

# Challenges for dignified care in homes for the aged

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## Abstract

This article aims to present a descriptive and qualitative study to understand how care is implemented at the end of life in homes for the aged in the metropolitan region of Porto Alegre, Brazil. We interviewed 19 members from the technical team and 13 staff responsible for taking care of the institutionalized elderly. In this sense, we sought to investigate whether institutions are structured to recognize the need for care to ensure comfort and dignity in the dying process of their patients. From the analysis of the content from interviews and observations, it can be said that some of these structures are precarious. A relationship between care quality and availability of financial resources was also identified, demonstrating reification of care, that is, care is regarded as a commodity. In this way, bioethics of protection would be a tool to overcome the challenge for dignified care.

**Keywords:** Homes for the Aged. Respite care. Palliative care. Elderly.

## Resumo

### Desafios para o cuidado digno em instituições de longa permanência

Este artigo tem como objetivo apresentar estudo de natureza descritiva e abordagem qualitativa para analisar como vêm sendo implantados os cuidados no fim de vida em instituições de longa permanência para idosos (Ilpi) na região metropolitana de Porto Alegre. Foram entrevistados 19 sujeitos do corpo técnico e 13 responsáveis pelos idosos institucionalizados. Nesse sentido, buscou-se investigar se as Ilpi estão estruturadas para reconhecer a necessidade de cuidados que garantam conforto e dignidade no processo de morrer de seus pacientes. A partir da análise do conteúdo das entrevistas e das observações, pode-se dizer que há precariedade nessas estruturas. Também se identificou uma relação entre cuidado de boa qualidade e disponibilidade de recursos financeiros, demonstrando indicativos para a reificação do cuidado, ou seja, o cuidado enquanto mercadoria. Como ferramenta para superação do desafio do cuidado digno está a bioética de proteção.

**Palavras-chave:** Instituição de longa permanência para idosos. Cuidados intermitentes. Cuidados paliativos. Idoso.

## Resumen

### Desafíos para una atención digna en instituciones de larga permanencia

Este artículo tiene como objetivo presentar un estudio de naturaleza descriptiva, con un abordaje cualitativo, para analizar de qué modo se están implementando los cuidados en el fin de la vida en las instituciones de larga permanencia para ancianos (Ilpi), en la región metropolitana de Porto Alegre. Fueron entrevistados 19 sujetos del cuerpo técnico y 13 empleados responsables por los ancianos institucionalizados. En este sentido, se procuró investigar si las instituciones están estructuradas para reconocer las necesidades de cuidado que garanticen la comodidad y la dignidad en el proceso de muerte de sus pacientes. A partir del análisis de contenido de las entrevistas y observaciones, se puede decir que existe una precariedad en estas estructuras. También se identificó una relación entre la calidad de la atención y la disponibilidad de recursos financieros, evidenciando una serie de indicadores tendientes a la reificación del cuidado, es decir, el cuidado visto como una mercadería. Una herramienta para la superación del desafío del cuidado digno es la bioética de protección.

**Palabras clave:** Hogares para ancianos. Cuidados intermitentes. Cuidados paliativos. Anciano.

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When considering the subject of end of life care in long-term care facilities for the elderly (LTCFs) we must also explore the theme of quality of life in the last years of such individuals. Problematizing the issue is a challenging exercise, given that there are few studies available that help to understand the phenomenon. Population aging brings with it an increase in chronic and disabling diseases, which has a direct impact on public health and the care capabilities of families and institutions.

Among the many study possibilities in the field of social gerontology, we have focused on the care and the structures that are available to elderly persons in the process of dying. This subject is pertinent to the discussion of social resources, family ties, medical structures, pharmacological support, hygiene and comfort and above all, the preservation of the dignity of institutionalized elderly persons. Therefore, this article presents the results of a study conducted in the metropolitan area of Porto Alegre in the state of Rio Grande do Sul on how end of life care is provided in LTCFs.

### Theoretical framework

Aging is a gradual process, and, according to existing sociological, psychological and biological theories, there are multiple ways in which it takes place. In the present study, we chose the critical theory of social gerontology<sup>1</sup>, which utilizes two dimensions as a research base: the structural and the humanistic. According to Salgado<sup>2</sup>, this theory functions at a macro level and is part of the set of sociological theories of the third generation correlated to Marxist perspectives. To understand the theory, elements such as society, economic trends, socio-structural factors, power and social action, as well as subjectivity, the interpretation of aging and the recognition of the heterogeneity of the aging process are key.

This epistemological choice of the critical theory of social gerontology<sup>1</sup> is based on the understanding of Marx's postulates, as explained by Dias<sup>3</sup>, according to which the study of society should start from a material base (economic facts), in which other dimensions of reality – such as politics, culture and art – are supported. From this perspective there is no specific interest in social harmony, but the outcome of the class struggle will establish the measures that will bring opposites together.

