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# *"They are here as a last resort"*: the dynamic in a long term care facility for the elderly

## "Estão aqui porque é o último caminho": dinâmica em instituição de longa permanência para idosos

# *"Están aquí porque es el último camino"*: dinámica en una institución de larga estancia para ancianos

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#### Abstract:

**Objective:** to identify the structural aspects and care practices in a long-term care facility for the elderly. **Methods:** this is a qualitative study conducted in a public long-term care facility for the elderly in a municipality in southern Brazil, between September and November of 2023. Data collection took place through semi-structured interviews with professionals from the institution, using participant observation. The data were managed in the Atlas.ti program and submitted to content analysis. **Results:** the five professionals interviewed had little to no experience in caring for the elderly. As for the elderly, they were institutionalized due to neglect, abandonment, and/or violence and generally had mental related illnesses. Structurally, the institution does not resemble a hospital environment, but it is also far from what can be considered a family home. The care practices are shaped by the institution's routine and the control over individual bodies. One of the thematic units listed was: *"They are here as a last resort"*: people, spaces, relationships. **Conclusion:** institutionalized elderly experience the end of their lives in a limited environment, with a breakdown in family and social ties, loss of autonomy and freedom. Family abandonment, loneliness, stillness and social isolation lead to the belief that the end of life is just waiting for the moment of death to arrive and, while waiting, they sit in front of the television. Despite this, actions were identified to promote the well-being of elderly people, meeting individual needs.

Keywords: Homes for the aged; Aged; Terminal care; Death; Qualitative research.

#### **Resumo:**

**Objetivo:** identificar os aspectos estruturais e a dinâmica do cuidado em uma instituição de longa permanência para idosos. **Método:** trata-se de uma pesquisa qualitativa, realizada em uma instituição pública de longa permanência para idosos de um município no sul do Brasil, desenvolvida entre setembro e novembro de 2023. A coleta de dados ocorreu por meio de entrevista semiestruturada com profissionais da instituição, com uso da observação participante. Os dados foram gerenciados no programa Atlas.ti e submetidos à análise de conteúdo. **Resultados:** os cinco profissionais entrevistados possuíam pouca ou nenhuma experiência de cuidado a idosos. Quanto aos idosos, estavam institucionalizados por negligência, abandono e/ou violência, e possuíam, em geral, doenças relacionadas a transtornos mentais. Estruturalmente, a instituição não se assemelha a um ambiente hospitalar, mas também se distancia do que pode ser considerado uma residência familiar. A dinâmica de cuidado é baseada na rotina ditada pela instituição e pela disciplinarização dos corpos. Uma das unidades temáticas elencadas foi: "*Eles estão aqui porque é o último caminho*": as pessoas, os espaços, as relações. **Conclusão:** os idosos institucionalizados sujeitam-se a viver a finitude em um ambiente limitado, de quebra de vínculo familiar e social, perda de autonomia e liberdade. O abandono familiar, a solidão, a quietude e o isolamento social levam a acreditar que o fim da vida é apenas esperar que o momento da morte chegue, e, enquanto esperam, ficam em frente às televisões. Apesar disso, identificou-se ações para a promoção do bem-estar dos idosos, atendendo às necessidades individuais.

Palavras-chave: Instituição de longa permanência para idosos; Idoso; Assistência terminal; Morte; Pesquisa qualitativa.

#### **Resumen:**

**Objetivo**: Identificar los aspectos estructurales y la dinámica de los cuidados en una institución de larga estancia para ancianos. **Método**: Se trata de un estudio cualitativo realizado en una institución pública de cuidados de larga estancia para ancianos de un municipio del sur de Brasil, entre septiembre y noviembre de 2023. Los datos se recogieron mediante entrevistas semiestructuradas con profesionales de la institución, utilizando la observación participante. Los datos se gestionaron con el programa Atlas.ti y se sometieron a un análisis de contenido. **Resultados**: los cinco profesionales entrevistados tenían poca o ninguna experiencia en el cuidado de ancianos. En cuanto a los ancianos, estaban institucionalizados por negligencia, abandono y/o violencia, y, en general, padecían enfermedades relacionadas con trastornos mentales. Estructuralmente, la institución no se parece a un entorno hospitalario, pero también está muy alejada de lo que podría considerarse un hogar familiar. La dinámica de los cuidados se basa en la rutina dictada por la institución y en la disciplinarización de los cuerpos. Una de las unidades temáticas enumeradas fue: *"Están aquí porque es el último camino*": personas, espacios, relaciones. **Conclusión**: Los ancianos institucionalizados están sometidos a la vivencia de la finitud en un entorno limitado, con ruptura de los vínculos familiares y sociales, pérdida de autonomía y libertad. El abandono familiar, la soledad, la quietud y el aislamiento social les llevan a creer que el final de la vida es sólo esperar a que llegue el momento de la muerte, y mientras esperan, se sientan delante de la tele. A pesar de ello, se han identificado acciones para promover el bienestar de los ancianos, atendiendo a sus necesidades individuales.

