

DOI: 10.4025/ciencuidsaude.v22i0.65964



# CARE FOR THE INSTITUTIONALIZED ELDERLY IN THE PERSPECTIVE OF A PEACEFUL END OF LIFE<sup>1</sup>

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#### **ABSTRACT**

Objective: to understand how care at the end of life is provided to the elderly in the Long Stay Institution for the Elderly (LSIE) from the perspective of the Peaceful End of Life Theory. Method: descriptive, interpretative study of a qualitative clinical nature, conducted with 12 collaborators of a Long Stay Institution for the Elderly in a city in the Northeast of Brazil. Data were collected in May and June 2021. They were organized with the help of IRaMuTeQ software and analyzed according to the Peaceful End of Life Theory. Results: two categories emerged: family support, lack of knowledge and fear of the team and their implications for the care of the elderly at the end of life and care for the promotion of comfort to the elderly at the end of life. Final considerations: pain control and physical comfort were more present on the care at the end of life in the LSIE, highlighting the need for greater investment in the permanent education of the caregiver team so that they can provide care to the elderly and their families, especially regarding autonomy and the preparation of mourning. The study allows us to understand how professional care is provided at the end of life of the elderly in a Long Stay Institution for the

Keywords: Aged. Palliative care. Homes for the aged. Nursing. Nursing theory.

# INTRODUCTION

End-of-life care refers to a set of actions provided by a professional team in the face of termination, "announced death" and near death, when all possibilities of restoration of health conditions have already been exhausted and finitude is predictable<sup>(1,2)</sup>. This type of health care is an integral part of palliative care (PC), an approach that aims to improve the quality of life of patients diagnosed with illnesses without cure and with limited prognosis, their families and caregivers, prevention and relief of suffering<sup>(3)</sup>.

Data from the World Health Organization show that the estimated number of people in need of palliative care at the end of life is 20.4

million. Of this number, 69% are elderly people aged 60 years or older<sup>(4)</sup>. In Brazil, over the years, there has been a continuous growth in the number of elderly people who have disabling diseases and that lead them to the state of terminality, such as oncological diseases without cure prognosis, dementia diseases, among others<sup>(5)</sup>.

These diseases cause limitation of the functionality of the elderly person and, consequently, dependence compromising the permanence of the elderly with their family<sup>(6)</sup>. Allied to this, the unavailability of a person in the family who assumes and/or feels prepared to care for the elderly with disabling diseases constituteas the main causes of transfer of elderly people from

<sup>1</sup> Article extracted from the Doctoral Thesis entitled "Model of Nursing Care for the elderly at the end of life in Long-Term Institutions", presented on 08/11/2022 at the Graduate Program in Nursing and Health at the Federal University of Bahia (UFBA)

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their homes to Long Stay Institutions for the Elderly (LSIEs).

Although LSIEs are not clinical or therapeutic health units, they admit elderly people in frailty, dependent on activities of daily living (ADLs), with incurable diseases in advanced stages, whether oncological or non-oncological diseasessuch as dementia<sup>(2, 7)</sup>. Thus, these institutions are configured as spaces in which care at the end of life is part of the daily work.

The elderly, for the most part, when they are institutionalized, remain in the LSIE until the end of life. Research conducted by the Bronw University Center in the USA in 2010 shows that one in two elderly people aged 85 years or older and those with dementia die in LSIEs<sup>(8)</sup>. In Brazil, a study on health policies in the LSIEs revealed that all patients evaluated had an average of three to four comorbidities, diseases that increase the risk of frailty, development of geriatric syndromes and this being a reality present in the LSIE investigated<sup>(9)</sup>.

Ensuring the well-being and dignity in the face of death of elderly people in a situation of terminality implies ensuring individualized care that does not succumb to the need for healing, but that aims to reduce suffering, the pain and other negative repercussions that the disease causes. In this light, the Peaceful End of Life Theory (PELT)<sup>(10-11)</sup>stands out as an important and guiding reference for care practices, since it focuses mainly on nursing care in relieving real and/or perceived fears and anxieties for the patient and his family. Therefore, the caregiver must have attitudes of listening and empathy, directing actions to comfort, relief of pain and suffering, in the physical, social, emotional and spiritual dimensions, thus ensuring necessary conditions for the person with a terminal illness to achieve a peaceful death<sup>(11)</sup>.

