Cadernos Brasileiros de Terapia Ocupacional
Brazilian Journal of Occupational Therapy

ISSN 2526-8910

Original Article

Occupational therapy interventions with elderly people at the end-of-life processes in public hospitals

Intervenciones de terapia ocupacional con personas mayores en procesos finales de vida en hospitales públicos

Intervenções de terapia ocupacional com pessoas idosas em processos de fim de vida em hospitais públicos

Natalia Paz Castillo-Núñez[a], Gisele Romina López Contreras[a], Diego Alonso Márquez Rojas[a], Valeria Liliana Vargas Silva[a], Nicole Vannesa Villavicencio Garrido[a], Cristóbal Javier Catalán-Águila[a]

[a] Universidad de Chile – UCHILE, Santiago, Chile.

How to cite: Castillo-Núñez, N. P., Contreras, G. R. L., Rojas, D. A. M., Silva, V. L. V., Garrido, N. V. V., & Catalán-Águila, C. J. (2023). Occupational therapy interventions with elderly people at the end-of-life processes in public hospitals. *Cadernos Brasileiros de Terapia Ocupacional, 31*, e3377. https://doi.org/10.1590/2526-8910.ctoAO258533772

Abstract

Introduction: The intervention of occupational therapy with elderly people in end-of-life processes in hospital contexts presents short scientific documentation in Chile. Given the increase in the elderly population, their high prevalence of chronic diseases, and the hospital mortality rates, the need to review the interventions carried out in the end-of-life processes of the elderly are identified. **Objective:** To characterize occupational therapy interventions with elderly people who are in their end-of-life process, from the perception of occupational therapists dedicated to the area, in public hospital contexts in Chile. **Method:** The research is of a qualitative type framed within the constructivist paradigm under the phenomenological approach, using the semi-structured interview as an information collection technique and subsequent content analysis. The study sample is made up of occupational therapists who work in public hospitals in the country. **Results:** Occupational therapists are identified as agents that provide humanizing care and support during interventions in end-of-life processes, and families mainly as a facilitator of the same. In these processes, an integral vision of the person is revealed. **Conclusions:** There is consensus on the occupational therapy approach and interventions identified by the participants, and it is similar to what is described in the international literature. There is a lack of local public policy guidelines that allow a better definition of the professional role in this context.

Received on July 25, 2022; 1st Revision on Aug. 2, 2022; 2nd Revision on Aug. 31, 2022; Accepted on Dec. 22, 2022.

Keywords: Occupational Therapy, Elderly, End of Life Care, Humanization of Assistance, Public Hospitals.

Resumen

Introducción: La intervención de terapia ocupacional con personas mayores en procesos de fin de vida en contextos hospitalarios presenta escasa documentación científica en Chile. Dado el aumento de la población mayor, la alta prevalencia de enfermedades crónicas en ella y las tasas de mortalidad hospitalaria, se identifica la necesidad de revisar las intervenciones que se realizan en los procesos de fin de vida de las personas mayores. **Objetivo:** Caracterizar intervenciones de terapia ocupacional con personas mayores que cursan su proceso de fin de vida, desde la percepción de terapeutas ocupacionales dedicados/as al área, en contextos hospitalarios públicos de Chile. **Método:** La investigación es de tipo cualitativa enmarcada dentro del paradigma constructivista bajo el enfoque fenomenológico, utilizando como técnica de recolección de información la entrevista semiestructurada y posterior análisis de contenido. La muestra de estudio está compuesta por terapeutas ocupacionales que ejercen su labor en hospitales públicos del país. **Resultados:** Se identifica a terapeutas ocupacionales como agentes que otorgan cuidados humanizantes y acompañamiento durante las intervenciones en procesos de fin de vida, y a las familias como un facilitador del mismo. Se releva una visión integral de la persona en estos procesos. **Conclusiones:** Existe consenso en el enfoque e intervenciones de terapia ocupacional identificadas por las/os participantes, y resulta similar a lo descrito en la literatura internacional. Faltan lineamientos de política pública local que permitan definir de mejor manera el rol profesional en este contexto.

Palabras-clave: Terapia Ocupacional, Persona Mayor, Cuidado Terminal, Humanización de la Atención, Hospitales Públicos.

