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### The experience of grief among elderly people after the loss of a family member or significant person

Vivência do luto em pessoas idosas após a perda de familiar ou pessoa significativa

Vivencia del duelo en personas mayores tras la pérdida de um familiar o una persona significativa

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## ABSTRACT

**Objective:** To understand the experience of grief among elderly people after the loss of a family member or significant person.

**Method:** Qualitative research supported by the theoretical-methodological framework of constructivist Grounded Theory, carried out in three Basic Family Health Units in Northern Santa Catarina, between July 2022 and February 2023. Data were collected through semi-structured interviews with 24 bereaved elderly individuals and analyzed by initial and focused coding, with the support of NVivo® software.

**Results:** The data analysis allowed us to identify the experience of grief among elderly people after the loss of a family member or significant person as the central category, consisting of the following subcategories: identifying the power position of healthcare professionals; finding themselves without clarification at the time of loss; and receiving support from healthcare professionals.

**Final considerations:** The study showed that the experience of loss among elderly people is strongly mediated by interactions with healthcare services during the illness and death of a family member, in a context still permeated by asymmetrical relationships between professionals and users and by weaknesses in communication. In contrast, Primary Health Care demonstrated potential for establishing bonds, attentive listening, and follow-up care within the community for bereaved elderly people.

**Descriptors:** Aged; Bereavement; Universal Health Care; Health Services.

## RESUMO

**Objetivo:** Compreender a vivência do luto em pessoas idosas após a perda de familiar ou pessoa significativa.

**Método:** Pesquisa qualitativa sustentada pelo referencial teórico-metodológico da Teoria Fundamentada nos Dados construtivista, realizada em três Unidades Básicas de Saúde da Família no norte de Santa Catarina, entre julho de 2022 e fevereiro de 2023. Os dados foram coletados por meio de entrevistas semiestruturadas com 24 pessoas idosas enlutadas e analisados por codificação inicial e focalizada, com apoio do software NVivo®.

**Resultados:** A análise dos dados permitiu identificar, como categoria central, a vivência do luto em pessoas idosas após a perda de familiar ou pessoa significativa, constituída pelas seguintes subcategorias: identificando o lugar de poder dos profissionais de saúde; encontrando-se sem esclarecimento no momento da perda; e recebendo suporte dos profissionais de saúde.

**Considerações finais:** A vivência da perda entre pessoas idosas é fortemente mediada pelas interações com os serviços de saúde durante o adoecimento e a morte do familiar, em um contexto ainda permeado por relações assimétricas entre profissionais e usuários e por fragilidades na comunicação. Em contrapartida, a Atenção Primária à Saúde demonstrou potencial para o estabelecimento de vínculo, escuta e acompanhamento no território de pessoas idosas enlutadas.

**Descritores:** Idoso; Luto; Assistência de Saúde Universal; Serviços de Saúde.

## RESUMEN

**Objetivo:** Comprender la vivencia del duelo en adultos mayores tras la pérdida de un familiar o persona significativa.

**Método:** Investigación cualitativa, sustentada en el marco teórico-metodológico de la Teoría Fundamentada constructivista, realizada en tres Unidades Básicas de Salud Familiar del norte de Santa Catarina, entre julio de 2022 y febrero de 2023. Los datos se recopilieron mediante entrevistas semiestructuradas con 24 adultos mayores en duelo y se analizaron mediante codificación inicial y focalizada, con el apoyo del software NVivo®.

**Resultados:** El análisis de datos permitió identificar la experiencia de duelo en adultos mayores tras la pérdida de un familiar o persona significativa como la categoría central, compuesta por las siguientes subcategorías: identificar la posición de poder de los profesionales de la salud; sentirse sin claridad en el momento de la pérdida; y recibir apoyo de los profesionales de la salud.

**Consideraciones finales:** El estudio demostró que la experiencia de pérdida en las personas mayores está fuertemente mediada por las interacciones con los servicios de salud durante la enfermedad y el fallecimiento de un familiar, en un contexto aún caracterizado por relaciones asimétricas entre profesionales y usuarios, así como por deficiencias en la comunicación. Por el contrario, la Atención Primaria de Salud demostró potencial para establecer vínculos, escuchar y brindar apoyo a las personas mayores en duelo en sus comunidades.

**Descriptores:** Anciano; Aflicción; Atención de Salud Universal; Servicios de Salud.

## INTRODUCTION

Grief is a natural response to the experience of loss. Despite advances in health research regarding the loss of someone significant and its consequences, the phenomenon of grief has only recently been studied and recognized concerning its impact on the health of those who experience it. The narratives of bereaved individuals highlight the need for better preparation for grief and the importance of receiving accurate information from healthcare professionals, using inclusive language throughout the care process, as well as during the loss and bereavement itself, especially in care settings closest to the bereaved individuals, such as community health services<sup>(1)</sup>.