Considering that in Brazil there are 100,000 elderly living in LSIEs<sup>(12)</sup>, many of them requiring long-term care, it is necessary to discuss the end-of-life care for this population in these scenarios, publications in national and international literature on this approach are incipient. In addition, this research may enable the production of new knowledge from the Peaceful End of Life Theory in the field of end

of life care in LSIEs. This study aims to understand how professional care is provided at the end of life to the elderly in the Long Stay Institution for the Elderly from the perspective of the Peaceful End of Life Theory.

## **METHOD**

Descriptive and interpretative study of a qualitative clinical nature, based on the Theory Peaceful End of Life (PELT), developed in a Long Stay Institution for the Elderly in a municipality in the interior of Bahia, Brazil. The institution philanthropic character and its choice was by the fact iustified that it multiprofessional nuclear team, in addition to having the largest number of elderly residents compared to other institutions in the city, understanding about the performance of this team in front of the care provided at the end of life.

It is noteworthy that, in the municipality where the research took place, there are five LSIEs registered in the Municipal Council of the Elderly and only two of them have a multidisciplinary team to serve residents. The coordination of bothLSIEs was contacted to participate in the study, but only one agreed with the participation of their team in the research.

The study included 12 participants, among them professionals with higher education and technique in the health area, as well as caregivers, with high school education, who are part of the effective staff of the LSIE. Initially, contact was tried with all 17 staff members, but the three doctors did not respond, even after three attempts were made, and a nursing technician and a caregiver did not accept to participate in the research, reported that they did not feel comfortable in addressing issues related to the process of dying and death.

The collaborators were presented to the researcher by the manager of LSIE and, at first, questions were explained about the objectives of the study, how the interviews would happen, the anonymity of the participants and the guarantee of privacy at the time of the interview. Then, the collaborators were asked about the willingness to contribute voluntarily

to the study and the interviews were scheduled according to the availability of each of them.

It was adopted as an inclusion criterion: to act in the service for a period of three months or more, since this time space is related to the need for collaborators to be set with the profile of care established in the institution.

Data were collected in May and June 2021, through individual face-to-face interviews guided by a script with semi-structured questions. The first part of the interview included questions about the characterization of the participants, including time working at LSIE, training and knowledge about palliative care. The second was composed of questions about the end-of-life care provided to the elderly in terminality condition, based on the five dimensions of the Peaceful End-of-Life Theory: No pain; Feeling comfortable; Experience of dignity/respect; Feeling at peace; Closeness to the family. The interviews were conducted in a reserved place, where only the researcher and the collaborator were, had an average duration of 30 minutes, were recorded and then transcribed. After the transcript of each interview, it was returned to the participant to read, evaluate whether they would like to change something and whether or not they would follow as a collaborator in the study, so that none of them gave up after reading their interview.

The empirical material of each participant, from the transcription of the interviews, went through the process of semantic approximation and lematization, which consists of reducing different forms of the same word to its base form. After cleaning the text with spelling correction and removal of informal character expressions, data processing was performed in the Software Interface de *R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ) identification of the nuclei of meanings.

After data processing in IRaMuTeQ, we opted for the adoption of the Descending Hierarchical Classification (CHD), so that the textual segments or elementary context units (UCE) were classified according to their respective words and their chi-valueshigher square, the words being organized in a Dendrogram (Figure 1). Thus, the Dendrogram

classes were composed of words that had p value < 0.001, indicating a statistically significant association.

For data analysis was adopted the technique of Qualitative Clinical Content Analysis that considers seven steps in the analysis process: Editing the material for analysis; Floating reading; Construction of analysis units; Construction of sense codes; General refinement of codes and construction of categories; Discussion and Validity<sup>(13)</sup>.

The construction of the manuscript followed the recommendations of COREQ (Consolidated Criteria for Reporting Qualitative Research), meeting the scientific requirements for the development of studies with a qualitative approach<sup>(14)</sup>.

All participants signed the Informed Consent Form (ICF) and, to maintain anonymity and preserve their identity, they were identified with the letter C and the acronym PS, which correspond to the caregiver and health professional, respectively. The letter E corresponds to the interviews and, to enumerate them, the numerals from 1 to 12 were added. The research project was reviewed and approved by a Research Ethics Committee under opinion n. 4,665,687.