Resumo

Introdução: A intervenção da terapia ocupacional com idosos nos processos de fim de vida em contextos hospitalares apresenta pouca documentação científica no Chile. Diante do aumento da população idosa, da alta prevalência de doenças crônicas nesta população e das taxas de mortalidade hospitalar, identifica-se a necessidade de rever as intervenções realizadas nos processos de fim de vida do idoso. **Objetivo:** Caracterizar as intervenções de terapia ocupacional com idosos em processo de fim de vida, a partir da percepção de terapeutas ocupacionais da área, em contextos hospitalares públicos no Chile. **Método:** A pesquisa é do tipo qualitativo na perspectiva do paradigma construtivista sob a abordagem fenomenológica, utilizando-se de entrevista semiestruturada como técnica de coleta de informações e posterior análise de conteúdo. A amostra do estudo é composta por terapeutas ocupacionais que atuam em hospitais públicos no Chile. **Resultados:** Os terapeutas ocupacionais são identificados como agentes que prestam atendimento humanizado e apoio durante as intervenções nos processos de fim de vida, e à família, principalmente como facilitadora deste processo. Nesses momentos, revela-se uma visão integral da pessoa. **Conclusões:** Há consenso sobre a abordagem e intervenções da terapia ocupacional identificadas pelos participantes, sendo semelhante ao descrito na literatura estrangeira. Faltam

diretrizes de políticas públicas locais que permitam uma melhor definição do papel do profissional nesse contexto.

Palavras-chave: Terapia Ocupacional, Pessoas Idosas, Assistência Terminal, Humanização da Assistência, Hospitais Públicos.

Introduction

According to the Population and Housing Census carried out in 2017, 2,003,256 elderly people live in Chile, which corresponds to 11.4% of the country's total population. The Superintendencia de Salud (2006) estimates that the population of elderly people in the country could reach approximately 20% of the total population by 2025.

The aging of the population in Chile and in the world is considered a relevant social transformation to be considered. In a narrative review conducted by Leiva et al. (2020), some needs that older people currently have in Chile are established such as: economic security and social protection, social participation, and full access to health and long-term care.

In particular, the need for care for elderly people has been linked, among other elements, to a higher prevalence of chronic diseases. In addition, the elderly population has a greater risk of domestic or work accidents, compared to other age ranges, according to the national survey of dependency on the elderly population of 2009 (González et al., 2010), which has meant higher rates of hospitalization for this population.

According to data from the Superintendencia de Salud (2019), hospitalizations of elderly people reached 28% of general population hospitalizations, measured in hospital discharges. On the other hand, the hospital stay in this group was longer, with an average stay of 8,5 days, higher than the average for the general population (excluding children under one year old), which is located at 6 days.

The health care required by the elderly population in Chile has been planned through the National Comprehensive Health Plan for the Elderly and its 2020-2030 Action Plan [*Plan Nacional de Salud Integral Para Personas Mayores y Su Plan de Acción 2020-2030*, Chile (2021b)], which proposes a model of assessment and care comprehensive service for the elderly people at various levels of care. One of the approaches is that the National Plan recognizes respect for the death of the elderly population. However, the approach to the end-of-life processes of the elderly in Chile would require further development. Only in 2017 (Leiva et al., 2020), the deaths of older people represented 72.7% of the total deaths in the country, which can account for the magnitude of the problem.

Given this background, the authors were interested to review the disciplinary contribution of occupational therapy with the referred population, in the referred context, specifically, in intrahospital processes. Within the literature about the role of occupational therapists in end-of-life processes in hospital contexts at an international level, Australia is recognized as the country with the greatest development of research and professional role within the area. In countries such as the USA and Canada (Talbot-Coulombe & Guay, 2020), a record has been provided on the characteristics of occupational therapy interventions, the approach in which they are implemented (Faria

& Carlo, 2015), the possible strategies to be used within the hospital environment (Gómez & Catalá, 2010), the importance of coping strategies (Sanchís, 2018), even educational strategies (Martínez, 2020) that are used in this process.

The development of the theme is less in Chile. Occupational therapy interventions have been studied in palliative care, and interventions in end-of-life processes as such (Celis et al., 2014). For all the above and through this study, we intended to contribute to the expansion of the existing field of knowledge on the subject.

Reference

Aging, end-of-life processes, and their occupational implications

There are multiple theories and definitions of aging. According to Alvarado & Salazar (2014), it is a phenomenon that occurs throughout the life cycle, which begins at conception and extends until death. From a biological point of view, the Organización Mundial de la Salud (2022) understands aging as the result of molecular and cellular damage over time, leading to a gradual decline in physical and mental capacities and increased risk of disease. However, according to Merchán & Cifuentes (2011), aging is not only a biological phenomenon but also a social and cultural event, where various components (social, biological, economic, ecological, and cultural) interact dynamically to get closer to its understanding.