Although it is a phenomenon that has recently become a concern among health professionals and researchers, providing care to individuals experiencing loss and grief is a constant practice in healthcare institutions. Professionals can and should position themselves as members of the support network for the family members and friends of those who have died, acting in the prevention of complicated grief and facilitating the free expression of emotions, different feelings, and the complexities related to this phenomenon. However, this is not what is observed in healthcare institutions, at any level of care. Therefore, professionals require resources that help them provide care to bereaved individuals free from stigma and with the potential to promote institutional changes regarding the culture of care for people experiencing grief<sup>(1,2)</sup>.

The loss of a close person is a recurring event during the aging process. Contrary to social stigmas, elderly people are not necessarily more prepared to say goodbye to their loved ones, and many experience difficulties in processing the loss and resuming a satisfactory daily routine. A portion of the population experiencing such difficulties develops pathological grief, with severe symptoms associated with a range of physical and psychological problems, such as depression, anxiety disorders, feelings of loneliness, and social isolation<sup>(2-4)</sup>.

Thus, it is necessary for healthcare professionals to systematize their knowledge regarding processes of terminality, death, and grief among healthcare professionals, including

implications for care practices, while recognizing and analyzing the needs of people who have experienced the loss of loved ones and are undergoing grief. It should be considered that experiences related to this phenomenon are unique and, therefore, complex, with no standardized logic that enables care practices without deep and continuous reflection<sup>(5)</sup>. Based on this topic and the importance of understanding the experience of grief in old age, the present study raises the following question: how do elderly people experience grief after the loss of a family member and/or significant person? The objective is to understand the experience of grief among elderly people following the loss of a family member and/or significant person.

## **METHOD**

This is a qualitative study supported by the constructivist Grounded Theory methodological framework (GT)<sup>(6)</sup>, used to understand social processes through the interpretive construction of meanings attributed by participants to their experiences. To ensure methodological rigor and transparency in the study description, the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ)<sup>(7)</sup> guidelines were followed.

The research was conducted in the community setting of three Family Health Units (FHU) in a municipality located in the northern region of the state of Santa Catarina, Brazil, within the context of Primary Health Care. This setting was selected because Primary Health Care represents the main point of contact between elderly people and the healthcare system, in addition to enabling the identification and access to elderly people living in the community who have experienced loss and grief.

A total of 24 elderly people living in territories covered by the FHUs participated in the study. The inclusion criteria were being aged 60 years or older, having experienced the loss of a close or significant person (family members, spouse, or individuals with an emotional bond) more than 30 days prior; and residing within the coverage area of the participating health units. Elderly people with hearing or speech difficulties that prevented communication during the interview were excluded, due to the absence of a research team member capable of conducting the interview in such cases.

For the purposes of this study, “close person” was considered to refer to family members who maintained direct interaction with the participants, sharing the same household. Thus, the criterion of closeness was defined primarily by the experience of daily coexistence rather than exclusively by the formal degree of kinship. Therefore, the study sought to encompass significant affective and relational bonds, recognizing that the intensity of closeness

may be more related to shared experiences than to genealogical position within the family structure.

Regarding the time elapsed between the loss and the interview, no specific maximum period was established. This methodological decision was adopted to broaden the understanding of the meanings attributed to the experience of grief, allowing the inclusion of different moments and phases of this process. It was considered that the inclusion of participants at different stages of bereavement would contribute to the identification and analysis of emerging codes related to the multiple manifestations of grief, as well as enable an understanding of how elderly people attribute meaning to events experienced over time<sup>(6)</sup>. Thus, the study sought to capture the dynamics and complexity of the grief process in this population.

Potential participants were identified with the assistance of nurses and community health agents from FHU, who indicated elderly people experiencing loss and grief. After this initial identification, the researcher contacted potential participants by telephone to present the study and invite them to participate. In cases of acceptance, a home visit was scheduled, during which the objectives, methodological procedures, and ethical aspects of the research were explained. Data collection began only after reading and signing the Informed Consent Form (ICF). All invited participants agreed to participate in the study.

The researcher responsible for conducting the interviews is a nurse and university professor in the municipality where data collection was performed. She has worked with qualitative research during undergraduate studies, master's and doctoral programs, as well as in research projects at her institution. She has previous experience in Primary Health Care, having worked as a nurse at this level of care for eight years. However, she did not work in the health units where data collection for the present study was conducted.

Regarding the researcher-participant relationship, the elderly people who participated in the study had no previous relationship with the researcher. The initial information provided to participants was that she was a nurse and doctoral student conducting research with elderly people who had experienced loss and grief. If participants expressed interest in obtaining further clarification regarding the researcher's background or experience, this information was promptly provided.