Palabras clave: Hogares para ancianos; Anciano; Cuidado terminal; Muerte; Investigación cualitativa.

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# **INTRODUCTION**

n developed countries, those aged 60 or over are considered elderly, while in developing countries, the elderly are those aged 65 or over<sup>1</sup>. In a few decades, it is estimated that there will be three times more elderly people in the world, representing a quarter of the world population. It is estimated that in 2025, around 1.2 billion people will be elderly, and by 2050, this number could rise to 2 billion<sup>2</sup>.

The growth of this population represents a social achievement, resulting from better living conditions, easier access to preventive and curative consultations, advances in the health area, improvements in basic sanitation and other determinants<sup>3</sup>.

In Brazil, natural aging is defined as senescence, a time when physical, functional and psychological changes manifest themselves. When the condition goes beyond the natural process and becomes pathological, it is characterized as senility, defined by the emergence of diseases associated with the aging process that compromise functional capacity if not treated or monitored<sup>4</sup>.

It is during this stage that the elderly become dependent on care, which may have direct implications for their autonomy, and may lead to emotional imbalances, feelings of helplessness and uselessness<sup>5</sup>. In some cases, depending on the context in which care is provided, there is a lack of response to disease-modifying treatments, which gradually leads to the end of life. At this point, a relevant issue is who will become responsible for the care of these elderly people and how this will be carried out. Some can still be cared for by a family member, but for others, institutionalization is the only alternative.

With regard to home care, in most families, women become responsible for it, since, historically, the responsibility for care is linked to the female gender identity. It is women who stay at home caring for children and the elderly, while men go to work and provide for the family<sup>6</sup>.

However, this constitution is constantly changing, and there is a balance in the progression of aging and women's independence, in addition to the trend towards a reduction in the number of family caregivers. Furthermore, with the decrease in the fertility rate, there has been a reduction in the number of children per family and, consequently, in the number of potential future caregivers<sup>7</sup>. Thus, the need to institutionalize those who have no one to care for them is reinforced.

Historically, in Western societies, institutional spaces, such as nursing homes and asylums, were intended for those who were considered unworthy of living in society or who were no longer useful, whether for health, economic, legal or political reasons<sup>8,9</sup>. In Brazil, currently, the institutions previously known as nursing homes, shelters, retirement homes and

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similar, have had their names replaced by an expression: Long-Term Care Facilities for the Elderly (LTCFE)<sup>9</sup>. LTCFEs consist of establishments for comprehensive institutional care, whose target audience is elderly people, aged 60 or over, dependent or not, who are unable to remain with their family nucleus<sup>10</sup>.

Regarding the country's legislation, LTCFEs are subject to RDC No. 502 of May 27, 2021, which provides for their operation, and to Article 25, VI, of Federal Law 8,625/93, and Article 74, VIII, of Law 10,741/2003, which place the responsibility of the Federal Public Ministry's Office for the inspection of establishments that accommodate elderly people. In addition, the Statute of the Elderly (*Estatuto do Idoso*), Law No. 14,423 of July 22, 2022, also provides important rights for elderly people living in institutions.

Current studies on the end of life in long-term care facilities, especially in Brazil, and on the care provided by health professionals in these places, are scarce, and focus on reporting the care provided by teams directly to the elderly, such as body care, and indirectly, such as team meetings and training. However, they do not specifically address the end of life of institutionalized individuals and what the guarantee of care is<sup>11-13</sup>.

Therefore, this study aims to identify the structural aspects and dynamics of care in a long-term care institution for the elderly.

# **METHODS**

This is a qualitative study conducted with professionals working in a public Long-Term Care Facility for the Elderly in a city in Southern Brazil, aimed at men and women aged 60 or over who are unable to stay with their families and/or who live in situations of violence and/or neglect. This article will present part of the results of a larger study entitled: End-of-life care for the elderly in a public Long-Term Care Facility (*Cuidados no fim da vida a idosos em instituição pública de longa permanência*).

The data were collected between September and November of 2023, and the data collection techniques used were semi-structured interviews and participant observation. As for the observation, a participant observation script was followed and the product of the observation was captured through field notes. There were five stages, with a total of approximately 17 hours, in three different shifts during the week, twice in the morning, twice in the afternoon, and once in the evening.