Consequently, older people can be understood as human beings who experience processes of physiological, psychological, and social changes, among others. These changes must be considered in such a way that societies maintain conditions and guarantees that protect the rights of elderly people and their aging processes (Dueñas et al., 2011). In the same way that aging is identified as a process (Forero et al., 2014), its end, understood as the death of the person, is also visualized as a process, in which life ends. According to Hawley (2014) and Hui et al. (2014) end of life is understood as the period preceding the natural death of a person, as part of a process that cannot be stopped by the health team, from the early stages of an irreversible disease. Several authors (Betancourt, 2014; Gempeler, 2015; Maglio et al., 2016; Marín, 2018) state that death is a natural process of the life cycle, and although it is a fact that occurs daily, there is low acceptance of it in today's society. This is associated with the fact that it frequently occurs away from daily and family life, to a greater extent within hospital contexts (Gempeler, 2015). In addition, end-of-life processes have been associated with a significant impact on the person and their family, implying a change in the roles of the person and their family, their family dynamics, and emotional consequences, among others (Díaz et al., 2013).

On the other hand, the concept of palliative care corresponds to an approach that seeks to improve the quality of life of individuals and families facing complications associated with life-threatening diseases, through the prevention and relief of suffering [World Health Organization, as cited in Briceño (2017)]. Palliative care can be part of the end-of-life process, but it is not necessarily specific to this context.

Linked to this, the concept of a dignified death is introduced below, which Marín (2018) defines as the process where the expectations, beliefs, and autonomy that each

person attributes to dying with dignity are respected, guaranteeing maximum well-being as possible, favoring the acceptance of death with serenity and in the accompaniment of the family. Therefore, it is necessary to provide a dignified death that guarantees the maximum degree of well-being within hospital contexts (Marín, 2018), where health professionals promote and preserve the dignity of the person as a human being (Betancourt, 2014). Dignified death is "to accept and commit to the care of human life in this final stage, keeping in mind that life should not be shortened, but agony, suffering, and death should not be prolonged either" (Marín, 2018, p. 3).

According to Carsi & Nicora (2011), a person who is in an end-of-life process within the hospital context, with any cause, will not only be weakened by the physical or mental disability that the disease may entail, but also by the lack of motivation and initiative to develop their daily occupations. As Briceño (2011) mentions, they could not have equal opportunities to participate in occupations and activities that are significant, which in turn would only allow them to carry out perform occupations that could be devoid of desire, without will for habitual performance. This is how these authors (Carsi & Nicora, 2011) propose that the intervention should facilitate the search for significant occupations for the person who is in the final process of life within hospital contexts according to remaining skills and/or capacities.

Public policies related to end-of-life in Chile

In 2020, the Pan American Health Organization [PAHO] updated its conceptual framework regarding the Essential Functions of Public Health, given the need for a more comprehensive vision for public health in the face of current health challenges. These Functions are based on four fundamental pillars, which refer to the application of ethical values in public health, the approach to social, economic, cultural, and political conditions that determine health, guarantee universal access to public health services, and expand the function rectory of health authorities (Organización Paranmericana de la Salud, 2020). Chile, as a Member State of PAHO, assumes the need to work around public policies, of comprehensive action, that guarantee respect for human rights under the aforementioned pillars, paying specific attention to the needs of people in vulnerable situations - as elderly people are in end-of-life processes – adopting the necessary protection measures at various levels of intervention in the health network.

Within the current national context, the National Comprehensive Health Plan for the Elderly Population and its Action Plan 2020-2030 (2021), which establishes guidelines to "generate a favorable environment for older people to develop their lives healthily" (Chile, 2021b, p. 11), represents a relevant guideline aimed at the well-being of the old person in Chile. However, this Plan does not develop the concept and approach to end-of-life processes. Only the existence of palliative care in the health network and some ethical considerations in this regard are mentioned, but it does not delve into their development. On the other hand, within the existing Clinical Practice Guidelines in Chile, a single GES Guide (for Explicit Health Guarantees) (Chile, 2017) is recognized that explicitly considers palliative care, in the context of oncological pathology, for all age ranges, establishing evidence-based recommendations and courses of action. Currently, this issue has been the subject of political discussion in Chile, in

such a way that 2021 Law 21,375 (Chile, 2021a) was enacted, which establishes palliative care and the rights of people suffering from terminal or serious illnesses. The purpose of this law is to "recognize, protect and regulate, without any discrimination, the right of people who suffer from a terminal or serious illness to adequate health care" (Chile, 2021a, p. 1.) and comes into force as of March 2022.