With the advent of capitalism and changes in the relationships of production and the demands on

those individuals who sell their labor, vulnerabilities arising from fatigue and advancing age are overlooked. Once the worker no longer possesses ideal production conditions, he or she is relegated to a lower status in the capitalist social context.

With this in mind, we can begin our discussion about aging and care at the end of life, taking into account the fact that neoliberal capitalism considers these issues as secondary. Making the individual responsible for the conditions of his or her development and quality of life are reflections of a crisis that results from the break with the industrial capitalist society way of life and the transition to a lifestyle of financial capitalism<sup>4</sup>.

Among these elements is the trajectory of the institutions that house the elderly, which in the twentieth century have become profit-oriented businesses, or in other words, aware of the incompatibility between family structures and the provision of specific care for elderly persons suffering from illness. Forms of consumption and capital accumulation can be seen today in the gerontological services of reception and residence, which have emerged as a promising market. As it becomes a necessity, human care has also become a product to be exploited economically.

Although there are institutions that approach this task as a social commitment, depending on public and social resources (and the elderly themselves), there are a significant number of private institutions that exploit care as a commodity. In other words, the reification or objectification of care is permeated by alienation and the fetishism of the commodity "care":

*Formal care is understood as that which involves the provision of comprehensive care to the elderly in LTCFs and/or day centers or outpatient care, in addition to formal home care. It is offered by professionals from both the public and private sector. It is common to think of only two types of care: family or residential facilities. However, the scope of alternatives is much wider<sup>5</sup>.*

In this sense, the Statute of the Elderly<sup>6</sup> presents LTCFs as structures of a social nature involved in the field of welfare, but which receive or continue to care for the elderly in specific health care situations. However, there are mixed health structures – hybrids – as well as multidisciplinary teams that care for these subjects at the end of their lives.

*For the Agência Nacional de Vigilância Sanitária (the National Health Surveillance Agency) (Anvisa), LTCFs*

are governmental or non-governmental institutions, residential in character, aimed at offering a collective home to people aged over 60 years, with or without family support, under conditions of freedom and dignity and citizenship. In other words, they are collective households offering care and some kind of health service. They are hybrids and as such should not only comprise systems of care and health, but also of housing<sup>7</sup>.

Data from the 2010 census shows that 0.8% of the elderly population of the south of Brazil live in collective households (LTCFs, hotels, convents, prisons) – representing 19,000 elderly persons. In the city of Porto Alegre, the percentage is 1.9% (n = 3.061) of those aged over 60<sup>8</sup>. The increasing trend of elderly residents in LTCFs means the issue of care at the end of life in these institutions must be discussed, considering that subjects who enter these facilities have not only their continuity of life protected, but that there is also understanding of the inevitability that fatally will take place in this space.

From a conceptual perspective, care at the end of life refers to people with “expected death”, when said death is predictable and there is a prior knowledge of its arrival. That is to say, there is the presence of disease that is refractory to therapeutic treatment, that is predictably fatal in the short term, the definition of which presupposes the existence of an illness that is in an advanced stage and is terminal and incurable: *it is when the possibilities of recovery of the conditions of health of the patient have been exhausted and the possibility of approaching death seems inevitable and predictable. The patient becomes “irrevocable” and is on the path to death, without being able to reverse this path*<sup>9</sup>.

The quality of life at the end of life should not necessarily be considered solely from the diagnosis of disease, but should take as its parameters the quality of life of older people and meet their needs throughout the progressive aging process. This is reinforced by studies such as that of Trotta<sup>10</sup>, which when discussing multiple chronic diseases in residents of nursing homes, leading to a death that is usually uncertain or unpredictable, characterized deaths in such locations as either prolonged or sudden. Another study suggests that death is usually caused by the progression of a chronic disease, which is often the reason for admission to the home for large numbers of residents<sup>11</sup>.

There has been a continuous growth in the number of elderly people with chronic diseases, which indicates a need to adapt healthcare models.

This is a given for institutionalized elderly persons who require specific attention, but who, in the process of disease at the end of life, do not receive the necessary attention and lack the resources needed to ensure a death with good quality care<sup>5</sup>. When curative care is no longer possible, we enter the field of palliative care, which, according to the Organização Mundial de Saúde (World Health Organization):

*(...) is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*<sup>12</sup>.

In Brazil, palliative care began in the 1980s, but has only grown since 2000, when the Conselho Federal de Medicina (the Federal Council of Medicine) established the technical commission on the terminality of life and palliative care<sup>5</sup>. In this field, the basic guided team is composed of medical, nursing, psychological and social work professionals, being supported by other areas in accordance with the reality of institutions and families.