The field notes for this study were analytical, methodological, and descriptive. The notes were prepared on the day the field observation was conducted. A table was created to control each note, with a description of the file title of the note, followed by the identification of type,

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date and shift. In this article, they will be identified by "DN" and "AN", descriptive notes and analytical notes, respectively.

The data collected during the observation phase were written in a field notebook. After the end of each shift, what was observed during the stay at the institution was transcribed into an online document on the Google document management application platform.

The inclusion criteria were: professionals working with institutionalized elderly individuals at the facility for at least three months. Professionals who were on some type of leave were excluded. The intentional sampling technique was used.

The interviews were guided by a protocol consisting of questions that addressed: work within a Long-Term Care Facility; the situation of institutionalized elderly people; the family; the care provided and its advantages and disadvantages. The individual interviews were conducted in person at the institution and lasted between 13 and 72 minutes, recorded in audio and transcribed into documents on the Google document management platform. The individual characteristics of the interviewees were respected, with only language errors and repetitive expressions being corrected to ensure reading fluency.

The data were analyzed using thematic Content Analysis, which consists of three main stages: pre-analysis, material exploration, and result interpretation<sup>14</sup>. The text files were managed and coded using the Atlas.ti. program, a cloud version for students.

To preserve identification and guarantee anonymity, the interviewees were identified by numbers in the order in which the interviews occurred. This research complied with the precepts of Resolution 466/2012 of the Brazilian National Health Council and was approved by a Research Ethics Committee under No. 6,221,692.

### RESULTS

Five professionals participated in the study, three of whom were directly involved in elderly care and two were part of the institution's technical team. Four were women and one was a man. They were between 43 and 56 years old, and had worked at the institution for between 11 months and 20 years. None of the interviewees had specialized training in geriatrics, gerontology, or aging.

In the analysis, 600 excerpts were assigned 26 codes. Two major thematic units emerged. In this article, one of them was given priority: "*They are here as a last resort*": people, spaces, relationships. Chart 1 shows the codes and their subunits.

Chart 1. Thematic unit and subunits about interviews with professionals from LTCF. Brazil,

2023.

Code	Subunit	Thematic Unit
On the profession	"They are resigned, and we help them, assit them so they don't become depressed": who cares and who is cared for	"They are here as a last resort": people, spaces and relationships
Emotional state of professionals		
Aging		
Health issues		
Emotional state of the elderly		
Institutionalization	"Each person has their own reality, with a history, a type of vulnerability, violence, aggression, experience": the paths of institutionalization	
Reasons for institutionalization		
Stories		
Physical structure	"Here they have everything. A home, food, everything is clean, everything is brand new": the space and the dynamics of caring relationships	
Organization		
Routine/institutional routine		
Socialization/interactions		
Visitation		
Pastime activities		

# Subunit 1: "They are resigned, and we help them, assist them so they don't become depressed": who cares and who is cared for

The professionals interviewed told how they arrived at the institution, the reasons that led them to work there and their first feelings when they entered the facility:

I took the civil service exam, I didn't even know what it was for [...] it's something I got used to and ended up liking, and today I love what I do. [...] When I got here, it was a shock [...] for me at first it was hard [...] "I'm going to have to give baths, I'm going to have to change diapers, I'm going to have to... I'm not going to adapt to this". [...] after we get used to it, we learn the tricks of the trade and we get on with it and it becomes easy, even enjoyable, and it's good to work with the elderly. (Interviewee 1)

I had been working with the elderly for a while [...] I took the city service exam, but I never imagined I would end up here. I had always worked as a private caregiver, in homes [for the elderly], and in hospitals too. [...] This was a surprise. [...] I had never worked in a nursing home before [...] You get used to it over time. [...] I had a kind of shock here, right? I saw a wheelchair user, two people who couldn't see [...] I was taken aback. (Interviewee 2)

I didn't know where I was going [...] it wasn't a choice or anything, they just told me, look, your job post is at the nursing home. [...] at the moment they told me where it was, I was a little scared [...] I had no idea what it was like to work in a long-term care facility. But for me it was a pleasant surprise. (Interviewee 4)

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The feelings built from the interaction and daily care with the elderly and the emotional impact of the profession:

We get very attached to them [...] It's a family member who leaves [when they die]. We suffer, we get more attached to some, and less attached to others, obviously. There are some that we have a lot in common with. (Interviewee 4)

It seems like we never change our rhythm, whether it was at home or at work, you're always living the same thing, and that's very mentally exhausting. [...] it's enriching as a human being, we change our perspective on a lot of things, it makes you value things that sometimes go unnoticed. [...] this work is enriching. (Interviewee 5)