Occupational therapy approach in end-of-life processes

Occupational therapy intervention is internationally recognized by several authors (Gómez & Catalá, 2010; Queiroz, 2012; Trevisan et al., 2019) as essential within the teams that intervene with people who are in their end-of-life process because their work produces a direct impact on the experiences lived and the quality of life of these people. Also, the professional role of occupational therapy that meets within multidisciplinary teams has been recognized, contributing to the process from various perspectives:

(1) Occupational perspective of the end-of-life process (World Federation of Occupational Therapists, 2016), which has been identified as facilitating better communication between the team and the user (Gómez & Catalá, 2010).

(2) Educational perspective, which contributes to the preparation of the user and her family for a quality and adequate death process (Martínez, 2020).

(3) Functionalist perspective, in which the functional and physical needs of the user are recognized, allowing their approach and alleviating their suffering (Gómez & Catalá, 2010).

On the other hand, support from the discipline in the farewell processes is identified, facilitating the development of preparation activities for the end-of-life and/or evaluating the physical and social environment of each user (Viviens, 2012). This is achieved by taking into consideration different strategies such as attentive listening, active communication, and the expression of feelings or fears among family members, the user, and with professionals (García-Schinzari et al., 2013).

Objectives

General objective

To characterize occupational therapy interventions with older people who are undergoing end-of-life processes in public hospitals in Chile, from the perception of Occupational Therapists linked to the area.

Specific objectives

1. To identify occupational components of the occupational therapy intervention with older people in end-of-life processes in public hospital contexts in Chile.
2. To distinguish facilitators and obstacles for occupational therapy intervention with older people in end-of-life processes in public hospital contexts in Chile.

3. To analyze the perceptions of Occupational Therapists about occupational therapy intervention with older people in end-of-life processes in public hospital contexts in Chile.

Methodology

Study design

The research was carried out using a qualitative methodological approach of an exploratory type. The phenomenon studied was subjectively understood (Hernández et al., 2014), located under the constructivist paradigm that, together with an interpretive phenomenological approach with a descriptive scope, allowed detailing and understand the phenomenon within its context (Arantzamendi et al., 2017) through the lived experiences of people who share this phenomenon, recognizing its meaning and importance (Fuster, 2019).

Participants

Occupational Therapists who are working or have worked in intervention with older people in their end-of-life process for at least 2 years in a public hospital in Chile during the last 5 years participated in the study. The sample is obtained by a non-probabilistic sampling of voluntary participants, together with the "snowball" technique for the incorporation of participants (Cea, 1996). The final sample size was five occupational therapists, defined in part by data saturation, but mainly given the analytical capacity of the researchers and the nature of the phenomenon under study. Table 1 below describes some background of the participating occupational therapists.

Table 1. Characterization of the study participants.

Participant	Work region	Hospital unit where they work	Years of professional experience in the area	Weekly dedication to professional performance
E1	Metropolitan region	Special Care Unit	2	Part-time (22 hrs.)
E2	Metropolitan region	Intensive care unit	3	Full-time (44 hrs.)
E3	Aysén Region	Acute Geriatric Unit	8	Full time (44 hrs.)
E4	Metropolitan region	Geriatric Unit	8	Full-time (44 hrs.)
E5	Metropolitan region	Geriatric Unit	7	Full-time (44 hrs.)

Data collection techniques

As an instrument for data collection, a semi-structured interview was used (Hernández et al., 2014) on the topic of interest. The researchers prepared the script based on the conceptual reference. the judgment of an expert professional in the area evaluated the script and considered issues related to the occupation in end-of-life processes, intervention of occupational therapy and the health team, and conditioning

factors of the intervention. The interviews were conducted virtually, in a single individual meeting with each participant. Each interview lasted approximately one hour.

Data analysis

The interviews were transcribed and analyzed based on the content analysis technique of Elo & Kyngäs (2008), which considers a deductive approach made up of a priori categories based on the objectives of the research and the literature review carried out. It opens an inductive approach to emerging categories from the collection and analysis process carried out by the research team.

Ethical aspects

This research was approved by the Ethics Committee for Research in Human Beings of the Medical School of the University of Chile. Those who participated signed an informed consent document, where they were informed about the participation in the study, its voluntary nature, the confidentiality and use of the information, the objective of the study, the researchers in charge, and possible benefits, among other things.