According to Hanson, Henderson and Menon<sup>11</sup>, LTCFs are places where palliative care is part of the institutional routine. However, some points are suitable for problematization: the lack of studies in the field, Brazil's position in the quality of death ranking (38th out of 40 countries) and the non-recognition of finitude as a natural process that permeates the lives of those in an advanced stage of aging. This reveals the lack of careful observation or focused effort to create public care policies, particularly in the dimension of end of life for elderly residents of LTCFs. In relation to this question, Di Giulio et al. stated:

*(...) even if there are signs of improvement in terms of increased palliative care, much is to be done in long-term institutions, which are at the forefront of the care of older people. There are visible indicators of poor quality of care, such as physical restrictions, pressure ulcers, the use of psychoactive substances and the lack of documentation of advance directives. These findings suggest that older people are not perceived as “terminally ill”, and do not always receive appropriate palliative care*<sup>13</sup>.

In a systematic review of end of life care in nursing homes, which considered studies between 2002 and 2012 in Europe, the USA and Australia<sup>14</sup>,

nine areas were identified: comprehensiveness of care, the relationship with family, the personality and life history of the elderly person, teamwork, symptom control, advance planning and proper use of treatments. Factors that hindered or facilitated the implementation of the philosophy of palliative care in the context of LTCFs were also defined.

One of the interesting points in this meta-aggregation was the identification of difficulties in the establishment of global palliative care for the elderly, especially in the diagnosis and transition of curative treatments to a palliative approach<sup>10</sup>. Among the suitable tools and scales used to measure the quality of palliative care in residential care facilities for the elderly, the Quality of Dying in Long-term Care Scale (QOD-LTC-C)<sup>15</sup> was highlighted in the study by Simões<sup>14</sup>. However, there is no equivalent scale translated into Portuguese and validated for use in Brazil. This scale has five domains: a sense of purpose, closure, control, social connection, and preparatory tasks, as well as 23 items. It can be concluded that the use of the instrument helps to better understand the experience of dying from the perspective of relatives and the technical team.

This also includes the issue of advance directives of will, which are specified in a document signed by the elderly patient, notarized or otherwise, as defined the first of three articles of FCM Resolution 1.995/2012<sup>16</sup>:

*(...) advance directives of will are set of wishes, previously and expressly manifested by the patient, regarding the care and treatment that he or she wishes or does not wish to receive when unable to express his or her will freely and autonomously.*

There is no consensus on the use of these directives, nor their acceptance by family members, but the subject remains a resource on the limiting of therapeutic intervention that is little discussed within LTCFs<sup>7</sup>. In accordance with the above, there exists a set of factors, dimensions and issues that influence the quality of life in the process of dying of institutionalized elderly persons, of which we propose further study.

## Methodology

The research related to this study is qualitative and descriptive in nature, and takes as its data source semi-structured interviews with professionals and the family members or guardians of

institutionalized elderly people (see Appendix). The sample of subjects was performed using the convenience, rather than the probability method which, according to Marconi and Lakatos<sup>17</sup>, consists of not using random forms of sample selection. The analysis of the collected data involved content analysis methodology, as proposed by Bardin<sup>18</sup>.

The starting point of the present study was the following research question: *How is end of life care provided in long-term care facilities in the metropolitan area of Porto Alegre?* The main guiding question was: *Are LTCFs structured to recognize the needs of care that ensure comfort and dignity in the process of dying of their patients?*

The process of defining the research universe employed the following steps: 1) choice of municipalities; 2) mapping and selection of LTCFs; 3) contact with family members; and 4) contact with staff. Municipalities in the region and the LTCFs registered with public bodies were selected and mapped. The choice of the metropolitan area of Porto Alegre was intentional, and the criteria for selecting the participants of the survey sample were by convenience, based on the stratification of municipalities by size, according to the IBGE/2010<sup>8</sup>.

The research universe, therefore, relates to 20% of the municipalities of the metropolitan area (n = 6), or one institution by location, all of which had functioned for over 36 months, had more than six beds and was registered with the municipal Health Surveillance System. Relatives/carers (n = 13) and staff (n = 19) were interviewed, giving a total of 32 respondents. On average three families and three members of staff responded per LTCF, except in the city of Dois Irmãos, where it was not possible to interview any family members because of their unwillingness to participate in data collection.