Regarding the residents receiving care, the question was asked about the health issues of the elderly people living in the facility:

Mental illnesses, who shouldn't be here, but many come with a very serious mental illness. Diabetes, hypertension, Alzheimer's, some have a very advanced stage of Alzheimer's, schizophrenia. Schizophrenia and Alzheimer's are the most common ones. (Interviewee 4)

I can't tell you, because that's something the technician and the nurse know. I can't really tell you or specify the pathology exactly. But in general it's blood pressure, diabetes, that's what I see. I take a quick look at the medications when I have to administer them because the technician doesn't come on the weekends. But there are other medications that I don't even understand. Schizophrenia, I know there are a lot with that. If there's something else, I don't know. (Interviewee 3)

[...] "girls from the back room" (since they have a room at the back of the property, a room apart from the facility), referring to the managers, nurse, psychologist and social worker. (ND3)

Because professionals are directly involved in caring for the elderly, they have their own perceptions about the aging process and the emotional state of those who are institutionalized. They are afraid of new things, of going to a place where they don't know anyone, and they are worried about no longer living their own lives, as if they were giving up their freedom when they arrive at the facility. However, it is also possible to observe a concern on the part of professionals to ensure that the elderly feel comfortable and welcomed in this new reality:

I think they feel a bit abandoned here [...] left behind, abandoned, not by us, by their family [...] there are some who feel fine, they miss being part of their family, because whether they like it or not, we are... We are strangers to them, right? They only got to know us now, after they got old. Then there are some who don't adapt well. (Interviewee 1)

I think there are some who control [their feelings], but they don't talk about it [...] I don't know if it's just a matter of watching the days go by [...] they are resigned, and we help them, assist them so they don't get depressed. Because when they walk through the door they don't know what they're going to find, they don't know what it's going to be like, it completely changes their world. It's as if they're no longer going to live their own life, they're living a life that's imposed on them, and I think that's what I call conformity. It doesn't mean they're unhappy, but I think they're resigned. (Interviewee 2)

They are walking history books and that is really cool, this exchange, this conversation. They have a lot to share with us and you will see, the ones we can talk to, you will see how much they have been through, how many different things, how much they have suffered to end up here. [...] most of them arrive here very withdrawn, very nervous, very scared, those who had gone through violence [...] They arrive scared, depressed, they don't trust anyone. [...] most of them are grateful, they are polite, they are kind, they are happy with things. (Interviewee 4)

# Subunit 2: "Each person has their own reality, with a history, a type of vulnerability, violence, aggression, experience": the paths of institutionalization

When interviewees were asked about the reasons that led elderly men and women to be institutionalized, the answers converged on the function. In general, the reasons given were: neglect, abandonment and/or violence:

Each person has their own reality, with a history, a type of vulnerability, violence, aggression, experience. (Interviewee 5)

[...] I can't say, that's the technical team's responsibility, it's not something we've been told. We even know about some of them because they tell us, but for me it's not something I've heard about. I believe, based on my experience, that they're here because of negligence. (Interviewee 3)

Institutionalization should be done through the SUAS [Sistema Único de Assistência Social/Unified Social Assistance System] service, in this order: the basic works with the family, try to maintain bonds, in the second one the bonds are starting to break, but we still have to try to make them stay together, so that they don't get separated, so that no one will be institutionalized [...] They come from the prosecutor's office. There are some exceptions, but, in general, they all come from legal proceedings [...] they come for various reasons, and none of them are good, physical, psychological, financial, sexual violence. [...] There are exceptions, we have an elderly person who came here because he is alone, he didn't have children, he didn't get married, he doesn't have a family, he ended up alone and he has no income, his income is compromised by loans. [...] they are here because it is the last resource [...] when they come here it is because all the bonds were initially broken, all the attempts to maintain these bonds didn't work. Institutionalization should be the last resource, but unfortunately, sometimes it doesn't happen. Sometimes the judiciary system, the prosecutor's office, understands that it is better for the elderly person to be institutionalized, even if they have children, other family members, and income. (Interviewee 4)

# Participants bring their perspectives on the reasons for institutionalization:

It's sad, unfortunately, to think that, for example, people who have children, who raise their children with all their love and affection and then when they're at the end of their lives and end up in a facility because their children don't want them [...] like the case of this elderly woman, she has five children and none of her children want to take care of her, none of her children can, it's sad to think about that [...] where did I fail, what went wrong, why did they end up here and why these children don't want them. (Interviewee 4)