Data collection took place between July 2022 and February 2023 via semi-structured interviews conducted in the participants' homes at scheduled times. The interviews were conducted by the main researcher, who had received prior training in qualitative research and the adopted methodological framework. Given the COVID-19 pandemic, biosafety measures

were implemented during the interviews, including the use of N95 masks, frequent hand hygiene, and physical distancing when necessary.

During the interviews, no other people were present, with only the elderly participant and the researcher remaining in the room. Community health workers accompanied the researcher to the participant's home and conducted the initial introduction, subsequently returning to the health unit before the interview began.

The initial interview guide was developed based on previous knowledge regarding bereavement among elderly people, constructed during the research project development stage, and following the recommendations for the formulation of interview guides proposed by Charmaz<sup>(6)</sup>. The interviews began with open-ended questions related to elderly people's perceptions of the healthcare received during the experience of loss and grief. As data were analyzed and new hypotheses emerged, additional, more focused questions were incorporated into subsequent interviews, addressing aspects such as access to healthcare services, interactions with professionals, and care experiences during the grieving process. The inclusion of new questions throughout data collection and analysis is consistent with the recommendations of GT<sup>(6)</sup>. The interviews lasted an average of 1 hour and 10 minutes.

The data sources consisted of 24 initial interviews, four second interviews conducted with selected participants to explore emerging and more specific aspects, and more than 40 analytical memos developed throughout the data collection and analysis process. All interviews were audio-recorded with participants' authorization and subsequently fully transcribed.

In Grounded Theory, field notes are referred to as analytical memos<sup>(6)</sup>. These records were developed during the interviews, when necessary, immediately after the interviews, and throughout the data coding process. The data were organized and managed using NVivo® qualitative analysis software, which supported the systematization, coding, and retrieval of empirical data throughout the analytical process.

The analysis followed the procedures of constructivist Grounded Theory<sup>(6)</sup> involving the stages of initial coding and focused coding. In the initial coding phase, the data were examined line by line to identify actions, meanings, and processes present in participants' accounts. These initial codes were subsequently compared constantly, allowing the identification of similarities and differences among the reported experiences. This process was accompanied by the development of analytical memos, which supported theoretical reflection and the refinement of interpretations.

Coding was performed by the main researcher. After establishing the analytical categories, the material was reviewed by two other doctoral researchers with experience in

qualitative research. In the focused coding stage, the most significant and recurrent codes were grouped and reorganized, enabling the progressive construction of analytical subcategories and a central category with explanatory potential regarding the investigated phenomenon<sup>(6)</sup>.

Throughout the analytical process, three subcategories were identified and articulated around a central category related to elderly people's perceptions of the healthcare received during the experience of grief.

The coding tree was constructed based on the interactive analysis of the data, which refers to the continuous and cyclical process in which data collection and analysis occur simultaneously, following the principles of Grounded Theory<sup>(6)</sup>. Initially, open codes were identified in the interviews, which were subsequently grouped according to conceptual similarity, resulting in subcategories. These subcategories were integrated into broader categories representing dimensions of the grief experience within the context of healthcare. Throughout the process, the constant comparative method was used, which can be understood as a continuous process in which, as new data are collected, they are immediately compared with existing codes and categories, involving three levels of comparison: codes with codes (specific incidents in the data, such as statements and actions, which are compared to create codes); codes with categories (codes are compared with emerging categories); and categories with categories (conceptual categories are compared to refine their properties and dimensions)<sup>(6)</sup>.

Data collection was concluded when the theoretical-empirical saturation criterion was reached<sup>(8)</sup>, characterized by the point at which new data no longer contributed relevant information or new properties to the developing categories. The decision to end data collection was made by consensus between two researchers after an independent analysis of the collected data.

To strengthen the credibility of the findings, the results were validated with the participants. For this, four elderly participants were presented in interviews conducted after the completion of data collection and analysis, with an interpretative synthesis of the emerging categories of the study, written in accessible and understandable language for the participating population. During this process, participants were invited to comment on, confirm, or complement the interpretations presented, allowing verification of the consistency between the analytical results and the experiences they reported. All elderly participants confirmed the interpretations presented. This step contributed to ensuring the trustworthiness of the interpretations produced from the data.

It is worth noting that GT can generate studies resulting in formal theories, substantive theories, or sets of categories and propositions that explain a social process or behavior within a specific context, the latter being the case of the present study<sup>(6)</sup>.

Ethical aspects were respected at all stages of the research. The study was approved by the Human Research Ethics Committee of the *Universidade Federal de Santa Catarina* (UFSC) (Protocol No. 4.800.235/2021; CAAE No. 46870421.9.0000.0121) and by the Municipal Health Department of the participating municipality. Participants' identities were protected by replacing their names with codes consisting of the initials "EP" (Elderly Person), followed by a sequential number<sup>(9)</sup>.