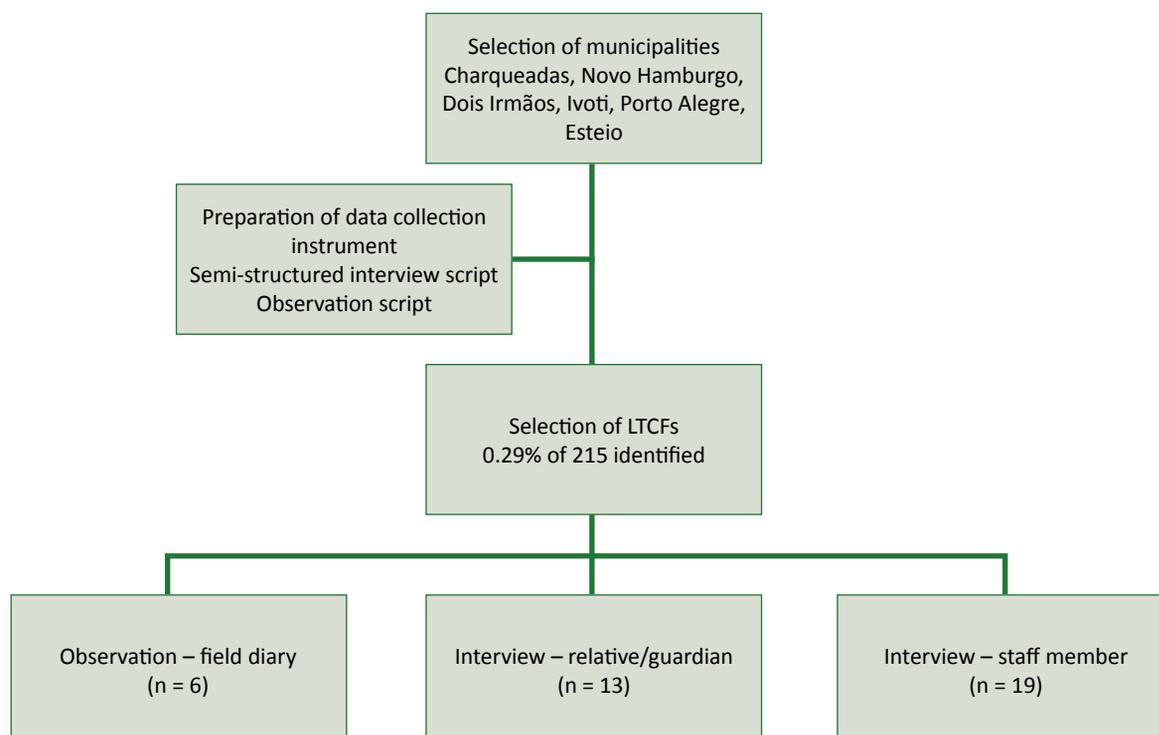
The interviews were conducted in the LTCFs, and family members were chosen as indicated by staff, based on the inclusion criteria. These were family members and/or guardians of elderly persons with a diagnosis of chronic degenerative disease in an advanced stage, that is, those with dementia or Parkinson's disease, with dependence in two or more activities of daily living due to the disease, or cancer with more than one year of chemotherapy treatment or in its final stage. The choice of family members, rather than the elderly individuals, as research subjects was based on the ethical understanding of the preservation of the subject's integrity, given his or her condition of physical, mental and psychosocial vulnerability.

**Table 1. Number of LTCFs by metropolitan region according to IBGE/2010 population data**

Municipality by size	Number of LTCFs by region	Distribution of LTCFs in %	Number of municipalities by size	Sample of municipalities by size
Metropolis (Porto Alegre)	94	43,72	1	Porto Alegre
Large	76	35,35	8	Novo Hamburgo
Medium	18	8,37	7	Esteio
Small 2	23	10,70	9	Dois Irmãos Charqueadas
Small 1	4	1,86	6	Ivoti
<b>Total</b>	<b>215</b>	<b>100</b>	<b>31</b>	<b>6</b>

The staff of the institutions were selected according to their availability on the day and time of visit, respecting the criteria of the Health, Provision of Care or Administration timetables. Considering the guidelines of the Post-Graduate Program, we state to the subjects who collaborated with the research and the scientific community in general that the research met all ethical requirements of human research, in accordance with CNS Resolution 466/12 19. A free and informed consent form was effectively explained, completed and signed by the participants.

Data collection took place between July 2014 and April 2015, with visits scheduled in advance. The choice of participants was based on the local availability of employees and their families. The institutions made prior contact with relatives so they could visit the elderly persons on the day that the researcher was on site. In situations where the family member could not be present, the interview was conducted by telephone, recorded with his or her consent, and a printed version of the FICF was provided to the participant.

**Figure 1. Selection scheme of study participants**

## Results and discussion

Care at the end of life is permeated by imperative requirements such as comfort, pain control, and also care and dignity. At different times of the analysis of results, a dichotomy was identified that was expressed in the discourse of the employees and the family members about what they perceived as the end of life and, therefore, care, life and death. So that the results could be presented in relevant analysis categories, we chose to first characterize the surveyed institutions, as well as the research participants.

Of the 215 LTCFs identified, 43.72% were located in Porto Alegre, and if aggregated to the percentage of 35.35% of LTCFs in large municipalities, it can be stated that 79.07% of the institutions are concentrated in nine of the 31 municipalities in the metropolitan area. It is important to emphasize that this information relates to LTCFs that are regularized or in the process of being regularized by the city council authorities. In Porto Alegre, we received a report containing 286 institutions, but only 94 had protocol numbers according to the Health Surveillance regulations, which indicates that 67.13% of the reported establishments are in irregular situations.