I thought it was a bit unfair that they were here. I thought it was neglect from their children, abandonment from their children [...] They are not here for no reason. They all have a story, they all, when they were younger, did something, committed themselves in some way that brought them here. So, this, in a way, consoles and changes this victim

perspective a bit. They are not victims because they are here. I think it is a consequence, it is a result of an action, of a choice, of a position. (Interviewee 5)

# Regarding institutionalization, the interviewees state the roles they play in this process:

The goal is this, that they structure or restructure their social, financial and clinical aspects and then they are sent to their family or to a [private] LTCFE. This is almost always the path, but some stay. (Interviewee 5)

As time goes by, they come here, we organize their lives. For those who don't have an income or those who do have an income but something compromises it, we organize their lives, and they go to paid institutions, but that's just a few, that's usually an exception [...] they come with so many loans, with so many years compromised behind them, that they end up having to stay for a long time until we get their lives together. [...] they stay because they don't have the social benefits to be able to pay for a house, to buy things they want to buy, so all of this drags on their stay here. [...] most of them stay here until they die. We try to preserve as much of their individuality as possible, for them to have a little wardrobe, their own things, clothes, we know that not everyone can have it, not everyone can manage to do that, but those who can, we try our best to preserve that, because they are human beings, they are people, they are worthy of respect, they are worthy of affection, of attention. So we try to preserve these rights of theirs as much as possible. (Interviewee 4)

# Subunit 3: "Here they have everything. A home, food, everything is clean, everything is brand new": the space and the dynamics of caring relationships

In relation to the physical structure of the institution, the observation moments contributed to a better perception of the environment:

The walls are white, without any other colors or pictures, giving the impression of a cold environment. There are some posters in the room walls [...] a closet in the hallway with four painted drawings stuck on it [...] The rooms have three to four beds each. In all of them, there are one or two bedside tables. In only one of the rooms, on a bedside table, I saw personal or decorative itens. It was a small vase with a flower, some clothespins, a bar of soap and a bag. This bedside table is next to an elderly woman's bed. [...] the table belongs to her, as does the wardrobe. She has a wardrobe just for her and on it there are two labels with her name. There are clothes that are hers and others that were donated [...] On the other tables, there are only small bottles of water or a shoe. (ND1)

[...] I think we have a lot of structure, support. The house is very good, spacious, that is very important. (Interviewee 3)

In the institution, all the spaces are shared. Only the bed is for individual use individual and the clothes, even those donated, are separated and evenly distributed, and the elderly respect each other's belongings. However, despite the collective feeling expressed by the shared spaces, there are not many moments of interaction inside the facility. The only sound in the facility is the television or the professionals talking with each other.

The house is cleaned daily and constantly, and the spaces are always clean. Even though the environment has some not so positive characteristics, such as the lack of personalization,

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white walls, no memories and no affection, the institution resembles a home, since it has separate rooms and shared spaces.

The elderly have a routine that must be followed in the institution, such as bathing, meals and the time to take their medication. It is clear that there is ambiguity in what was observed and in the professional's report when they state that the institutionalized elderly are free to do what they want, as long as they follow the routine of the facility:

The routine at the facility starts around 8/8:30 a.m. The elderly get up, those who have a shower day (they bathe every other day there, it's the institution's routine) are sent to the shower and have breakfast. Those who want to take a shower even when it's not their day can do so. [...] "They have complete freedom to do what they want, as long as they eat at meal times, take their medicine and take a shower, if it's the day" [professional's report]. (DN1)

The routine at home didn't change much regardless of the time I observed it. (AN5)

The institution's routine includes visits from Monday to Friday, when management is present at the facility, and only in the morning. The length of time that visits last depends on the elderly's wishes. They are supervised and, if they show any signs of discomfort, the visitor is asked to leave:

This woman's son had already arrived to visit her and was waiting in the courtyard of the house until she had finished eating her breakfast. (DN2)

He comes to visit, he's super loving, and there are days when she welcomes him very well, and there are other days when she fights, swears, sends him away, so we try to manage this. (Interviewee 5)

As evidenced during the observations, and later in the interviews, the minority of elderly people have bonds with outsiders and receive visits. The others are in fact alone:

Some receive visits, but not all of them. There are some who stayed here their whole lives and no one came to see them, no one wanted to. (Interviewee 3)

We have an [elderly woman] here whose son comes to see her. [...] He's the only one who comes. (Interviewee 2)

However, the importance of visits in the lives of the elderly people who receive them is clear. They are excited when someone comes to the institution, as if the daily routine of eating, sleeping and taking medication, which is mandatory due to institutionalization, becomes a little more pleasant and less monotonous with the arrival of visitors:

