

RESULTS

The sample is characterized as follows: 10 caregivers of elderly people, aged between 50 and 59 years (n= 04;40%), of whom (n= 04; 40%) are married. In terms of race/color (n=8; 80%), they consider themselves white. In terms of education (n=02; 20%), they have incomplete elementary school education.

In terms of work activity (n= 06; 60%), they consider themselves housewives and (n=5; 50%) earn less than the minimum wage. Among the caregivers of the elderly (n= 07; 70%) were daughters, while the others (n= 03; 30%) had some type of family relationship, being wives and daughters-in-law. In terms of time (n= 08; 80%), they have been providing care for over a year.

Two categories were identified: I. Information necessary for family caregivers to make decisions; II. Coping skills of family caregivers for decision-making.

CATEGORY I - INFORMATION NECESSARY FOR DECISION-MAKING

The help of other family members in caregiving was identified as a facilitator of comfort and security in decision-making.

It is necessary [...] now Fulana can help me, right, I ask for an opinion and everything, but before I didn't have that. I had to figure it out on my own. I can no longer count on him for these things. So... it's me, I either succeed or fail. (E3)

Another resource for TDC includes information from health professionals to clarify the entire process of the elderly person's illness, which would help overcome insecurities and fears.

[...] how to care for him properly. There are many things we don't know if we're doing right. For example, we

heard that it would be good for him to do physical therapy now [...] we really have doubts. (E3)

The information received by family caregivers is not as understandable as it should be. In other words, they are aware of their family member's condition, but they do not know how to explain it or do not have knowledge about treatment options, do not understand how chronic health conditions develop, and often do not know what to expect from the disease:

Then Dr. Livia said, "Look, you have a little problem there... you thought it was hemorrhoids, but I saw something more serious there. Your anemia has changed, your kidney has changed, and we'll have to treat that later [...] And she talked about the symptoms of the disease... The doctor said it was like... malignant cancer, he said. (E1)

Symptoms like that are what we observed. That she stopped talking, stood still like that, staring into the distance [...] We knew it was in her head, I think. I don't know what happens. (E4)

It is noted that the search for necessary information occurs through the internet, the exchange of knowledge with other people who have similar experiences, in addition to the assistance provided by the Primary Health Care team, such as doctors and community health agents.

[...] we talk among relatives to find out how it is, right? The thing my brother finds very strange is how careful she is. (E1)

I go to the clinic to ask for advice... something. It's the only place, there's nowhere else. (E2)

Now that the community health agent is here, I feel sorry for her, because I call her for anything. Poor thing. She's been a blessing in my life. Because she brings the doctor, checks the medication. (E3)

On the internet. (E8)

Medical expressions and terms were also cited as something difficult to understand.

The one I mentioned, he doesn't explain things, he's dry. It seems like you can't ask him anything. He did the surgery and never said anything or came and explained like the others did. (E3)

They clarify things, but sometimes they use a lot of medical jargon. That's annoying because I keep asking and asking until I really understand. (E4)

There is no adequate reception or explanation about the disease or changes resulting from the sequelae that impact his quality of life and well-being. (E6).

TDC involves receiving and assimilating information about the course of the disease, in addition to the risks and benefits of the treatments that are performed, such as pain management through drug treatment. The information precedes this stage.

CATEGORY II - COPING SKILLS FOR DECISION MAKING

The coping skills of family caregivers develop throughout the course of their loved one's illness. Therefore, beliefs and the development of faith and religion emerge as a predominant factor in coping with both the disease process and the relief of their loved one's suffering. They also have faith in their family member's recovery:

[...] the doctor said there's no turning back, right? But I believe this... in my God... that God knows... her time [...] the doctor may give up hope, but my God does not give up hope. (E1)

With God, my support. Only God himself. [...] God helps me a lot. (E3).

Coping skills are essential for family caregivers of elderly people in CP for TDC. Information and clarification are fundamental, as is resilience derived from faith, religion, and the reframing of personal beliefs.

DISCUSSION

The incorporation of palliative care into Primary Health Care must be consolidated, taking into account the specificities of the Brazilian community⁹. Studies indicate that making certain important decisions together with other family members can be an important factor in the non-traumatic protection of post-traumatic stress symptoms in the end-of-life context. When care is shared with other members, it can alleviate the burden on the primary family caregiver¹⁰.

It should be noted that this rotation strengthens the resolution of problems related to the disease, improving the care provided¹¹. It is mentioned that the caregiver of a patient in palliative care tends to face feelings such as fear, anguish, and suffering, lacking information and support for care and emotional support to cope. Therefore, health professionals, including nurses, are essential¹².

When exploring the experiences of family caregivers, patients, and the involvement of health professionals, it is important to mention that decisions in PC encompass existential aspects, desires, and wishes, as well as decisions about drug and non-drug treatment. Given this, transparency in information about what TDC actually is, how it should be carried out, and how healthcare professionals can contribute to this process is crucial¹³.

It is also pointed out that the resources, coping skills, and information necessary for TDC are associated with the provision of information by healthcare professionals in a sufficiently understandable and truthful manner. Dialogue about disease progression, comfort, quality of life, and death with patients and their families is essential. When implemented in Primary Health Care, TDC still needs to be further developed, and more research is needed on its applicability

due to its relevance in ensuring evidence-based practice and, above all, the basis for taking into account the patient's values and preferences¹⁴.

The importance of communication among the multidisciplinary team in sharing care is emphasized, since there are weaknesses in the dialogue between the team, the patient, and family caregivers. It is considered that if this multidisciplinary support does not occur, caregivers seek other means to resolve their doubts, which can have devastating consequences¹⁵.

Based on this logic, the implementation of palliative care in Primary Health Care by a multidisciplinary team in order to ensure the resolution of emotional, physical, social, and spiritual demands should include, at a minimum, a physician, nurse, psychologist, and social worker¹⁶. It is evident that the role and involvement of nurses and other health professionals in TDC in CP is not yet well defined, making the effectiveness of the person-centered approach a challenge in this process¹³.

On the other hand, nurses are fundamental in preparing caregivers to make decisions about palliative care for their family members¹⁷. In

this process, effective communication is essential in aligning the patient's wishes and desires¹⁸.

The competencies and skills of nurses to ensure TDC tend to impact patient outcomes and the positive experience of care¹⁰. It should be noted that this communication process involves looking at the finitude of life, covering numerous ethical issues regarding autonomy and beneficence, as well as emotional and support aspects that include educational actions that must be aligned with both symptom management and patient preferences²⁰.

Regarding the coping skills of family members for decision-making, beliefs and faith were mentioned. It is noteworthy that spiritual care integrates palliative care in a holistic and humanized way and should be part of care planning to offer emotional and spiritual support according to the values, faith, and preferences of patients and their families²¹.

It is necessary to emphasize palliative care in primary health care, the finitude of life as part of public policies aimed at people with life-threatening diseases beyond the possibilities of cure for decisive actions,

systematization of end-of-life care in primary care, and health education actions in this context to promote care and shared decision-making. Finally, palliative care in primary health care needs to advance significantly for consolidation in Brazilian territories²².

The main limitation of this study is the small sample size. As a contribution to the field of nursing, it is necessary to conduct studies with professionals and, at the same time, offer health education to strengthen the foundation and, ideally, conduct surveys with individuals receiving palliative care within communities.

CONCLUSION

The study provided insight into the experiences of family caregivers of elderly people in palliative care, which are permeated by the need for information to ensure effective decision-making. It is important to note that promoting knowledge, effective communication and listening, and awareness of palliative care among family members is essential. The healthcare team should facilitate the decision-making process by providing information and clarifying doubts.

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