# **RESULTS**

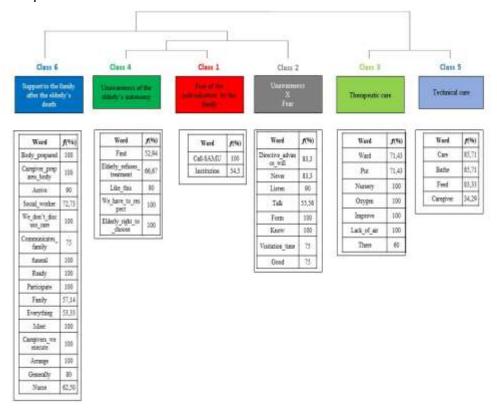
All participants are female and mean age 37.4 years. The time of operation in the institution ranged from 1 year to 11 years, and most employees have more than three years of relationship with LSIE. With regard to the professional category, five are professionals, three Nursing Techniques, one Nurse and one Social Worker. The other employees, seven, are formal caregivers acting in direct care to the elderly and do not have training in the health area or course of caregivers of the elderly, having learned the craft in everyday practice.

Caregivers provide direct care to the elderly, with regard to daily activities, such as hygiene care, food, clothing, change of position, among others. It is worth noting that, of the 12 interviewees, only four mentioned that they knew what palliative care is, but never took a training/updating course in PC.

The resulting corpus, formed after the transcription and organization of the interviews, was composed of 12 texts divided into 102 segments, of which 91 were analyzed by the IRaMuTeQ Software, equivalent to a use of 89.0% of the corpus, which is whereas the literature assumes as a good index the use above 75.0%<sup>(15)</sup>.

The disposition of the classes revealed that

the material suffered partitions, resulting in six classes, according to Dendrogram (Figure 1). Each of them was named according to the content it presents, represented by the words, and grouped into two categories, seeking to identify the central idea associated with it, its data interpreted and discussed in the light of the relevant literature, anchored in the PELT.



**Figure 01**. Dendrogram of the textual corpus and respective classes related to the interviews. Salvador, Bahia, Brazil, 2022.

**Source:** Created by the authors, 2021.

In the Dendrogram, it is possible to observe that this starts from class 6, called "Support to the family after the death of the elderly person". Then, class 4 appears, called "Ignorance about the autonomy of the elderly person", which, like class 1, "Fear of judicialization by the family", are subdivisions of class 2, "Ignorance X Fear". These four interconnected classes gave rise to category I, "Family support, lack of knowledge and fear of the team and its implications for the care of the elderly at the end of life". The text segments (TS) presented below demonstrate how health professionals and caregivers deal with the experience of

caring for the elderly at the end of life marked by actions to support the family while demonstrating ignorance of the principle of autonomy and feeling of fear reality of the judicialization of health.

The family arriving, the body is already prepared. Here I explain everything about the bureaucratic issues, how to call the funeral home and go to the registry office to issue the death certificate. (PS/E12)

Here is not this business of refusing. In my perception, you have to do it, regardless of what he wants. (PS/E9)

I think if he doesn't want to, we should respect, the person should be able to choose. (C/E7)

So it is better to revive, for them [family] not to think it was lack of assistance from the institution. (C/E3)

I do not know this term Early Will Directive. (C/E4, PS/E9)

Classes 3 and 5, "Therapeutic care" and "Technical care", respectively, appear interconnected and give rise to category II, "Care for the promotion of comfort to the elderly at the end of life"since they present words associated with care practices directed to questions of response to the disease, to examples of oxygen therapy, hemodynamic monitoring and administration of medicines, as well as hygienic care, feeding and relaxation, provided concomitantly for comfort and dignity in the process of dying and death.

We take them to the ward which is quieter, away from the noise. There in the Ward there is oxygen, they are monitored, we do time medication for pain. (PS/E8, C/E5)

We put music to calm down, watch TV with them. You have to have that other look, make a food they want, wear the clothes they want. He asked me for flour the day before he left and asked to eat by hand, I did. You can't deny these things. (C/E5)

We put egg box mattress, change decubitus, do comfort massage, keep sanitized, feed with syringe those who still swallow. They are entitled to a dignified death. (PS/E11)

### **DISCUSSION**

The team of LSIE professionals is formed only by women, being a requirement of the management team of the institution scenario of the study. Although the average time of performance of the members is considered a relatively long bond, it was possible to observe a profile of caregivers and health professionals without any training course in the gerontological area and/or palliative care.