She is radiant [...] she is happy, her eyes glimmer. [...] She takes a bath and waits for [the son's name], then he arrives and she hugs him and talks, and you swear she doesn't have schizophrenia, or anything at all. She is coherent, keeps eye contact with her son, like that, and her eyes glimmer. She hugs him and she knows he will come back again. That is crucial, even for the person to stay [...] it makes all the difference. I feel sad because there are some who don't have

children at all. But if everyone had a little joy every now and then, like her, it would even be a happier end to life. (Interviewee 2)

It caught my attention that this gentleman who received the visit from his son was always looking grumpy, with his eyes drooping and mumbling. I never saw him speak to anyone. When the visitor arrived, I saw him give the biggest smile. (DN2)

That scene touched me deeply, because I saw the importance of a visit that many there don't even know that feeling. [...] It made me reflect on the importance of the visit. (AN2)

The (lack of) socialization and interaction of the elderly with themselves and with the professionals drew attention not only in the observations, but also in the interviews. In general, the house remains silent, with little interaction between the elderly and professionals. They prefer to sit in silence, either in front of the television or staring into space, waiting for time to pass:

I think they have a good relationship with each other, they respect each other, they sit close to each other. I think they care for each other, they don't fight. [...] There are two ladies who sit close and hold each other's hands, this lady sits there and talks to that lady next to her, I think they have a close friendship, reciprocal. (Interviewee 2)

They hardly communicate and interact each other. During the days I came, I did not observe any conversation between them. They just said something to each other quickly and punctually. [...] They both paid attention, laughed softly and communicated in their own way, but only by commenting on the film they were watching. (DN3)

*Outside, most of them were smoking and didn't talk much to each other. The caregiver who was there kept trying to talk to them, but the dialogue didn't last long.* (DN5)

In leisure and pastime activities, it was observed that most elderly people spend most of their time in front of the television. When they are not doing what is part of the institution's routine and which must be followed, the elderly stay in the common rooms always watching the same channel:

Seven were watching television [...] and stayed there until lunchtime [...] A man was walking around the house listening to the radio on his mobile phone with headphones [...] three other elderly people were on the street drinking chimarrão. [...] the atmosphere was still the same. The elderly people continued with the same activities they had been doing since early in the morning. (DN1)

Around the house, some elderly people were watching television, others were outside and others were already in bed, ready to sleep. [...] after the meal, some went outside and others went to the living room in front of the bedrooms to watch television. (DN5)

After breakfast, they disperse around the house. Some go in front of the TV, others go outside, others go back to bed. [...] In general, most elderly people stay inside the house in front of the TV.(DN2) Furthermore, the activities provided do not encourage the elderly to interact with each other, creating a lonely and silent place:

Is this what it means to grow old? Is this our destiny? To grow old, spend the day watching television and waiting for the next meal? (AN1)

# DISCUSSION

The interviewees expressed similar sentiments about not knowing where they would work after taking the civil service exam, in addition to the impact they suffered when they found out they would have to work in an LTCFE. The professionals were not prepared to face possible situations that they might experience in such facilities. This was largely due to their lack of experience in elderly care.

The lack of prior experience is an obstacle faced by professionals when it comes to caring for institutionalized elderly people. However, this is not a problem found only in the research institution. Research conducted in a Brazilian institution found a gap in training in the area of gerontology and/or palliative care. The health professionals at the institution lacked specializations or training in elderly care<sup>15</sup>. The lack of understanding about death and dying and care at this stage can prolong the life and suffering of the elderly, neglecting another aspect of care<sup>15</sup>.

RDC No. 502/2021 states that "*The Facility must carry out continuing education activities in the area of gerontology, with the aim of technically improving the human resources involved in providing services to the elderly*"<sup>16:3</sup>. No reports of such activities were provided by professionals at the facility. Ongoing training and continuing education activities would be important for providing dignified, comprehensive care that meets the needs of institutionalized elderly people.

When asked about interaction, contact and daily care and the emotional impact of the profession, it was reported that, when there is a loss of a resident, they are sensitive due to the attachment and bond that is built, since they are elderly residents who stay in the institution for extended periods. On the other hand, there are those who see working in the institution as something rewarding and enriching, of exchanging affection and experience.

Not only for the professionals, but also for the elderly, the creation of bonds is positive in environments such as LTCFEs. This is because relationships are intensified, promoting what was previously a strictly professional relationship into a relationship that would be close to that of a family member, creating a happy and pleasant environment for both parties involved<sup>17</sup>.