Results

The following section summarizes the process of systematizing the results, carried out from the five interviews. It is presented in five categories of analysis based on the interviews carried out, which correspond to (I) humanization of care and dignified death; (II) characteristics of the occupational therapy intervention; (III) occupation at the end-of-life; (IV) facilitators of the end-of-life processes; (V) obstacles of the end-of-life processes.

I. Humanization of care and dignified death

Within this category, different perspectives arise. In the first place, the humanization of care is understood as a differentiating approach, which from occupational therapy it seeks to position transversally in health practices in all hospital units and carried out by the different disciplines. An example of this corresponds to the following quote,

> *Humanization* [...] *should not be an act of goodwill, it should be a culture, that is the most important thing,* [...] *it should not be because someone is born, no, I do this and It's nice, the practices should be part of a process or a protocol.* (E4).

From a disciplinary perspective, in the different hospitals and according to the different interviewees, occupational therapy is positioned as a discipline that has a humanization approach and is characterized by granting greater comfort and respect towards end-of-life processes with dignity and responsibility.

As part of this process, the concept of dying well emerges in the interviews, revealing the feelings of the users. E2 shows the words of a user in the example of the following quote

> *If I'm going to die, I want to die well, I don't want to drown, I don't want to die in pain, I don't want to die in a bed unable to move,* [...] *be independent until the last of my days.* (E2).

From the interviewees, we considered it important that the interventions should consider the user as the center of them, and the health professionals can generate a real awareness about the person in their end-of-life process. In this regard, E3 says:

> *Always validate a lot that, if he tells you no, that he doesn't want to get up, that he doesn't want to do anything, that he doesn't want to eat, you're going to say, okay, this is the most important opinion.* (E3).

The interviewees realize that maintaining humanization approaches in interventions means valuing the dignity of the person and respect for how each user experiences their end-of-life process.

II. Characteristics of the occupational therapy intervention

In the first place, the interviewees realized that occupational therapy intervention usually occurs in an interdisciplinary work **context**, which for some even points to transdisciplinary. Within the end-of-life process teams, E1 states that they are part of:

> *traumatologists, geriatricians geriatric fellowship doctor with scholarships in geriatrics, "Mmmmm", internists, general practitioners, nurses, assistants, NT (nursing technicians), kinesiologists, speech-language therapists. Other occupational therapists, nutritionists, clinical pharmacologist specialists in geriatrics.* (E1).

Regarding the **role of occupational therapy** in end-of-life processes, the interviewees stated that occupational therapists have strongly positioned in health teams thanks to their versatility and comprehensive vision centered on the person. E1 says:

> *Our work is highly valued, the occupational therapist, "eeehh", as a result of this versatility of functions and roles that he can fulfill in the hospital context, has positioned himself like never before.* (E1).

The interviewees identify an educational role in occupational therapists within the end-of-life process, with great relevance not only for the user but also for his/her family, seeking to facilitate the farewell between the user and those close to them. The role of the evaluator was another one of the most relevant roles pointed out, generating an initial comprehensive assessment of the people and their context, determining, for example, the basal state of an elderly person who arrives at hospitalization, and then being able to contribute to establishing the guidelines of adequate treatment. According to E2, this point would be a hallmark of the discipline since the integral evaluation that is carried out supports the formulation of intervention objectives, as cited:

> *I think that our differentiating role is to integrate precisely all these areas and see if the person is in pain, moving or not moving, how is their support network, if*

> *they have any cognitive alteration, according to the combination of everything, to be able to deliver a focused intervention that aims at the objectives that we set ourselves with each user.* (E2).

It is also recognized in the interviews that occupational therapy is positioned as an agent of transformation or change within the health team, especially regarding the vision of the person who is undergoing an end-of-life process. It is exemplified by the following quote from E5

> *I feel that occupational therapy here changed the vision of the person* [...] *it was not just sitting, but seeing him differently, that he was an occupational being, and that he had tasted, it made sense to do things for him.* (E5).

On the other hand, in the **main characteristics** of the occupational therapy intervention, the interviewees highlight the following elements as relevant:

1. The therapeutic bond. It is mentioned as a coadjuvant of the intervention and a great facilitator in future processes with the person. It is referred to as the basis of interventions. E3 highlights its importance in the following quote:

> *cases in which people who do not want anything and until you create a bond with her, with him, everything changes, especially in the feeling of comfort of being in a space where you can bond with this other person.* (E3).