This reality may be linked to a limitation of resources by LSIEs, which end up not prioritizing trained professionals for gerontological care. Regarding training in

palliative care, this is still incipient in the Brazilian scenario. There are still many gaps in the training and preparation of professionals to work in PC and end-of-life care<sup>(16)</sup>. It should be noted that gaps in academic training and in the performance of professionals who care for institutionalized elderly people, especially those in palliative care, often lead to a practice of care that ensures the prolonged existence of life and neglects a thorough understanding of dying as a natural process inherent to the human being as well as death.

The coexistence with dying and death is part of the daily work of health professionals and caregivers of institutionalized elderly people, especially by the residents of these institutions are, for the most part, elderly in frail condition, diagnosis of progressive, degenerative diseases, with no possibility of cure and with a reserved prognosis. Conceived as the stopping of vital functions, death is a natural process of life and, although it is inherent in the human being, to work with it, for many, is still a difficult experience<sup>(17)</sup>.

For being a unique moment that deserves a respectful and ethical attention, by the workers of LSIE, to the person who died and their families, human values, singularities and cultural diversity should be taken into account with the rituals of post-body preparation death and farewell by relatives and close people, since such practices can interfere with the grieving process, sometimes making it a complicated mourning.

In this study, the statements of health professionals and caregivers showed that the preparation of the body after death happens soon after death and family members do not participate in this preparation, which leads us to reflect on the unpreparedness of health professionals for this moment.

Studies on death and dying bring that the support to the relatives of the patient who has just died should be promoted through simple attitudes, such as respecting their moment of dealing with the pain of loss, leaving them alone with the one who has just left, respecting the singular moment of each subject in his farewell according to his cultural values and his spiritual beliefs, including the preparation of the body<sup>(17-18)</sup>. A practice that seems to us a

reality still distant in the context of LSIE and that requires reflection in order to promote a change of paradigms regarding the preparation with the body and the concern of the team for the mourning of the family.

Still on the support given to family members in the face of the death of the elderly, the communication of death must be performed by a professional designated according to the protocol<sup>(19-20)</sup>. In institutional the LSIE Worker the researched. Social the professional who usually talks with family members about what happened, also advising on the bureaucratic issues necessary for burial. This action is based on the PELT, which brings, among its dimensions, the importance of family participation in the post-death care of the person, in order to contribute to a process of natural mourning, in which the bereaved tries to gradually accept the death of this family This practice reinforces importance of addressing the questions and concerns of family members, as well as the importance of guiding them on practical issues related to patient death<sup>(10,11)</sup>.

Among the concepts of PVPT, being at peace refers to providing greater tranquility in the physical, emotional and spiritual aspects<sup>(10,11)</sup>. For this, the actions of health professionals should be aimed at reducing anxiety, promoting an atmosphere of serenity, calm, harmony and contentment, helping the family to face the death of their body and their grieving process<sup>(3)</sup>.

The speeches portray the lack of preparation of most health professionals and caregivers in dealing with issues related to finitude, when they bring hospitalization, the submission of the elderly person to treatments and unwanted interventions, thus violating the bioethical principle of autonomy. Such attitudes demonstrate a care practice that goes against the perspective of care assumed by the PELT and the philosophical principles of palliative care.

It is also noticed that the lack of respect for the autonomy of the elderly goes through the lack of qualification of these workers to act based on the principles that guide palliative care, the difficulty in dealing with death, beyond the fear of the LSIE team being judicialized by the family. Added to this, there is a lack of knowledge, both by professionals and by caregivers and residents, about the Anticipated Will Directive document<sup>(21)</sup>.

On the other hand, speeches emerge, such as "we have to respect" and the "elderly have the right to choose", which brings us to the idea that there is a consideration regarding the decision-making of the elderly person in choosing the refusal of treatment, the importance of respecting the patient's will, singularity and autonomy. From the Theory of the Peaceful End of Life, it is possible to infer that respect for the wishes expressed by the patient guarantees him, in addition to tranquility, the perception of feeling at peace when his desires are fulfilled.

The practice of end-of-life care, as part of PC, for patients with terminal disease should be based on respect for the principle of autonomy, which establishes the freedom of choice of the patient in consenting or refusing to undergo medical-hospital procedures<sup>(22)</sup>.

The promotion of autonomy guarantees the right of the elderly person to self-determination, maintaining their dignity and freedom of choice, while avoiding paternalistic practices that violate the full exercise of manifestation of their desires. By denying this principle, the health team tends to significantly increase the erroneous view that the elderly patient is unable to participate in decisions regarding their own care<sup>(23)</sup>.