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The professional relationship with the elderly is closely linked to care. The most common illnesses among institutionalized elderly people are those related to mental disorders such as schizophrenia, Alzheimer's and dementia. Cognitive impairment leads to dependence on the elderly, since they prevent them from achieving self-care and managing their lives. The main illnesses that are related to old age and that lead to cognitive impairment are dementia, depression, delirium and mental illness<sup>18</sup>.

In the reports of the interviewees, those who are directly involved in care reported health problems in general, but were unable to specify the previous history and the real reasons that led to the institutionalization of the elderly, highlighting the distance between the care team. That said, it is important to point out the role of the caregiver, to know who they are caring for and why they are caring for them.

Supporting the results, a study identified from the professionals' reports that the lack of communication between teams harms the attention and care provided, as it becomes fragmented, since each shift establishes a different routine<sup>19</sup>. The professionals reported the need to develop strategies to address the problem, such as organizing a message board to maintain a standard in the provision of care<sup>19</sup>.

Multidisciplinary meetings would have a positive impact not only on those who provide care but also on those who receive care, as they are a strategy that makes it possible to look at the demands of the workplace, discuss priorities and plan the care that should be offered. In addition, they bring professionals working in the location closer together, and there is recognition of their work and organization of services<sup>20</sup>.

Institutionalization significantly impacts the social interaction, autonomy, and privacy of elderly individuals. In addition, it is constantly related to abandonment, since many are left behind and no longer receive visits or family calls. Furthermore, when entering the facility, the elderly face challenges such as shared spaces, feelings of anxiety around with strangers, even if these manifestations are similar<sup>21</sup>.

Institutionalized elderly people go through a complex process ofloss of autonomy and social exclusion due to aging as a result of institutionalization. Health professionals must be attentive and recognize the particularities of each elderly person and their history, with a view to providing autonomy, independence and a better quality of life, offering comprehensive care, meeting their main needs.

Regarding the reasons for institutionalization, in line with the findings of this study, a study conducted in different LTCFEs found that the main reason was situations of domestic violence or vulnerability, such as mental and/or cognitive illnesses, homeless people or having

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no family. The interviewees indicated that violence was the fact that the elderly person was removed from their family to be institutionalized, inducing the idea that the LTCFE is not a place of affection and dignity<sup>22</sup>.

On the other hand, another study found that the lives of the elderly before institutionalization were vulnerable, with social risk, and dependency on daily activities, which is why the elderly accepted the institution as a place of care, company and respect for individuality. However, even though they recognize the vulnerabilities experienced before institutionalization and the importance of the care received there, they continue to carry the suffering from past experiences when recalling their life stories that led them there<sup>23</sup>.

In the interviews in this study, while one of the interviewees reports how sad it is for the elderly to have a family, more specifically children, and yet have no one to take care of them, other interviewee's speech reflects that this abandonment by children has a reason, there is a story behind it and that in a certain way makes the institutionalization of the elderly more understandable when one thinks about it this way. There seems to be a way of elaborating, in the sense of an attempt to understand, on the part of the team, in relation to the life stories, with a view to not judging the elderly and their family and, in this way, providing care and support regardless of such stories.

The speeches reveal the work done when an elderly person enters the institution, which ranges from searching for family members and close people to adjusting and/or stabilizing the financial life of the institutionalized person so that they do not need to stay there until death. In other words, it goes beyond something technical; it is a work of social reintegration, of rescuing the human being.

A study found that elderly people who do not have family bonds, spouses and/or children, or retirement or health insurance are placed in public, non-profit institutions due to precarious socioeconomic conditions.<sup>24</sup>. The efforts to maintain family bonds indicates care and concern on the part of professionals in maintaining the social life of the institutionalized individual. Some elderly residents are left without family bonds and the work perspective changes. In these situations, professionals need to seek to do something that makes the elderly feel comfortable and as close to home as possible<sup>25</sup>.

Regarding the spaces, it is clear that they do not resemble a hospital. The beds are "normal" and not hospital beds, there are bedside tables scattered throughout the rooms, wardrobes and the rooms are spacious. However, the lack of personal items, decorations and colors on the walls make the environment empty, not only for those who live there but also for

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those who work there. While it resembles a normal family home, it is far from a welcoming and pleasant home.

A study carried out in an LTCFE with elderly people in greater dependence in France found that the rooms are individual and similar to hospital rooms, but the environment was personalized, with family photos on walls, a personal bathroom and a television just for the elderly person, making the environment more welcoming<sup>26</sup>.

While the environment is far from a home, the elderly follow routines that must be respected, as adhering to the institution's rules is part of communal living. Institutionalization restricts the freedom and individuality of the elderly, even if only partially, since they do not have the right to come and go, to leave the institution whenever they wish, but they are free in the sense that they can take control of their own lives within the institution. Thus, adapting to the routine of the home is not an option and is necessary in view of the changes faced<sup>27</sup>.