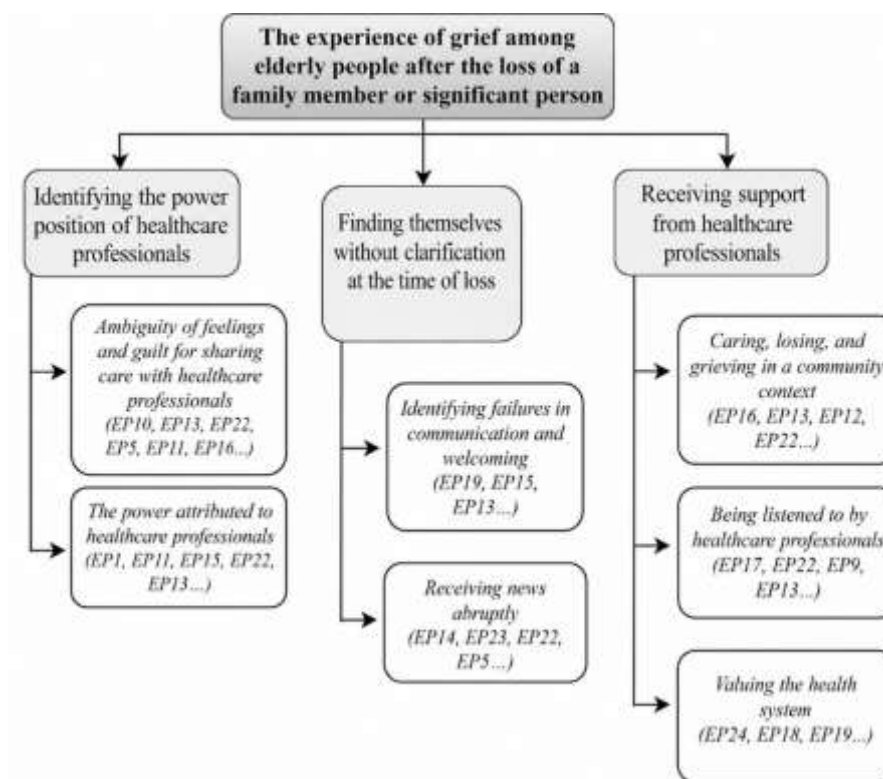
## RESULTS

Among the 24 elderly participants, eight were linked to each of the three Family Health Units (FHU) included in the study. There was a predominance of women (18). Ages ranged from 60 to 82 years. Regarding living arrangements, eight lived alone, eight lived with their children, six shared their household with their spouse, and two lived with siblings. Regarding the level of independence, 19 considered themselves independent in daily activities, three were partially dependent, and one was dependent. Regarding religious practice, 10 identified as Lutherans, nine as Catholics, three as Evangelicals, and one as Umbanda practitioner. Regarding the causes of loss and bereavement, 12 elderly people had lost their spouse, four had lost their father or mother, three had lost children, two had lost siblings, and three had lost a father-in-law or mother-in-law with whom they shared the household.

Regarding the causes of death of close persons, five deaths were due to cancer, three to stroke, three to acute myocardial infarction, three to COVID-19, two to alcoholism, one to a traffic accident, one to drowning, two to pneumonia, and four participants were unable to specify what exactly led to the death within the hospital setting. The time elapsed since the loss of the close person ranged from two months to 15 years.

In this study, after identifying several properties of the phenomenon investigated, the central category was named: grief experience among elderly people following the loss of a family member or significant person, along with its respective subcategories and the dimensions of each subcategory. The representation of the coding tree of the present study is presented in Figure 1.

**Figure 1** - "Coding tree: the experience of grief among elderly people after the loss of a family member or significant person, Joinville, Santa Catarina, Brazil, 2023".



Source: Author, 2023.

### Subcategory I: Identifying the power position of healthcare professionals

The ambiguity of feelings was common in the face of the finitude of a close person. Although elderly people experience fear when saying goodbye to their loved ones, they need to share care and decision-making with healthcare professionals at this moment. However, this sharing of care is accompanied by feelings of guilt for having to leave their loved ones under the responsibility of healthcare professionals, without being completely confident about their decisions.

Although these experiences occur in the period preceding death, they are part of the process of elaborating the loss. In the literature, this dynamic is understood as anticipatory grief, wherein family members begin to emotionally experience the prospect of death while accompanying their loved one through their illness and care. Thus, decisions made and interactions with healthcare professionals become part of the grieving experience itself.