In the script prepared for observation of the institutional space, some aspects are worth noting as they are key to understanding the context in which care was offered (or not) in the LTCF: physical structure, building maintenance conditions, location, compliance with RDC 283/2005<sup>20</sup> – the technical regulation that defines the operating rules of the LTCF – the presence of family members at time of visit, the number of residents and the number of staff on duty.

Although the mean built area in the universe surveyed was 2,095 m<sup>2</sup> for 55 residents, with adapted and renovated structures, the facilities still did not completely comply with legal requirements<sup>20</sup>, except for one LTCF built around five years ago. Family members were present at the time of data collection and visits at five of the six LTCFs. The operating time of the facilities ranged from 5 to 85 years, with the oldest having the largest number of residents (n = 120).

Of the family members in the sample, four were men and nine women, with a mean age of 61 years. In terms of relationships, the following categories were found: 73% were children, 9% were grandchildren, 9% were siblings and 9% were parents. The average family income was 3.5 minimum

wages, while the average income of the elderly person was 1.6 minimum wages. Minimum wage was considered to be that in force in April 2015: R\$ 722.00.

With regard to staff, of the total of 19 respondents, the average age was 39.9 years, 89% were female and 11% were male. We did not prioritize only health professionals as protagonists of knowledge of care, as we understand that caring is an activity that goes beyond the aspects of hygiene and comfort<sup>21</sup>. With this in mind, the distribution of the professionals interviewed according to position held is set out below:

- Nutrition (nutritionist, nutrition technician, cook, kitchen assistant): 5%;
- General services: 5%;
- Volunteers: 5%;
- Administration / management: 16%;
- Social work, psychology: 16%;
- Nursing (nurse, nursing technician, carers): 53%.

According to RDC 283/2005<sup>20</sup>, an LTCF must provide human resources in the form of formal labor to ensure the following activities are carried out: technical supervisor, caregivers (as described earlier), and staff in the areas of leisure activities, cleaning, catering and laundry service. The staff in the areas of leisure activities in the surveyed entities were volunteers; however, whether in terms of number of staff hired, or in terms of the categories of staff, LTCFs still need to meet recommendations and guidelines.

When asked about the time they had worked in their chosen area (working with the elderly), the average response was five years. Staff were also asked about what we understand as external and preparatory conditions for the provision care, i.e. if they had had specific training to perform their chosen activity. According to respondents, from questions with yes/no answers, 84% described conditions (structural and material) suitable for general care (n = 16), while in terms of possessing specific training in the area of elderly care, 73% said they did not have any such training (n = 14). In terms of “palliative care”, while 42% (n = 8) said they had knowledge of the subject, this statement will be problematized throughout this article, in view of the common sense nature of “palliative” understood by respondents.

In other words, although staff claimed that to possess adequate conditions and expertise to carry

out their work and expertise, the reality observed and analyzed from the content of the interviews tells a different story, with deep socially and historically constructed contradictions about elderly care.

In terms of the profile of the elderly people who were in situations indicative of end of life care, the interviews found 11 women and two men. The skin color/ethnic background declared by family members indicated ten white and three black elderly persons, with no other color being declared. The average age was 80.8 years. The average time of institutionalization was five years. This is a period considered long in comparison with the six-month period identified by Kelly, in accordance with the analysis of Simões<sup>14</sup>, in a study that studied the time of institutionalization of elderly people from diagnosis of chronic illness until death.

Regarding the situation of the elderly persons before they moved to the LTCF, research indicates that 42% (n = 5) lived alone, 25% with children, 17% with spouse or family, 8% in LTCFs and 8% in hospital. According to the IBGE<sup>8</sup>, in 2005, 18.4% of people aged 60 or older in the metropolitan area of Porto Alegre lived in single person households. Living alone is not a risk factor for institutionalization, but according to one study<sup>22</sup>, risk factors include: female, over the age of 80 years, marital status (single, separated, widowed), followed by low level of formal education, inactivity and physical dependence for activities of daily living. These factors were corroborated by the profile of the elderly persons in this study.

Deciding to institutionalize a relative is not a simple process, as, in addition to recognizing the need for specialized care, the family must deal with feelings of failure, shame and helplessness at not being able to offer the care that their family needs. Data collected indicated that children are primarily responsible for the decision to institutionalize (42%; n = 5), followed by shared decisions made with the elderly (8%, n = 1) or with a former spouse (8%, n = 1). Although 17% (n = 2) said that the decision to reside in a LTCF was made by the elderly person, literature suggests that decisive factors for this are the desire to “not inconvenience”, the feeling of being a nuisance to the family. Only finally is there recognition of the limitations of the social context that leads elderly persons to decide to alter their living arrangements in a calm and accepting manner<sup>23</sup>.

According to ScharDOSim<sup>23</sup>, there are contradictions in the discourses of elderly persons and their relatives about the decision to institutionalize.