In the routine to which they are subject, there are visits. These are accompanied by rules that must be followed, such as restrictions on days and times. It is possible that this rule is a factor that justifies the scarce visits in the institution. The limited visiting hours is a rule that causes family members to distance themselves from the elderly and impairs care, since the presence of the family is considered an important factor in the quality of the service<sup>25</sup>.

In a study with elderly people, feelings of abandonment and loneliness were found related to the absence of family during the institutionalization process, as well as the scarce or non-existent visits, and the doubt as to why they were placed in a residence where they do not know anyone<sup>28</sup>. Family is important in the lives of elderly people. It is through visits to their new home that bonds are reestablished and that elderly people still feel that they are part of the social and family bond that was taken away from them, often against their will<sup>25</sup>.

In addition, as an attempt to alleviate feelings of abandonment and loneliness, the institutionalization environment should encourage interaction and socialization, as this would result in greater independence for the elderly in all aspects of their lives. Another study conducted with institutionalized elderly people demonstrated that, when there is greater socialization, there is better health, functionality and absence of depressive symptoms, with social interaction being a fundamental element in the promotion and recovery of health<sup>29</sup>.

The lack of leisure activities in the institution, coupled with the fact that many elderly residents pass the time watching television, makes it feel like they are simply waiting for the next mealtime or bedtime. Leisure is directly related to pleasurable activities in the midst of the mandatory routine activities in the institution. In addition, they have several benefits for the

life of the institutionalized person, improving communication, the bonds of friendship established in the environment and interpersonal interaction<sup>30</sup>.

The lack of interaction, socialization, and leisure activities provided by the institution creates an sterile and unwelcoming environment. It is enough to simply accept that this is an environment of waiting for the end of life and that, at least then, television should be used as a pastime so that the wait does not become long and boring.

# CONCLUSION

LTCFEs are institutions designed to accommodate the elderly, but they face challenges such as prejudice and the general invisibility of these facilities. There should be no better place for the elderly than a family environment, of welcome, care and love. But this home is not always like that, since it can be a place of mistreatment that can compromise the health and well-being of the elderly. Thus, living the end of life in an institutionalized setting is not always a choice, but rather a last option to receive attention and care.

When institutionalized, the elderly experience the end of their lives in a restricted environment, marked by a breakdown of family and social ties and a loss of autonomy and freedom. It is a quiet place with an established routine, far from resembling a hospital but not quite like a family home either.

Visitors play a crucial role within LTCFE. The data from this research revealed that the arrival of visitors at the institution makes the elderly feel welcomed and still part of the social bond. Furthermore, it keeps the elderly away from the routine of the institution and from watching television.

However, most of the time, the family does not seek out the institutionalized elderly person, abstaining from any contact. Family abandonment, loneliness, silence and social isolation were situations that appeared both in the observations and in the testimonies of the professionals, leading one to believe that the end of life for these elderly people is just waiting for the moment of death to arrive and, while they wait, they sit in front of the television.

The professionals interviewed were not prepared to work directly in the care of elderly residents when they began at the institution. Furthermore, they do not receive updates on how to do so. Unpreparedness, lack of knowledge and lack of training in the area of gerontology and/or palliative care can interfere with the care of the institutionalized elderly person, prolonging suffering and interfering with autonomy. Therefore, it is necessary for institutions, at all levels, to invest in updates, training, qualifications and ongoing education activities,

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aiming at providing dignified and comprehensive care to meet all the needs of the elderly person.

There is a lack of communication and a distance between the professionals who provide direct care and those responsible for management. This distance affects the care of the elderly and reinforces the need for information sharing strategies.

LTCFEs should be places of life, sharing and interaction. Before being institutionalized, the elderly had their own lives, routines, bonds and interactions. The institutionalization process disrupts all of life's pleasures, especially when they are not stimulated. The lack of socialization between the elderly and professionals, as well as the absence of leisure activities, were noted. The inclusion of physical and intellectual activities could have a positive impact on interactions, social life and the well-being of institutionalized elderly people.

The research in a single LTCFE is a limitation. However, this reality may be similar to many others, and understanding it can contribute to improving practices in LTCFEs.

Conducting research in places like LTCFEs is challenging, but necessary. Institutionalization is not just a reality for many elderly people; it can also provide an opportunity for them to live with dignity and receive the care they need. The findings of this research reflect professional practice and the reality experienced by elderly people within an LTCFE. Studies in this area can help redefine institutionalization and the way elderly people are perceived, emphasizing their need to be included in social life and to receive care and attention.

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