*There was also her occupational therapist, who kept saying, "Don't hospitalize her!" Then, I feel this pain in my chest because she did not want us to hospitalize her, and then she gave up. (EP 10)*

*They had already performed the procedure, inserted the tube, and he hadn't even been admitted. He was about to be discharged. Then he stopped breathing. He had gone there just to have the tube inserted, but his condition worsened. The nurses said that he did not want to die at home, so he became paralyzed. The nurse did not allow us to bring*

*him home; they could not discharge him like that. But he stayed in the hallway, and then he died. (EP 13)*

*But on the very day he got worse, my daughter wanted to stay at the hospital, I did not want her to, but I allowed it. At noon, she called me saying that he was feeling unwell, they wanted to intubate him, and I said I did not want that, I would not allow it! I went there because I thought it would be too much suffering. When I arrived, the entire team was around him, and then the doctor said to me: this is the last time I am asking you, do you want him to be intubated or not?" My heart tightened, do it or don't do it? And then I said, "Intubate, go ahead and intubate!" So, they intubated him, there were no ICU beds available, so we went to another room. Oh, the suffering. He stayed there for quite a long time, going back and forth to the ICU. It was really hard! (EP 22)*

*We took him to the hospital many times It was only to make him suffer. They kept him there in the emergency department, and because there was no bed, they left him on the sofa, only receiving fluids, just so he would suffer. (EP 5)*

*At that moment, I rushed to the phone, spoke to the doctor, and said, "I'm taking him to the hospital." He said, "There's nothing to be done; there's no way he'll make it there alive. (EP 6)*

Among the participants' statements, there was an implicit attribution of power to healthcare professionals. Elderly people felt afraid to speak about professionals and to challenge their decisions. Participants also demonstrated some distrust regarding healthcare professionals' practices, but they also demanded listening and humanized care as a way of challenging this established power. This aspect is revealed below:

*On March 23, she fell ill during the night, and I took her to the emergency department for an exam, but there was no turning back. From the moment I took her in, she was put on oxygen and her condition never stabilized. I don't know if I can say everything that happened inside the ED...? (EP 1)*

*But I will tell you, the hospital did something wrong there. On the last day, they called my daughter and said, look, she does not want to make an effort to leave the ICU. The person is sick; how can she make an effort? I say, I suspect they turned off all her machines so that she would die. Let's say they removed her equipment, everything. She did not even look like she was 60 years old; she was strong and everything. But now, what can be done? (EP 15)*

*She was hospitalized here in the emergency unit for a week, and we couldn't see her anymore. I used to bring her breakfast and afternoon snacks, but she started refusing food. My worry grew significantly. So, I asked the social worker if I could speak to the doctor, but she kept telling me, "Look, it's so hectic here right now." And this was at a time when the pandemic was at its peak. I said, "I know, but the thing is: I'm not leaving here without seeing my wife! I want to know how she's being medicated, how she's being treated, and what condition she has. (EP 13)*

*And there at the hospital, when we ended up in oncology because there was nowhere else to go, they would bathe him and he would scream a lot. Twice I let it go. On the third day, I said, no, do not do this anymore. Then I entered the room saying that I was going to get my watch, but that was a lie, and then I told them: do not do this to my*

*husband anymore. I went downstairs to complain. Then they said that I was not the first person to complain, and they transferred him (the technician) to another place, but he was the only one who bothered me there. He used to tie him very tightly, like that, and he no longer had any strength. Why? He was skin and bones! I do not think he wanted to do that, and another man told me that he had done the same thing to him. (EP 22)*

## **Subcategory II: Finding themselves without clarification at the time of loss**

Participants reported a lack of information provided by healthcare professionals, which led them to feel unsupported at the time of losing a close person. It is noteworthy that the absence of a clear, welcoming, and concise flow of information was perceived by elderly people as a failure in the care provided, highlighting that effective and compassionate communication is an important tool in caring for bereaved individuals.

The way in which information about clinical progression and the possibility of death is communicated may influence family members' understanding of the situation. Abrupt or insufficiently explained communication may trigger shock reactions and hinder the initial process of coping with the loss.

*He stayed in the hospital, and I didn't. I didn't even go to visit because I wasn't well. I didn't know he was in such bad shape. No one told me! (EP 19)*

*She stayed in the ICU for two months. But nobody was allowed in there, you know? My daughters went there and talked to the doctor. Every night the doctor called, but only to say, she is stable, she is stable. Uh-huh... stable... look what happened! (EP 15)*

*When it was early in the morning, I was ready to go there for the hospitalization. We talked to the doctor, but they were, in my opinion, negligent. When they arrived there, they should have said: look, we did everything we could, but it was not enough. But no! They kept saying they were taking over the shift and that they would see what happened. Only later did he say that he had died. My daughters were outraged, you know? They even argued with the doctor and everything! We took good care of him; we did everything that was within our power. But I do not know what happened there in the hospital. We do not know what happened. (EP 13)*

The news received about the worsening health condition or death of a close person was identified by elderly people as a specific moment of vulnerability in the process of loss and grief. Such news carried symbolic meanings involving definitive changes in the lives and future of those who received it. Elderly people reported that the way in which they received this information was sometimes abrupt and harsh, deeply affecting them.

