



# Desire and will of institutionalized older adults regarding end-of-life terminality

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## Abstract

**Objective:** The present study aimed to explore the desires and wishes of older adults residing in Long-Term Care Facilities (LTCFs) regarding end-of-life terminality. **Method:** This was a descriptive and exploratory qualitative research, involving 18 older adults from two LTCFs in a city in the central region of the state of Rio Grande do Sul (RS), Brazil. Data collection took place from March to May 2022 through semi-structured interviews and using the "cards on the table" technique. The data were subjected to discursive textual analysis. **Results:** Five categories emerged: Family welcoming and acceptance: death in LTCFs or at home and the fear of dying alone; End-of-a-life cycle: a moment of personal reflection, farewell, affection, and faith; Preservation of the human dignity of older adults who are institutionalized in the terminal phase of life; Not being pressured and not being a burden to the family: desires related to the actions of professionals and family members toward the older adult; and Maintenance of senses and awareness of death: desire for a beneficial experience with pain control, purification, and surrendering of life through faith. **Conclusion:** The desires and wishes expressed were related to broad aspects of life. Understanding these desires has emerged as an opportunity for healthcare professionals to introduce topics related to finitude, allowing these older adults to have their voices heard, felt, and respected.

**Keywords:** Death. Attitudes towards death. Long-Term Care Facilities for older adults. Aged. Nursing.

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## INTRODUCTION

Aging predisposes to a higher prevalence of non-communicable chronic and degenerative diseases, for which there is no curative treatment, and is associated with a lack of response to disease-modifying treatment, which can lead to situations of dependency and the need for long-term care<sup>1</sup>. In light of this observation, the number of older adults residing in Long-Term Care Facilities (LTCFs) has increased in several countries, including Brazil<sup>2</sup>.

LTCFs should serve as specialized homes with a dual function: to provide gerontogeriatric care according to the degree of dependency of their residents and to offer a homely, cozy environment capable of preserving the intimacy and identity of its residents<sup>2</sup>. It is emphasized that the desires and wishes of institutionalized older adults need to be considered.

However, care in LTCFs has received a significant amount of criticism in recent years. Typically, the care in these institutions corresponds to automated technical actions that prioritize meeting physiological needs, neglecting the demands arising from individual uniqueness<sup>3</sup>.

It is observed that, in the daily context of living in LTCFs, nursing teams emerge as the frontline caregivers, spending a significant portion of their time in direct contact with the residents, shaping their well-being conditions. Therefore, in the perspective of considering the wishes and desires of the institutionalized older adult at the end-of-life, the role of these professionals and the aspects that intersect health and quality of life are highlighted<sup>4</sup>.

It should be emphasized that end-of-life stage is defined when the possibilities of recovering health conditions are exhausted, and the possibility of imminent and predictable death seems inevitable<sup>5</sup>.

Although the perception of older adults regarding aspects related to the end-of-life is recognized as an important indicator of quality, considerations and investigations related to this sphere are still scarce in institutional environments. From the perspective of institutionalized older adults having their desires and wishes met to experience a good death, the principles

of palliative care are urgent. These are holistic, active care approaches provided to individuals of all ages experiencing health-related suffering due to serious illnesses, and to those nearing the end-of-life; their aim is to improve the quality of life for both patients and their families and caregivers<sup>6</sup>.

The healthcare team in LTCFs needs to recognize the significance of this moment and strive to provide the best care conditions for this final stage of life, considering the individualities associated with this process and the complex needs linked to the physical and psychological state of the residents, as well as their preferences and desires.

Advanced care planning is considered particularly relevant for older adults residing in LTCFs due to the high likelihood of developing cognitive impairment and loss of decision-making capacity at the end-of-life<sup>7</sup>. In this logic, the life information and values of the older adult should be combined with technical care issues to build an individualized care plan that makes sense for that person; ensuring that as the clinical and/or cognitive condition progresses, they receive health treatments and care in line with their preferences<sup>8</sup>.

Understanding that preserving the capacity for decision-making, or autonomy, of older adults should be respected, it is considered relevant to individually discuss end-of-life issues with this population. In this light, there arises the need to recognize the older adult as an autonomous being and subject of their own will. Thus, the objective of this study is to understand the desires and wishes of older adult residents in LTCFs regarding end-of-life.

## METHOD

This is qualitative research with a descriptive and exploratory nature. Qualitative research aims to understand and analyze phenomena explored from the perspective of participants, individually or in small groups, within a context related to the study<sup>9,10</sup>.