Among the different reasons given in this study were widowhood, family conflicts, and difficulties involved in keeping the elderly person with the family for work reasons or a financial situation. These factors contribute to the decision-making process, guided by the belief that the elderly person is no longer able to manage his or her own life.

Remaining with the description of the profile of the elderly persons studied, there was a prevalence of diagnoses of Alzheimer, Senile and Pike type dementias, as well as strokes, with sequelae for the performance of activities of daily living. Literature describes cardio-circulatory, respiratory, and neurological diseases as prevalent among the elderly, which together with traumas, fractures and infections, especially urinary and broncopneumonic, are the main causes of hospitalization of institutionalized elderly persons<sup>24</sup>. While literature lists neurological diseases in third place, these illnesses have the greatest impact in LTCFs, according to data from the present study. Next are strokes, which are the third cause of mortality in developed countries, behind cancers and coronary heart disease. In Brazil, strokes are one of the main causes of mortality, according to data from the Ministry of Health collected between 2010 and 2011<sup>25</sup>.

Data regarding these diagnoses comes from information from family members regarding the health status of the elderly; there was no access to patient records. It is with this information that the categories that emerged from the interview content and observations were established.

### *End of life: what time is it?*

Although literature describes the end of life as the 48 hours prior to the final breath of patients in the process of terminality, those within the LTCFs did not agree with this definition, considering the real possibility of death occurring at any time, as previously mentioned. According to studies, there are visible indicators of poor quality of care, such as physical restrictions, pressure ulcers, substance abuse and a lack of documentation on advance directives. These findings suggest that older people are not perceived as “terminally ill”<sup>13,14</sup>.

It is also important to reflect and analyze the perceptions of family members and staff and systematize this content into categories that can be discussed on a theoretical level. The twilight of life is a unique, personal and nontransferable time. No one can experience the terminality of the life of another. The very perception of terminal illness is individual

and refers to structures constructed internally that guide our understanding of life and death. In this process both the structure of the environments of care and the preparation of caregivers, as well as the multiple compositions of the act of caring help us to problematize the reality of the surveyed LTCFs.

Simply put, we can understand structure (from the Greek *struo* = order) as the organization of the elements of a whole. Wholeness/totality is one of the components of the structuralism perspective, a social science theory which aims to understand the functioning of society from its social structures, based on the functioning of the economy, the real basis on which a legal and political framework is built, and which corresponds to determined forms of social consciousness<sup>26</sup>.

In this sense, in accordance with Carrascoza and Furtado<sup>27</sup>, Althusser, when applying structuralism to the field of Marxism, defined which institutions are considered ideological apparatuses of the state, through which capitalism guarantees its ideological domination. From the ideological domination of capitalism, there is the pursuit of profit and the accumulation of wealth. However, in the LTCFs surveyed – most of which were private in nature (n = 4), the reality of the quest for profit is conflicted with the obligation and the social commitment to provide good care.

To analyze this conflict, we begin with the guiding question: *are LTCFs structured to recognize the need for care in a way that ensures comfort and dignity in the process of dying of their patients?*

During the process of observation and interviews, we seek to observe the care approach at the end of the lives of institutionalized elderly persons. For the analysis of content, as proposed by Bardin<sup>18</sup>, the register units were defined in the following groups of subjects and words: 1) “Training”; “Technical preparation”; “Knowledge”; “Work conditions”; “Hygiene”; “Cleaning”; “Comfort”; “Equipment, supplies and medications”; “Donations” - identified from interviews with staff; 2) “Physical structure”; “Accessibility”; “State of the building”; “Brightness”; “Ramps”; “24h Reception”; “Safety”; “Types of environment offered”; “Types of activity and service offered”; “Perception of appropriate environment” – defined from the observation script and field diary recordings. The fact that the register units referred to the category “structure” with recurring frequency in the staff group and the frequency of the themes indicating the preparation of the caregivers (52.6%) as well as the dimensions of hygiene (42.1 %) and comfort (21%) in the

interviews indicated how relevant these issues are in day to day work.

Regarding the physical structures and their characterization, three of the LTCFs surveyed were built of masonry and were houses that had been adapted to accommodate the elderly; while the other three LTCFs were designed for the reception of elderly, with only one being newly built and fully compliant with RDC 283/2005<sup>20</sup>. Six LTCFs provided accommodation for the elderly in single, double or triple rooms, where equipment such as feeding and urine drips were just some of the issues.

Only one LTCF was in an extremely precarious condition of conservation – people of different ages and conditions and diagnoses shared the hallways. There were few staff to meet the needs of residents and the infrastructure was inferior to that expected, which contributed to the strong odor of urine and immobilized residents, tied in wheelchairs, watching TV with a poor picture. In contrast, one of the institutions visited, designed specifically for the elderly, required no structural repair; on the contrary, it featured a glass wall overlooking the woods, large common rooms and bedrooms – like a hotel (temporary accommodation).