*My husband died in the hospital. And, even now, I can't accept it, because he got sick one week and was gone the next. The doctor wouldn't give me a clear explanation, he just said it was a heart problem. He was hospitalized for eight days. At the hospital, they wouldn't tell me what was going on. I even had the onset of a heart attack there once. (EP 23)*

*It hurt, you know, but what could I do? The doctor arrived very early and removed the feeding tube, then the young woman came with the food, and the doctor just said, "No, there won't be any more, there is no need." When I heard that, I thought, "Good God, this is the end!" So I asked, "Is he really in bad shape?" He said, "Yes, he is." (EP 22)*

*At the time, I did not know whether he had died or not. He had passed away, but then, later, a doctor came. They called my daughter's house; they probably already knew what had to be done, but I did not know. When my daughter, my granddaughter, and my son-in-law arrived, they said: look, I spoke with your daughter because your husband has just died. If you want, you can go in there. The professionals only told us what we had to do, and we immediately started arranging the coffin and those things. (EP 5)*

### **Subcategory III: Receiving support from healthcare professionals**

The participants' statements revealed another reality: the experience of loss and grief at home, within the community context, most often away from the hospital environment, with contact now occurring with primary health care professionals. Relationships with healthcare professionals in these circumstances assumed different meanings. For participants, receiving healthcare professionals at home through home visits contributed to the experience of the finitude of their loved one, making them feel more secure and fostering the construction of bonds with these professionals.

*The day before, the doctor had already told me he wouldn't last much longer, but she told me to stay calm, that he would have a peaceful death and that I would be right there with him. The nurse from the local clinic also used to come to the house to give him injections; they were very kind to me. (EP 22)*

*The health team also came here and everything. The nurse came here several times, a very lovely nurse. (EP 12)*

*The team from the local clinic was constantly here, they even came to vaccinate him. (EP 13)*

*The doctors and nurses came here, explained to me how to perform the dressing. It would take a little while, but it would heal. (EP 16)*

The bond with primary care health professionals was also strengthened through welcoming practices and by the experience of being listened to during the period in which care was provided at home to a person in the dying process who required a palliative approach and significantly impacted the experience of loss and grief. The healthcare team that provided home visits, offered support, listened, and provided guidance was perceived through the perspective of a personal and trusting relationship.

*The health unit, for me, is my home. They know us, they come to our house, they arrive, sit here, and we talk. The nurse asks about everything, but I really like it. In the beginning, when my husband was bedridden, the health unit technicians came here,*

*checked his oxygen saturation, and they would already adjust his pillow, he would improve, so we have this support. The nurse also comes here! I thank God that we have this wonderful health unit. I was also part of the meetings, the council, I was always there fighting and expressing my gratitude. So, if someone speaks badly about the health unit, I respond, because they do what they can and they do their job very well. (EP 13)*

*My physical therapist does a lot of good, she's practically a psychologist, she talks, she does a bit of everything, and she says it does her good too, which makes me happy. The community health worker sends me messages as well, I really like that, it helps me a lot, she sends audio messages and talks to me, so that part is really great. (EP 9)*

*Then he developed throat cancer, and it started to have a bad smell. I went to the doctor at the health unit, and she said, let's find a way. He did not want to go to the doctor, but she said she would come with the team. Then she arranged everything, including referral to a psychologist. It was a very difficult struggle, but he accepted the treatment because of the doctor from the health unit. He even stopped drinking. (EP 22)*

*The health unit helped a lot. I even went to talk with the nurse, that girl was a blessing. She knows everything that happened. Even now, after everything, she still helps me. (EP 17)*

Thus, the participants' statements show that the presence and support provided by the Primary Health Care team, through home visits, guidance, and qualified listening, constituted important support strategies for elderly people in coping with the process of death and grief of a family member and/or significant person.

## **DISCUSSION**

The results of this study show that the experience of grief among elderly people is strongly influenced by the interactions established with healthcare professionals during the illness and death process of their family members and/or significant persons. The way these relationships are managed can impact how these individuals understand the dying process and how they process their grief.

In this context, healthcare faces increasingly complex challenges. The adversities encountered by healthcare professionals often exceed their preparation, raising reflections on the limits of care and the role of institutions in the caregiving process. In this scenario, professionals are immersed in a constant need to adapt in order to respond to increasingly diverse health conditions, often dealing with more questions than answers. Therefore, adaptability becomes an essential skill in daily healthcare practice<sup>(10)</sup>.

Faced with these situations, limitations and challenges become even more evident, particularly regarding the relationships established between healthcare professionals, patients, and family members. For elderly people experiencing the loss of someone close, the way these

interactions occur may influence their understanding of the dying process and the elaboration of grief.