According to the assumptions of PELT, the experience of dignity and respect is about valuing the patient with a terminal disease as a human being, who must have their needs and wishes met, being included in the decision-making about their care, besides being treated with dignity and empathy<sup>(10,11)</sup>. Although it does not bring a clear concept about the term dignity, the theory relates the definition of this construct to the right that people have to decide on their own goals, that is, personal autonomy<sup>(24)</sup>.

In the field of health, professionals are trained in a conception that aims to cure through interventional and drug treatments, with the aim of prolonging or saving the lives of patients, making death an uncomfortable event. They understand death as generating failure, impotence and pain, trying to push it

away at any cost. When, despite all efforts, death happens, the professional is defeated and "losing battles".

Dignified death or "good death" comes from the central idea of a natural death, which is imminent and inevitable and must occur from measures aimed at relieving pain and suffering, ensuring physical, psychosocial and spiritual comfort, which, in bioethical terms, is defined as orthothanasia<sup>(25)</sup>. The patient should have the opportunity to choose where to experience their dying process and their death, either at home, in the LSIE or in the hospital, provided that their wishes and desires are respected, with the support of the health team.

To consolidate orthothanasia as a manifestation of the autonomy of the patient's will in PC, CFM Resolution n. 1995/2012 came to deal with a legal document that can contribute to resolve doubts and support the medical professional, which is the Anticipated Directive of Will, which consists of a document expressing the will of a patient with terminal illness to choose in advance the therapies to which he wishes or not to submit if he is unable to freely express his desires<sup>(24)</sup>.

The concepts and assumptions of the Peaceful End of Life Theory are based on the philosophical principles of Palliative Care. Its theoretical assumptions bring that the main focus of care of the health team is not only in the course of the process of dying and death, but in the actions that aim to provide the sick person a peaceful and significant life in the last moments that remain relieving real or perceived fears and yearnings for both him and his family and for close and important people<sup>(24)</sup>. In addition, promoting comfort, paying attention to the needs and desires of patients and controlling pain are also concepts listed by the PELT so that the patient has a dignified and peaceful death.

In category II, the results indicate that the care practices developed in the LSIE are carried out in order to promote comfort and pain relief, as well as to meet the last wishes of those who are in a providing comprehensive care to the patient, as bring the philosophical principles of PC and the concepts proposed by the Theory of Peaceful End of Life in the categories not feel pain, feel comfortable and experience dignity

and respect.

Thus, it was possible to observe that the elderly are transferred to a unit within the LSIE called the ward, characterized by the team as a calm environment, away from noise and excessive lighting, where they are under the care of the nursing team. It is noticed that in this research the participants bring reports about their work routine, and each professional develops a different role in the care of the elderly. However, all work towards a common goal, which is to provide comfort and wellbeing to the patient, corroborating with the concepts of PELT.

In PELT, not feeling pain was defined as the experience of patients not reporting pain based on comprehensive and proactive care care care. Reflective study on palliative care in LSIE and PELT addressed that pain assessment should be performed by the nursing team, who, through a daily assessment, identifies the type and intensity implementing of pain, pharmacological therapies (by medical protocol of the institution) and non-pharmacological measures such as: application of heat or cold; body alignment with the use of cushions to relieve pressure on the joints; control of environmental stimuli that can potentiate pain, relaxation exercises<sup>(11)</sup>. It is worth noting that for those elderly people with cognitive deficits who do not express pain verbally it is necessary to consider the manifestation of non-verbal signs of pain that can be expressed by signs such as clenched teeth, pain facies, curved posture and groans<sup>(26)</sup>.

The relief of pain, respiratory distress, as well as avoiding the performance of invasive procedures that will not modify the course of the disease nor even provide comfort in the face of the suffering of the person are measures capable of reducing discomforts before the terminality. In addition, it should be noted that comfort is not achieved by performing especially techniques, but from establishment of a human and compassionate relationship that must take place between the team, the patient and the family, to express an environment of tranquility and empathic understanding. The realization of techniques is support for the promotion of comfort as a subjective construct.

Dignified and peaceful death, defined in the five categories of PELT, should be a priority for the planning of care for people who are terminally ill in LSIEs. Discussions about the prognosis of the elderly, decision making among professionals, the patient and the family, as well as preparation of the family for the process of dying and death of their should be part of the holistic care plan capable of providing a constructive environment for a dignified end of life.