Location is often a challenge for LTCFs as they tend to be built far from cities, regardless of the number of inhabitants. The LTCFs surveyed were no different - 66% were located outside the urban perimeter or in hard to reach places.

There was an absence of family members at the time of the visit in only one institution. However, the information boards in front of the buildings providing information about visiting hours, days and periods were noteworthy. One such board read “please do not insist” (Observation report, October 2014). Information such as this should not be overlooked in the content analysis process. Of those surveyed, only one institution did not define visiting hours.

The number of caregivers per elderly person is also important data and contributes to our understanding of the possibility of humanized care for the elderly. ANVISA RDC 283/2005<sup>20</sup> defines a caregiver as a person trained to assist elderly persons who have limitations in performing activities of daily living. Although the spectrum of caregivers was greater in our study, for calculation purposes and compliance with legislation, nursing technicians and caregivers of elderly persons with employment contracts registered in this professional area, in accordance with the Brazilian Classification of

Occupations<sup>28</sup>, will be considered as caregivers. Table 2 compares the ideal number, based on number and degree of dependence, and the actual number of caregivers, obtained during data collection.

To perform the calculation, data about the number of elderly persons by degree of dependence was required, as RDC 283/2005<sup>20</sup> determines the number of caregivers required in relation to this information. These are:

- Dependence Grade I: one caregiver for every twenty elderly persons, or fraction thereof, with a shift of 8 hours/day;
- Dependency Grade II: a caregiver for every ten elderly persons, or fraction thereof, per shift;
- Dependence Grade III: a caregiver for every six elderly persons, or fraction thereof, per shift.

The differences indicate the efforts of non-profit institutions to provide the number of caregivers specified in the guidelines. However, the day-to-day difficulties are expressed in the following discourses:

*"There are staff and caregivers now, which I think is good, of course it could be better, but it was worse in the past, it's gotten better" (Jasmim – Ivoti, 17/12/2014);*

*"In fact, when I started working here there were no nursing technicians, just the caregivers, and they were trying to, you know, hire a doctor, now there are nursing technician, there are three, two during the day and one at night, which they didn't have before" (Bromélia – Charqueadas, 24/9/14).*

There was a clear conflict between the care requirements and the potential resources for care

in the LTCFs. But, behind this conflict, there was a sense of compliance in the discourse, in the clear recognition that the ideal was difficult to achieve, as well that the caregiver himself or herself was responsible for the conditions of his or her work, in an attempt to minimize the impact of structure on these conditions. This can compromise values such as the dignity and integrity of the elderly, as revealed in the following excerpts:

*"I think here we try and prioritize the care for them, so they can have a peaceful end of life. But what is that? We worry about their hygiene, and their food, and also their activities. At the moment we are unable to develop anything, because we can't afford to pay for it and you can't use volunteers, but today the goal is that: peace, respect, so that they feel that the home is an extension of their family, so that they feel welcomed by us here" (Crisântemo – Charqueadas, 24/9/2014);*

*"And in these conditions, that we have, no one goes without bathing, everyone took their baths using a bucket and a cup, sometimes we don't have enough staff, but no one misses out on getting changed" (Sálvia – Porto Alegre, 17/9/2014).*

The question remains: are the LTCFs structured to care for the end of the lives of their residents? Is there a specific approach to care at the end of life? Considering the items analyzed, it can be argued that the institutions are not structured in this way, nor is there any specific approach that addresses this particular time of life of the elderly.

*"(...) we're talking about elderly persons, they have to be well-cared for, well-treated, with love, with affection until the end of their life, until they die, I think. We have to treat him or her even better than*

**Table 2.** Comparison between ideal and actual number of caregivers in the institutions surveyed

Municipality	Legal basis	ideal number of caregivers/RDC	Actual number of caregivers	Difference	Mean monthly fees
Charqueadas	Private	16,5	2*	-14,5	1 MS
Ivoti	Private	6,9	7	+0,1	1 MS
Esteio	Private	16,2	4**	-12,2	1.5 MS
Porto Alegre	Non-profit	30	31	+1	1 MS
Novo Hamburgo	Non-profit	11,4	13	+1,6	1 MS
Dois Irmãos	Private	15	20	+5	5.5 MS

\* 8 general staff performed care provision roles.

\*\* 14 general staff performed care provision roles.

*we would if he or she were well” (Iris – Porto Alegre, 10/9/2014).*

There is no differentiation between care at end of life with the general care provided to anyone with emotional and physical vulnerability. Care in the LTCFs was experienced through the contradiction between dedication and precariousness. We should also mention the study of Hall, Kolliakou, Petkova, Froggatt and Higginson<sup>29</sup>, which cites the lack of staff, as well as the set of pressures to reduce staff numbers, maintain the profit margin and still provide care for an increasingly fragile population. This creates many obstacles for these institutions to provide care from a humanized and bioethical perspective.