2. The strengthening of daily routines, related to basic activities of daily living [BADL].
3. Comfort at the end-of-life, which is relevant to lead people undergoing this process to a good death, as stated by E3:

> *What we do is to follow up, comfort management, that if the person can still move and wants to go to the bathroom, you will go with him/her.* (E3).

4. Belief-based therapeutic follow-up is exemplified in the following quote from E4:

> *As an occupational therapist… he knows that the person is religious, he is evangelical, Jehovah's Witness, one even learns the songs, you know?* […] *The accompaniment is part of it.* (E4).

5. The significant activities, or occupations, of each older person who is undergoing an end-of-life process. These are an active part of the hospital stay, which contributes to giving meaning to participate in activities within this context.

Regarding the main **strategies** used within the interventions, involving the family in the process is mentioned at a transversal level, increasing or maintaining communication with it, in addition to also providing support. This can be done through video calls, letters, postcards, posters, etc. and they are established as communication alternatives that favor dialogue with close people. Environmental management is also one of the intervention strategies referred to in this context. The optimization of positioning and facilitation of daily activities are also strategies cited by the interviewees. E2 stated:

> *One helps a lot with the whole issue of orthotic support, more than anything soft orthoses, which are anti-edema wedges, literalizers, anti-equine stops that also favor a lot and the positioning that one can give, trying to favor the positions.* (E2).

Regarding the **theoretical references** used in the interventions, the participants mentioned at a general level that they do not fully use specific occupational therapy models/references, but it is a practice centered on the humanized patient, which collects elements from different theoretical/practical perspectives. In this regard, E2 stated:

> *you start to take elements of each model, I couldn't tell you yes, all my practice is based on the "MOHO" (Models of Human Occupation), but I take elements from the MOHO, I do take elements from the rehabilitative approach, sometimes it is super important, and then one moves on to much larger approaches, such as the humanization of care, the rights approach, which should guide all our practice, the gender approach, which is also extremely important.* (E2).

III. Occupation at the end-of-life

Transversal to the various stories, the assessment by the patient refers to the activities that have meaning for them, that is, significant occupations. The possibility of carrying out basic activities of daily living independently, whenever possible, stands out as highly relevant for the older person in this context.

Carrying out activities centered on the person, according to their interests, poses an important challenge for occupational therapists since the hospital context can limit the planning of activities of total interest to people. Occupation as a means of intervention can also represent a challenge since the hospital represents a limitation for the performance of many of them, if we consider infrastructure and spaces, required implements, and collaboration with other professionals, among other elements. Because of this, occupational therapists try to promote simple general activities that the hospital context allows, such as reading the newspaper, listening to music, watching television, and going out on the balcony, and activities that allow patients to be comfortable. However, these activities do not necessarily have an occupation as a means. From this intention of occupational therapists, the attempt to adapt activities of interest in the hospital context arises, highlighting the creativity that each professional must have to create, incorporate and/or adapt activities of interest to people and that allowed by the hospital.

In addition, the perception of the participants in this study suggested that there is a loss of interest in the hospital context when an elderly person is hospitalized, which is accentuated when the elderly person is in the final process of life. Therefore, it becomes complex to intervene based on lost or forgotten interests, even when they were present before their hospitalization. This is partly why, in these cases, activities that aim to provide comfort are prioritized.

Finally, it is worth mentioning that one interviewee raises the performance of occupations, not allowed in a hospital context, as part of the humanization of care practice, which transcends a therapeutic bond and is situated within a bond between two human beings. In this regard, E5 stated:

> *But one day we let a person smoke, which for us was maybe closing all the windows and letting him smoke his last cigarette, and I think... this is the first time I've told it, but I think it was very satisfying for him.* [...] *those things that sometimes one does from one human being to another human being.* (E5).

IV. Facilitators of the end-of-life processes

From the analysis carried out on the category of facilitators, we identified two subcategories. The first is related to **internal facilitators**, where it is recognized that when the work team collaborates and dialogues with each other, it facilitates intervention processes at the end-of-life, highlighting the importance of effective communication, the coordination of interdisciplinary objectives and the disposition that the work team must have regarding care. On this last point, E4 stated:

> *The most important protective factor is also the human quality of each professional who is accompanying a person in the end-of-life process.* (E4).

Another facilitator that arises is the formation of work teams with a focus on rights and humanization of care because as mentioned by several interviewees, it is essential to have trained teams that have these approaches to facilitate a good death within the hospital. Also, the interviewees assure that by modifying the vision globally within the team, changes are achieved, guiding the way to die with dignity. Linked to this, from the hierarchical organization of the institution, it is important to have heads that endorse specialized interventions in end-of-life care, reducing the limitations that may exist in the practice of the team, and in particular, of occupational therapy.