The study was conducted in two philanthropic LTCFs in the Southern region of Brazil. It was chosen to propose the study in these two settings to have samples of older adults of both genders, female and male. In total, 18 older adults residing in LTCFs

participated, aged 60 years or older. The approach was made through prior contact with the nurses of the institutions, who suggested a list of names. Based on this list, the older adults were invited to participate in the research and were briefed on the need to previously undergo the Mini-Mental State Examination (MMSE).

In this context, participants who met the inclusion criteria were considered: older adults of both biological genders, aged 60 years or older, who achieved the cutoff scores stipulated by the MMSE; while those who did not reach the suggestive score for cognitive impairment were excluded. Data collection took place from March to May 2022. To obtain the information, a semi-structured interview technique was used, where closed-ended questions regarding sociodemographic data were initially applied, and the open-ended questions of the interview were conducted with the aid of the "cards on the table" resource.

This instrument, a deck of 24 cards, describes the desires and wishes of individuals at the end-of-life<sup>11</sup>. The older adult was instructed to divide the deck into three piles; and in each pile, the resident placed the cards representing their desires and wishes at the end-of-life, considering those that were very important, somewhat important, and not important. Subsequently, participants were asked to select only ten desires from the pile labeled "very important," arranging the most important one at the top of the pile and the others in sequence. Shortly after, participants were invited to reflect and express how they would justify the "very important" and "not important" wishes and desires to their family, friends, and/or LTCFs professionals.

This study respected the ethical aspects of research involving human subjects in accordance with Resolution number 466/2012 and Resolution number 510/2016 of the National Health Council. It is emphasized that, before the research was conducted, the informed consent form was presented to the participants, following the approval of the project by the Research Ethics Committee of the Universidade Federal de Santa Maria – Pró-reitoria de Pós-graduação e Pesquisa (PRPGP), under protocol number 5,219,665. It is worth noting that the anonymity of the participants was preserved using codes with the initials "M" for male gender and "F" for female gender, "Rx" for the word resident, and an Arabic numeral indicating the participant's study number.

## DATA AVAILABILITY

All the dataset supporting the findings of this study are available upon request to the corresponding author, Fabiane Marzari Possatti.

## RESULTS

The data analysis employed was textual-discursive, consisting of four stages: deconstruction of the texts; establishment of relationships (categorization); capture of new emergent themes; and the realization of a self-organized process<sup>12</sup>. After establishing 163 units of meaning, an intensive reading of the transcripts continued, resulting in the formation of 18 initial categories, which eventually converged into five final categories.

**Chart 1.** Construction of initial and final categories of desires and wishes of institutionalized older adults. Santa Maria, Rio Grande do Sul, 2022.

Initial Categories	Final Categories
Having Friends and Family Nearby	Reception and family acceptance: death in LTCF or at home and fear of dying alone
Dying at Home	
Not Dying Alone	
Family welcomes and accepts death (appeared twice)	
Possibility to Say Thank You, I'm Sorry, I Love You, and Goodbye	End of a life cycle: personal closure, farewell, affection, and faith
Assisting Others	
Preserving human dignity	Preservation of the human dignity of older adults in the end-of-life institutional setting
Relief from pain and shortness of breath (appeared twice)	
Listening to favorite music	
Relief from pain and shortness of breath	
Caring and trustworthy physicians and nurses	
Organized finances	Freedom from pressure and not being a burden to the family: wishes related to the actions of professionals and family members towards the older adult
Freedom from pressure	
Not being a burden to the family	maintenance of senses and awareness of death: desire for a beneficial, pain-free experience, of purification, and surrender through faith
Being alert when passing away	

Source: Authors (2022)

**Chart 2.** Sociodemographic data of the research participants. Santa Maria, Rio Grande do Sul, 2022.

Sociodemographic data	Men	Women
Absolute number	12	6
Age range interval of the researched population	62-81years	65-80 years
Marital status		
Single	6	2
Divorced	5	3
Widowed	1	1
Maternity	0	6
Paternity	6	0
Being grandparents	0	6
Not having children	5	0
Did not respond	1	0
Previous occupation		
Farmer	6	0
Homemaker	0	3
Others	6	3
Education level		
Four years or more of schooling	6	1
Less than four years of schooling	5	4
Illiterate	1	1
Monthly income		
01 minimum wage	11	4
More than 01 minimum wage	0	1
Does not receive a salary	1	1
Average length of institutionalization among participants	5 years and 3 months	5 years and 6 months

Source: Authors (2022)

## 1. Family Welcoming and Acceptance: Death in LTCFs or at Home and the Fear of Dying Alone.

Older adults residing in LTCFs expressed a desire to die at home; for some, the concept of home was associated with the LTCF itself, while for others, it was linked to their relatives' residence. The recognition of the institution as their domestic sphere endorses the social role these institutions fulfill; however, regardless of the location stratification, they signaled the desire to die close to their family and relatives.