It is attributed as a limitation of the study the investigation to have occurred in only one Long Stay Institution, a condition resulting from the pandemic scenario, which limited the trip to the field for data collection, when it was suspended by the leaders of one of the LSIEs selected. In addition, direct observation could add relevant information to the understanding of care at the end of life of the institutionalized elderly person.

As contributions to practice, palliative care and Gerontology, the study offers a compression of how professional care is provided at the end of life of the elderly who live in Long-Term Care Institutions, Listing the elements necessary for the integral and holistic care of the sick and their families, in order to

promote a dignified death for those who are in a situation of terminality.

#### FINAL THOUGHTS

The research revealed that the health team of the Long Stay Institution scenario of the study demands knowledge and technical training on the theme palliative care. The lack of training in this area may favor the failure to care for elderly people in the process of dying, especially with regard to the preservation of autonomy and the preparation of the family for mourning.

In the light of PELT, along with comfort, pain control and spiritual care were the most present categories regarding the provision of professional care at the end of life to the elderly in the LSIE. However, the results raised the need for greater investment in the permanent education of the care team working in the LSIE, so that it can provide care to both the elderly and their family in the form of palliative care, especially with regard to the bioethical principle of autonomy and greater communication and interaction of the family with its institutionalized entity.

# CUIDADO À PESSOA IDOSA INSTITUCIONALIZADA NA PERSPECTIVA DE UM FIM DE VIDA PACÍFICO

# **RESUMO**

Objetivo: compreender como são prestados os cuidados ao fim da vida às pessoas idosas na Instituição de Longa Permanência para Idosos (ILPI) sob a ótica da Teoria do Final de Vida Pacífico. Método: estudo descritivo, interpretativo de natureza clínico qualitativa, realizado com 12 colaboradoras de uma Instituição de Longa Permanência para Idosos numa cidade do Nordeste do Brasil. Os dados foram coletados nos meses de maio e junho de 2021. Foram organizados com auxílio do software IRaMuTeQ e analisados de acordo com a Teoria do Final de Vida Pacífico. Resultados: emergiram duas categorias: suporte à família, desconhecimento e medo da equipe e suas implicações no cuidado à pessoa idosa no fim da vida e cuidados para a promoção do conforto à pessoa idosa no fim da vida. Considerações finais: controle da dor e conforto físico foram mais presentes sobre os cuidados ao fim da vida na ILPI, destacando a necessidade de maior investimento na educação permanente da equipe de cuidadores para que possam prestar cuidados ao idoso e a sua família, especialmente no tocante à autonomia e à preparação do luto. O estudo permite compreender como são prestados os cuidados profissionais ao fim da vida de idosos em Instituição de Longa Permanência para Idosos.

Palavras-chave: Cuidados paliativos. Enfermagem. Idoso. Instituição de longa permanência para idosos. Teoria de enfermagem.

# ATENCIÓN A LA PERSONA MAYOR INSTITUCIONALIZADA EN LA PERSPECTIVA DE UN FIN DE VIDA PACÍFICO

# **RESUMEN**

**Objetivo**: comprender cómo se prestan los cuidados al final de la vida a las personas mayores en la Institución de Larga Permanencia para Ancianos (ILPA) bajo la óptica de la Teoría del Final de Vida Pacífico. **Método**: estudio descriptivo, interpretativo de naturaleza clínico cualitativa, realizado con 12 colaboradoras de una

Institución de Larga Permanencia para Ancianos en una ciudad del nordeste de Brasil. Los datos fueron recolectados en mayo y junio de 2021. Fueron organizados con la ayuda del *software IRaMuTeQ* y analizados de acuerdo con la Teoría del Final de Vida Pacífico. **Resultados**: surgieron dos categorías: apoyo a la familia, desconocimiento y miedo del equipo y sus implicaciones en el cuidado de la persona anciana al final de la vida y cuidados para la promoción del confort a la persona anciana al final de la vida. **Consideraciones finales**: control del dolor y confort físico fueron más presentes sobre los cuidados al final de la vida en la ILPA, destacando la necesidad de mayor inversión en la educación permanente del equipo de cuidadores para que puedan prestar cuidados al anciano y a su familia, especialmente a lo que se refiere a la autonomía y preparación del luto. El estudio permite comprender cómo se prestan los cuidados profesionales al final de la vida de las personas mayores en Institución de Larga Permanencia para Ancianos.

Palabras clave: Cuidados paliativos. Enfermería. Anciano. Institución de larga permanencia para anciano. Teoría de enfermería.

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**Submitted:** 13/11/2022 **Acceptde:** 15/05/2023