The second subcategory is related to existing support networks and the role of the family as an **external facilitator**. Regarding the support networks, the social worker is relieved as a fundamental professional in this context since he or she is usually in charge of articulating the end-of-life care networks of the elderly person. The interviewees consider it necessary to have them, always respecting the opinion of the family to make decisions.

The facilitating role that the family can fulfill, this is linked to the possibility that occupational therapy interventions generate greater motivation and meaning for hospitalized older people, so their participation in the therapeutic process is essential to contribute to the well-being and comfort of the person.

V. Obstacles in the end-of-life processes

Within the category of obstacles, two subcategories were identified. The first is related to **internal obstacles**, alluding to work teams, where the interviewees consider that health professionals have little training on end-of-life processes from different approaches, and therefore, on many occasions, they lack the skills to deliver bad news or humanized treatment, as well as the role of occupational therapy, is unknown. E3 stated that:

> *another professional to tell you: no, I don't think that's important. Or the typical one that they tell you many times: but why are they going to see it if she is going to die?* (E3).

The interviewees emphasize that there is a great need for training and reflective instances on the subject. They also mention that, in some hospital contexts, the biomedical approach is predominant, and creates a barrier in the occupational therapy intervention since it is situated from broader perspectives and visualizes different needs and requirements of its intervention. E1 indicated:

> *As long as the human person is not placed at the center as the most important thing, we are going to continue operating with scarce and limited resources.* (E1).

The normalization of the disease of some medical procedures, the different points of view of the professionals, and the dynamism of the hospital contexts often hinder a dignified and humane end-of-life process. E4 stated:

> *We see a person who is not well, who is very serious and we say doctor please go to see him… let his family come to say goodbye and it is like "no, he is fine, no, he is fine" and he passed away two hours later. And he drowned, he died suffering and he died agitated with delirium. And it's like… under what conditions?... And he is undignified, very undignified.* (E4).

Therapeutic cruelty also represents an obstacle for the interviewees. This occurs when health teams prioritize saving the patient's life through disproportionate methods, without considering contextual elements and the person's well-being in the end-of-life process. Faced with these practices, the interviewees stated that they must deal with the professional who makes these decisions and that when they are in the hands of internists, it becomes more difficult, which is also stressed by the lack of guidelines in most cases. E1 stated:

> *The approach that we always see in the hospital, and especially in intensive care, is to save life at all costs, without thinking about what might happen next.* (E1).

The second subcategory relates to **external obstacles**. The interviewees stated that they have found differences between families. Although they refer to the family as a facilitator of the process, they are also referred to as an obstacle to it. The foregoing is understood from the denial of imminent end-of-life, as well as the lack of support and concrete actions toward the family member. E5 stated

> *They are but they are not. The one who calls and does not contribute anything. The one who wants to take him away but once he can take him away so that he can die in his house, he doesn't take him away and lets him die in the hospital.* (E5).

The social taboo of death is also considered an obstacle in the end-of-life process. For those interviewed, in our society little is said about it, people are hardly aware that

eventually, our family is going to die, as well as ourselves. Due to this, it is mentioned that most of the people who go through this process do not manage to say goodbye but only encourage to recover even in the face of imminent death. E2 stated that:

> *People are always going to fight until the end, it is difficult to assume a death in a country or in a world where it is so stigmatized.* (E2).

The COVID-19 pandemic is recognized as a new context that has changed the way hospital health teams work and has exacerbated the hostility of the hospital environment. The interviewees indicated that interaction between hospitalized patients was restricted, isolation increased, the use of personal protection elements and the generation of new protocols, etc. E1 stated:

> *Before the pandemic, everything was easier, it was more humane, there was more contact, there was more containment* [...] *there was greater permissiveness, we had more flexibility, fewer protocols, fewer risks.* (E1).

The interviewees also commented that this increase in the mortality of people from the spread of COVID-19 overwhelmingly harmed the mental health of health professionals.

Discussion

The analysis of the results allows us to identify different characteristics of the occupational therapy intervention with hospitalized elderly people in the final process of life, as well as different facilitators and obstacles that encompass it. Below, there is a discussion of the findings of this study with the literature review on the topic.