"It's part of the family bond, all together in this moment (death). I wanted it to happen right here, at home." (M1R1)

"At the time of my death, it's important because they (family members) were my life (...). I wanted to be there at home, with them." (M4R4)

The discourse of these older adults highlights the cherished bond with family. Older adults residing in LTCFs do not wish to die feeling abandoned and anticipate the embrace of their family with acceptance of their death.

From the perspective of the desire of older adults to be able to die at home, other issues were also cited, such as the possibility of reducing costs associated with hospital care, delays in receiving attention, and concerns about overcrowding and bed optimization in hospitals.

"I prefer to die at home, which is here in the nursing home, rather than in the hospital, so I can pass away more peacefully." (M7R7)

"I don't need to be occupying someone else's bed, taking away the bed from people who could be hospitalized, sometimes even in a worse condition than mine and have no place." (M12R12)

In the perspective of not dying alone, spirituality and protection were considered relevant and pointed out as aids and hope for the final moments of their lives.

"I want to die asking the enlightened spirits, my saints and holy protectors, God and Jesus, to receive me." (M4R4)

Reaffirming the desire for the end-of-life to be built with support, resident seniors express their apprehension and fear of dying alone.

"(...) I am afraid of dying alone. I have no words." (M11R11).

"Because dying alone, having no one by your side, is sad." (M5R5)

## 2. End-of-a-life cycle: a moment of personal reflection, farewell, affection, and faith

Older adults expressed their desire to convey their gratitude and affection to their family members; a demonstration of respect and affection that should be expressed both throughout life and in the final stage.

It is identified that, for the participants, it was important to reframe emotional bonds, resolve past conflicts or disagreements, value the final moments of their existence, and take the opportunity to bid farewell. Thus, remaining socially connected or rebuilding bonds with their loved ones is shown to be the desire and will of older adults residing in LTCFs.

"It's important, because you're going to bid farewell, won't see anything anymore, it's over, to at least have a memory." (M12R12).

"Because I believe that in the past when I was younger, I said a lot (...), but it hurt. And I couldn't contain that impulse to speak harshly to people I didn't like, and 'it's wrong.'" (F2R14).

Associated with the desires and wishes of older adults for direct benefit, the possibility of assisting other residents stands out. The willingness to help others is displayed as a form of reciprocation for the assistance received from others during the course of their lives.

"I feel like a different person, better (referring to helping others)." (M11R11)

"Today they are doing it, tomorrow they might be receiving a bath." (M12R12).

### 3. Preservation of the human dignity of older adults who are institutionalized in the terminal phase of life.

Regarding their expectations of how they want to receive care in the terminal phase of their lives, older adults refer to attentive and respectful care in old age, with humanization manifested through touch, and they expect the professionals involved in their care to be present and preserve human dignity.

"If they serve me with ill will, then they shouldn't serve me at all. I said: (...) Have a little respect and dignity for her, go to her room to see if she's still alive. They wouldn't even touch her anymore (...) Don't you think that's a lack of dignity?" (F4R16).

"Because respect is everything." (F1R13)

In the perspective of preserving the dignity of older adults in the terminal phase of their lives, they desire to listen to their favorite music. This gesture has been considered a promoter of joy, a sense of freedom, pain reduction, and also promotes mental relaxation.

"My wish has always been to have music (...) even for certain people, music is a medicine when the end is near. Turn on some music and just listen to it." (M12R12).

"Music is one of the few things that moves me and calms me down (...). It takes me on a journey, it does me good, I don't know why." (F6R18).

Another desire mentioned aligned with the perspective of wanting to be attended to and cared for by careful and trustworthy healthcare professionals.

"I have physicians who are very sincere. I think sincerity should be used with the person who is ill. It's a way of respecting the person, they will decide what they want, and what they need or don't need." (F2R14).

"Because it has to be someone you trust to talk to about your problems (...) there has to be empathy, unity, communion." (F6R18).