### Final considerations

The implementation of specific care for elderly people who are in the process of the end of life is a difficult subject as it involves overcoming prejudices and the recognition of death as part of life. Care provided for institutionalized elderly persons should not be perceived as the defeat of the healing effort, as argued by professionals and researchers in medical sciences, as life and death is not a game with winners.

From the objective of the present study, it was observed that the approach to care at the end of the lives of institutionalized elderly persons is not differentiated, which decharacterizes this particular moment of human finitude. Therefore, such care does not function from the perspective of the relief of suffering and a death with dignity. Throughout this study, the understanding of what is dignity is based on the understanding that it is something that has value in itself, a value that is not replaceable. As

such the study seeks to answer to the question: “Are the LTCFs structured to recognize the necessities of care that guarantee comfort and dignity during the process of dying of their patients?”.

Based on the content analyzed and the field observations, it can be said that they are not. Although the institutions try to develop strategies to ensure the minimum of comfort and dignity, there is a strong relationship between economics and care, especially the tendency to commercialize these processes. Therefore, to consider the structure of the LTCFs is also to consider the socio-economic context in which they operate and the financial capacity of the elderly or their family group to provide support, since public policy in Brazil does not have mechanisms to meet the demands of those living through the process of dying.

Taking into account the fact that ethics is essential for care with dignity, an interesting method to approach the issue is through the bioethics of protection<sup>30</sup>. Considering the LTCF in its dialectical and hybrid sense, it puts the dimension of health into focus and recognizes the conflicts that arise in the care of elderly individuals in vulnerable situations who, in extreme situations, are unable to ensure their own well-being. The responsibility and the search for alternatives cannot be reduced to the interventional limits of family or professionals of gerontology and geriatrics. Bioethics of protection involves mobilizing policymakers and individuals in the aging process, fundamental if the philosophy of palliative care and care at the end of life are to expand and become part of the routine of institutionalized elderly persons. The direct confrontation of the commodification of care, social protection and the implementation of appropriate structures are the challenges for care with dignity.

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#### Participation of the authors

Study derived from doctoral thesis. The two authors participated in all the phases of production of the article. Michelle Bertóglcio Clos participated in the capacity of a doctoral student, while Patrícia Krieger Grossi participated in the capacity of a teaching professor.



## Annex 1

## Script of relative/guardian

<b>COD identification data:</b>		
<b>Name:</b>		<b>Relationship:</b>
Age of relative: Age of elderly person:	Decision to institutionalize:	Educational level:
Approximate income in MS (then R\$722.00) of Relative:	Situation prior to institutionalization:	Diagnosis of elderly person:
Approximate income in MS (then R\$722.00) of Elderly Person	Time of institutionalization:	Age of elderly person: Ethnic background:

1. What is your perception of life?
2. What is your perception of death?
3. What is your perception of institutionalization?
4. What is your perception of the needs of elderly persons in terms of care at the end of life?
5. What is your position on letting the elderly person establish in writing his or her wishes regarding the medical conduct and treatment that he or she wishes or does not wish to accept when no longer in a position to express his or her will?
6. What do you understand as important in the process of dying with dignity in a LTCF?
7. Does your relative have space to dialogue with his or her family, the community or in a religious context about the process of dying?
8. What type of care do you consider important for your relative at the end of life?
9. What type of care is your relative receiving?
10. What type of care would you like your relative to have access to?
11. Does the institution take into consideration the life history and personality of your relative in the day to day care provided?
12. Who plans the treatment of the elderly person?

## Interview script – technician

<b>COD identification data:</b>		
<b>Name:</b>		<b>LTCF:</b>
Age	Gender:	Position:
Time of care:	Do you have formal training in the field of elderly care:	Do you have knowledge in the area of palliative care:
Do you have adequate work conditions to provide care:		

1. What is your perception of the treatment given to elderly persons at the end of life in the institution?
2. What is your perception regarding the death of patients in the institution? Is he or she prepared for this event?
3. What is your perception of the integrality of care provided for the elderly person in the process of finitude?
4. What is your perception of the needs of elderly persons in terms of care at the end of life?
5. What is your position on letting the elderly person establish in writing his or her wishes regarding the medical conduct and treatment that he or she wishes or does not wish to accept when no longer in a position to express his or her will?
  - 5.1 Do you know what an advanced directive of will is? Has such a situation ever occurred in the institution?
6. What do you understand as important in the process of dying with dignity in a LTCF?
7. Considering the reality of the institution, to your perception, what are the weaknesses and the potentialities in care for the elderly at the end of life?
8. Does the team discuss situations that involve the care provided for elderly people at the end of life?
9. What resources does the team have access to for the maintenance of care of elderly persons?
10. Does the institution encourage family members to spend time with elderly persons in the institutional environment?
11. Does the institution develop actions that stimulate the technical team to learn about the life history of the elderly persons and respect the individuality of each one?
12. Is there a plan of individualized care for elderly persons at the end of life?
13. What do you understand by palliative care?