The quality of care is directly related to the bond between professionals and patients. A study with hospital nurses indicates that a good relationship improves health outcomes. When patients resist or question, nurses may resort to persuasion or coercion to achieve therapeutic goals. This practice reveals tensions between technical approaches and listening. Despite the appreciation of communication, biomedical criteria still predominate and may limit patient autonomy. This becomes even more evident in the care of elderly people experiencing loss, requiring greater sensitivity. It is essential to reflect on the ethical limits of this relationship<sup>(11)</sup>.

When discussing the data from this study that gave rise to the subcategory - identifying the power position of healthcare professionals - it can be stated that contrary to what might be expected, nurses working in environments that promote the institutional empowerment of their profession tend to adopt a transformational leadership role, positively influencing users' engagement in their care plans. Equipped with intellectual stimulation, individualized consideration, and inspirational motivation, these professionals recognize their relevance and, consequently, their responsibilities and sensitivity when communicating bad news<sup>(12)</sup>.

A study conducted with vulnerable users of healthcare services found that the level of trust these individuals place in nurses is higher than that placed in other members of the healthcare team. In light of these findings, it is important to recognize that the trust established between users and healthcare professionals is a multifactorial phenomenon involving values, attitudes, and cultural aspects present in their interactions<sup>(13)</sup>. However, even in the presence of such trust, healthcare relationships can still be characterized by power imbalances.

Regarding healthcare professionals, a study involving physicians, nurses, psychologists, and physiotherapists found that nurses and psychologists demonstrated greater sensitivity in dealing with issues related to patients' cultural competence. Despite these findings, the same study highlighted the gap in knowledge and skills surrounding health issues that involve cultural interpretations, such as grief<sup>(14)</sup>. This gap may directly influence the way relationships between healthcare professionals and users are established, particularly in situations marked by suffering and loss.

The data from this study provide an important reflection on the subcategory "finding themselves without clarification at the time of loss." Caring for bereaved individuals directly involves healthcare professionals, who play a central role in organizing care practices and managing the information provided to family members. However, work within healthcare

institutions is complex and has historically been marked by power relationships between professionals and users, initially more evident in medical practice.

This "hidden power" may distance users from decision-making processes and promote care centered on service provision rather than on people's actual needs. Furthermore, institutional and political factors may limit users' autonomy, maintaining this imbalance in care relationships<sup>(15)</sup>. This context aligns with the findings of the present study, in which some participants reported difficulties questioning clinical decisions or obtaining clarification at the time of loss.

It is noteworthy that users of healthcare services are increasingly aware of their rights, healthcare procedures, and the legality of actions performed during care, in addition to having greater access to information. This may challenge healthcare professionals who still occupy a position of authority that was once rarely questioned. Although this has become increasingly common, the relationship between users and healthcare professionals remains asymmetric, and stigmatizing attitudes resulting from insufficient attention to users' preferences are still not uncommon, preventing the establishment of trust within the therapeutic relationship<sup>(16,17)</sup>.

As observed in this study regarding the subcategory - receiving support from healthcare professionals - when decisions throughout the health-disease process are shared more horizontally, users gain greater autonomy and begin to view professionals as advisors. The role of healthcare professionals should be to support patients' autonomy and informed decision-making without imposing changes in their values. To achieve this, professionals must promote users' active participation and listen comprehensively to their needs, going beyond the mere collection of signs and symptoms<sup>(17)</sup>.

Communication with elderly people is a fundamental pillar of care. In the context of grief, it becomes even more important. The incorporation of therapeutic communication facilitates the implementation of care actions, especially in Primary Health Care. In this context, it is important to highlight that the organization of care for elderly people within the Unified Health System (*Sistema Único de Saúde*) assigns Primary Health Care a central role in coordinating the healthcare network and ensuring comprehensive care, as established by the National Policy for the Health of Elderly People. Therefore, the support provided by professionals at this level of care becomes strategic for identifying grief-related needs, promoting qualified listening, and coordinating referrals when necessary<sup>(18)</sup>.

Communicating bad news is essential in the care of bereaved elderly people, who frequently face distressing information, from diagnosis to the death of loved ones. For this communication to be effective and empathetic, healthcare professionals must be prepared to

deal with difficult situations and intense emotions, while also assessing family members' understanding of the clinical condition beforehand. Although common in healthcare practice, this moment requires seriousness and should follow best practices. Furthermore, healthcare professionals are especially valued when they remain present and available after delivering the news, rather than withdrawing from the support and comfort that families need<sup>(19)</sup>.

In the context of this study, it is also important to consider the COVID-19 pandemic, during which data collection took place. The public health measures implemented in healthcare services, such as visitor restrictions and the isolation of hospitalized patients, changed families' experiences during the illness and dying process. Many family members were unable to follow the clinical progression in person or say goodbye to their loved ones, relying instead on information conveyed by healthcare professionals or through technological means. Recent evidence indicates that these restrictions on family presence and the difficulties in communication with healthcare teams intensified feelings of helplessness and suffering and may have hindered the grieving process<sup>(20,21)</sup>.