Another concern of older adults relates to financial matters. This organization gives them more security and enables them to achieve autonomy to make decisions and tranquility in the terminal phase of their existence.

"Leaving it to the children so that they don't struggle later." (M3R3).

"With money, I'm at ease, let's put it that way, I don't depend on many anymore. I can already solve the problem on my own, I have enough." (M12R12).

### 4. Not being pressured and not being a burden to the family

Older adults mentioned feeling pressured by situations of fragility in communication from professionals, family members, and other affectionate bonds; not aiding in the therapeutic process in the terminal phase of life.

"I don't like it when someone says something or tells me (...) it could be the same words, but the way they say them. Because the decision is mine." (F2R14).

Regarding the desire of older adults not to feel like a burden to their families during this period, there is an expressed wish to be able to take care of themselves.

"There won't be a shortage of people to care for me, to look after me. May I have a peaceful illness, where I can help myself. Maybe I'll end up in the hospital, then I don't know." (F5R17).

### 5. Maintenance of senses and awareness of death: desire for a beneficial experience with pain control, purification, and surrendering of life through faith

From the perspective of the desires of older adults, they considered themselves conscious enough to ask for forgiveness from God for the mistakes made in life. Additionally, there is mention of the desire to experience death as a passage with positive feelings.

"If I am conscious and aware of death, let the cleansing come, because to die you need to be conscious and know that you are going to die." (F2R14)

"I didn't want to die in my sleep, I wanted to feel death, have a good vision (...) and hand life and death over to God." (F5R17)

In this sense, the residents wished to be conscious but with adequate analgesia to be able to die without pain, and they preferred to have a sudden death.

"I want to be conscious in the sense that I have already taken that morphine, for pain. And to be pain-free, you know?" (F4R16).

"I want to be awake when I die. I want to die suddenly." (F4R16).

One resident also mentioned wanting to preserve their senses to stay alert to the care received near the end-of-life; as they were afraid of not receiving the attention they needed.

"I want... in the senses, like a policing of the person. Because, when you are on the brink of death, when you are very ill, they treat you a lot like trash, I think." (F6R18)

## DISCUSSION

Among the sociodemographic aspects of the older adults in this study, it is noteworthy that the female population is larger than the male population. Studies conducted in Brazil have reported that older adults residing in Long-Term Care Facilities (LTCFs) were mostly women and had a higher average age than men. Furthermore, the age group with the highest number of older adults in Brazilian LTCFs is between 71 and 80 years old<sup>15</sup>.

Regarding the income of older adults in LTCFs<sup>13,15-17</sup>, it has been identified that almost all older adults were retired and received, on average, one minimum wage. Additionally, concerning the duration of institutionalization, a study reported similar data to those of this research by indicating that the length of stay for older adults in LTCFs

ranged from one to five years<sup>15</sup>. Regarding the motivations that led older adults to reside in LTCFs, the reasons reported were due to family members being unable to provide them with the necessary care, as well as issues related to severed bonds<sup>16,17</sup>.

In a study informed by a scoping review, it was reported that family is considered essential in the final moments, and therefore, the majority of residents wish to die close to their family members<sup>18</sup>. Furthermore, the family is considered to play an important role in distracting worrisome thoughts; it is beneficial to be there, despite the patient's physical and/or mood changes, and to strive to remain until the end<sup>19</sup>.

The desire to be at home at the end of their lives is expressed by institutionalized older adults. Recognizing the LTCFs as a domestic sphere is established by preserving identity, privacy, and ensuring a welcoming environment of respect and dignity for older adults<sup>2</sup>. Reasons include previous instances of unsuccessful care, the comfort of home, and concerns about the costs of prolonged periods<sup>20</sup>.

Among the main desires and wishes of the participants is the desire to avoid loneliness. The fear of dying alone is linked to the fact that loneliness is a subjective experience. Thus, loneliness is often identified as a feeling that can be present even in the company of others<sup>21</sup>.

In this context, it can be inferred that for older adults in LTCFs, the significance of dying feeling alone is the abandonment by loved ones, in addition to feeling fearful of this condition<sup>22</sup>. Some individuals may view death with serenity; others, with overwhelming fear<sup>23</sup>. Faced with the question of the fear of dying alone, the older adult should be understood in their singularity and entirety; as the experiences at the end-of-life will depend on the context in which they are placed, their history, and their exposure to situations that make them vulnerable<sup>24</sup>.

In this sense, personal redemption at the end-of-life does not diminish the need to love and be loved, to forgive or be forgiven, and to maintain intimate and trusting relationships. Perhaps, at this stage, these needs are even more urgent to recognize as

the "last opportunity"<sup>15</sup>. The desire to bid farewell to one's bonds of affection and to seek forgiveness and reconciliation allows their shortcomings not to be considered of great importance in retrospect, and for these bonds to remain within them as fond memories after their death<sup>4</sup>.

From the perspective of older adults developing resilience at the end-of-life, the presence of relationships of assistance to others aids in better coping with adverse situations such as debilitating illness or death<sup>25</sup>. The principle of human dignity establishes protection and autonomy for the individual by imposing minimal conditions for humans to truly live, die, and not just survive<sup>26</sup>.

Physical proximity, human warmth, support, and respectful, open, and honest communication are of great importance to people who are nearing the end-of-life<sup>4</sup>. Preserving the dignity of residents is the responsibility of healthcare professionals and is a central value in the perspective of palliative care<sup>27</sup>. They also attribute the possibility of maintaining dignity in being able to manage their finances, maintain friendships, not feel pain, listen to their favorite music, and have interactions among them conducted in a respectful manner.

In the mentioned aspect, older adults living in LTCFs desire to be cared for by professionals within a relationship based on trust, respect, and communication, so that they perceive that the caregivers are concerned about their well-being<sup>28</sup>. Therefore, it is seen that the resident's concern about death is related to the outcome it may have on others<sup>29</sup>.

Empathy should be established among the older adult, the family, and the professionals; and exchanges of ideas and information about the needs of the older adult should occur through harmonious dialogue<sup>30</sup>. Along the same lines, professional conduct should provide singular attention in order to enable greater comfort for the discomforts felt by the ailing individual, understanding that they are unique, personal, and non-transferable<sup>31</sup>.

In this sense, professional conduct should provide singular attention and empathy to enable greater comfort for the discomforts felt by the ailing

individual<sup>22</sup>. The older adult should have decision-making autonomy until death; as this makes them feel more secure and less pressured<sup>30</sup>.

From the perspective of maintaining awareness of death and consciousness, spirituality can improve the psychosocial stability of the individual, strengthen their self-identity, and promote adjustment to death<sup>21</sup>. Experiencing spirituality as a central component in life proves to be an important resource in maintaining psychological well-being, especially for vulnerable institutionalized older adults<sup>5</sup>. Furthermore, faith and support driven by spirituality provide inner balance in the face of terminal situations<sup>22</sup>. Older adults wish to die conscious as a foundation to fulfill and enforce their other desires or due to religious reasons<sup>4</sup>. From the standpoint of remaining vigilant to observe the care that will be provided, older adults in palliative care wanted to stay alert, as they believed that a Long-Term Care Facility would provide inferior care<sup>32</sup>.

In this context, the desire for freedom from pain was central for the residents. Personal experiences or previous illnesses were cited as concerns regarding symptoms already experienced<sup>3</sup>.

It is worth noting that the research has limitations as it only encompassed two LTCFs and disregarded residents who did not achieve a minimum score on the Mini-Mental State Examination (MMSE), whose desires and wishes were not known.

## CONCLUSION

The results of the study provided insight into the desires and wishes of older adults residing in LTCFs at the end-of-life. It was evident that such desires and wishes are characterized by concerns related to how they are cared for by healthcare professionals; however, primarily, by aspiring to broad aspects of life.

In the study, it was observed that the majority of participants were willing, wanted, and felt the need to speak about their desires and wishes. From this perspective, the reception, acceptance by family, and the possibility of death occurring in the LTCF or at home constitute desired situations. Furthermore, the moment of death represents the end of a life cycle

in which there is a need for personal reconciliation, farewell, affection, and reinforcement of faith.

This research also enables collaboration so that the actions of healthcare professionals, especially nurses, can be enriched with knowledge of desires and wishes regarding the end-of-life. It leads to developments in which these desires and wishes can be documented to positively influence older adults to preserve their autonomy and dignity at the end-of-life.

## AUTHORSHIP

- Fabiane Marzari Possatti - conception and design or analysis and interpretation of data, drafting the paper or critical revision, approval of the version to be published, and responsibility for all aspects of the work, ensuring that issues related to the accuracy or integrity of any part of the work are addressed.
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- Larissa Venturini - Drafting the paper or critical revision, approval of the version to be published, and responsibility for all aspects of the work, ensuring that issues related to the accuracy or integrity of any part of the work are addressed.

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