An international report published in 2022 proposes a broader perspective on the “value of death,” recognizing death as a relational and spiritual phenomenon that is inseparable from life, rather than merely a physiological event. Healthcare professionals' lack of preparedness to deal with death and grief reflects the low priority governments assign to relieving suffering and supporting bereaved individuals. This denial of finitude within healthcare systems contributes to negative indicators, such as the poor quality of death in Brazil, which ranks 42<sup>nd</sup> worldwide. Structural and conceptual advances depend on greater commitment from the Legislative and Executive branches of government<sup>(22-24)</sup>.

Among the most significant healthcare needs of bereaved elderly people are receiving support through encouraging professional contact, being listened to and understood, and being treated with respect. A relationship between healthcare professionals and elderly people grounded in these principles empowers both parties and brings dignity to the human encounter. Particularly in community-based care, dignity perceived within these relationships increases elderly people's sense of trust and their positive perception of healthcare professionals<sup>(25)</sup>.

Therefore, it is suggested that care for elderly people should begin with recognizing how they understand their own situation, considering the intrinsic factors as well as the cultural and family issues involved throughout the process. It is essential that the different levels of healthcare remain connected and continuously informed about the decisions made at each level<sup>(16)</sup>. Furthermore, being recognized and valued as a person, and being kept continuously informed about the condition of their ill family members, are aspects that elderly people who

provide care, experience loss, and grieve tend to value. In addition, allowing elderly people to describe their experiences throughout the processes of loss and grief is fundamental to ensuring their sense of belonging<sup>(26)</sup>.

A significant portion of the participants identified as Lutheran. Religiosity has been recognized in the literature as an important element in the grieving process, offering symbolic, spiritual, and community support in coping with loss. Studies indicate that spirituality and religious teachings may facilitate meaning-making and contribute to coping with grief among family members following the death of a loved one by promoting hope, resilience, and symbolic resources, such as rituals and faith-based practices, which help individuals adapt to loss and manage the emotions associated with grief<sup>(27)</sup>. Although the present study did not seek to compare religious groups, it is reasonable to consider that the spiritual dimension associated with religiosity may have influenced how participants made meaning of their loss.

Optimal grief care benefits from coordinated, multidisciplinary actions grounded in support and user education strategies. Facilitating holistic care for the bereaved individuals requires patient-centered planning that incorporates open and accessible communication, empathy, mutual trust, and the normalization of diverse grieving experiences<sup>(28)</sup>.

By understanding the experience of grief among elderly people following the loss of someone close, this study provides contributions that may support care strategies related to this phenomenon, both at the individual level and through social and cultural changes that facilitate bereaved elderly people's access to healthcare services. Furthermore, it may contribute to improving the education of healthcare professionals and, consequently, to the development of public policies directed toward this population.

The study has limitations regarding the conditions under which the research was conducted. Data collection took place during the COVID-19 pandemic, when social distancing measures and mask use were in effect, which may have influenced aspects of the interaction between the researcher and participants and, consequently, the observation of nonverbal elements that are important during interviews. In addition, the complexity of the phenomenon investigated — which encompasses emotional, relational, institutional, and cultural dimensions — poses challenges to its full understanding within a single study, highlighting the need for further research to explore different aspects of care for bereaved elderly people across diverse healthcare settings.

## **FINAL CONSIDERATIONS**

By analyzing the accounts of elderly people who had lost close family members, this study showed that the way healthcare professionals communicated throughout the illness and, particularly, at the time of death had a direct impact on how grief was experienced. In several cases, news of the death was delivered abruptly, with little explanation and without allowing space for questions, generating uncertainty and intensifying suffering. The findings also revealed an imbalanced relationship between healthcare professionals and users, in which decisions and information were rarely shared, making it more difficult to recognize and address participants' emotional needs.

In contrast, in situations managed within Primary Health Care, especially by teams that had already established a bond with the elderly people, participants reported receiving home visits, active listening, and follow-up after the death. These actions helped elderly people talk about their loss, clarify doubts, and cope with their suffering, suggesting that proximity to the community and continuity of care make healthcare more sensitive and effective in this context.

Based on these findings, the study points to practical ways for improving care: investing in the training of healthcare professionals to communicate death clearly and compassionately; preparing healthcare teams to recognize and manage grief reactions (such as intense sadness, isolation, and confusion), and organizing follow-up routines after a death, including phone calls or home visits. These measures may contribute to more attentive care to the emotional and relational dimensions involved in the loss experienced by elderly people.

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**Data and material availability:**

“Access to the dataset is available upon request from the corresponding author”.

Justification: The dataset is available upon request from the corresponding author due to the presence of sensitive information related to the research participants. This restriction is intended to ensure confidentiality, privacy, and compliance with the ethical principles established by the research ethics committee.

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