Within the results, we could appreciate that from the perceptions of the participating occupational therapists, the stigma towards death present in society is also visible within their hospital contexts and therefore within occupational therapy interventions. This is consistent with the approaches of Gempeler (2015) and Martinez (2020), in which there is a low acceptance of death, especially in the hospital since due to this stigma there is a limitation of the interaction between hospitalized people and the family and the presence of a constant struggle to face and/or deny death, even though it is often imminent.

Marín (2018) states that dignified death implies respecting expectations, beliefs, and the autonomy of people, as well as the interviewees who highlight the validation of the patient's needs, opinions, and personal tastes, even mentioning as a facilitator of the integration of religiosity in the intervention process, elements developed in the category of "Characteristics of the intervention" of the results of this research. In addition to the above, Marín (2018) states that the objective of this guideline is to guarantee maximum well-being during this process, favoring serenity, which is consistent with the interviews, when professionals opt for actions such as home hospitalization and family support.

However, the concept of **humanization** is currently one of those that encompass the elements mentioned and developed in this article. We emphasize that, as pointed out by Bermejo as cited in Rojas (2019), humanizing health care "reclaims the intrinsic

dignity of every human being and the rights that derive from it [...] are a genuinely ethical commitment to a human vulnerability that generates health and accompanies in suffering." (Rojas, 2019, p. 121). This is related to the perceptions of the participants in this study, which refers to human dignity, respect for informed wills and decisions, and the right of health patients, more specifically older people in end-of-life processes, should be considered as a fundamental basis for the teams that work in this area, also referring to the fact that the training from the social/humanistic sciences that occupational therapists have compared to other health professions, provides a strong vision in terms of being able to consider the integrity of people, as well as carrying out practices that undoubtedly consider a rights-based approach and aim to dignify the end-of-life processes of older people.

Marín (2018) also states that care for human life must not only seek the maintenance of life but also try not to prolong the agony and suffering of the person. Thus, following the perceptions of the interviewees of this research, saving life regardless of the quality that it will have later, shapes the therapeutic cruelty that hinders a good death and does not consider the humanitarian nature that the intervention requires in this stage.

Another characteristic mentioned regarding occupational therapy interventions within these contexts shows the idea of Carsi & Nicora (2011) who refer to the loss of interest experienced by hospitalized older people due to the lack of motivation and initiative in these environments. This was following what was mentioned by the professionals participating in this study, who report a loss of interest typical of aging, and which is accentuated when undergoing an end-of-life process in hospital contexts.

Due to the above, the search for significant occupations for older people who are in their final process of life should be part of the intervention process, as mentioned by Carsi & Nicora (2011). However, despite it is of great importance to the interviewees, they report that its implementation is limited by the physical, paradigmatic, and sociocultural hospital context, which is related to the postulates of Trevisan et al. (2019) and Gómez & Catalá (2010), who point out that the main focus of the interventions in this stage is not necessarily linked to occupation but rather to a more functional perspective, focused on pain control, postural corrections and/or functional losses.

Based on the role of occupational therapy, in these contexts, Chow & Pickens (2020) and Queiroz (2012) mentioned that it is essential to intervene by educating both the patient and his/her family, regarding what the death process implies. Thus, it is expected that it will be of quality, based on their rights and in search of a good death. The foregoing is consistent with what was stated in the interviews, where the educational role of occupational therapists in end-of-life processes and the relevance of the therapeutic bond between professionals and patients and family is highlighted, which can undoubtedly be built as a respectful space of trust, where all doubts, fears, and desires that exist around this process can be raised and it is also constituted as a collaborative space in search of a humanized process.

Finally, Viviens (2012) and García-Schinzari et al. (2013) identify the importance of three elements. First, the support of occupational therapists in facilitating the farewell processes; second, the evaluation of the physical environment as a relevant factor; and third, the evaluation of the patient's social aspects. This is consistent with the perceptions of the interviewees, who consider that the farewell with the family and those close to them enables a pleasant and accompanying end-of-life process; that it is essential

to grant a more affable and safe physical context, even opting for home hospitalization; and finally, they mention that evaluating social aspects such as family support would allow favoring, extrapolating, and maintaining actions that seek a dignified, serene end-of-life process, focused on dying well, in cases where they become facilitators of the intervention.

Conclusions

From this study, it has been possible to analyze the perceptions of occupational therapists who work or have worked with the PM who are undergoing their end-of-life process, regarding the characteristics of their interventions in public hospital contexts within Chile, highlighting key elements, which are consistent with the existing literature on the subject and which highlight the need for research in the area.

Considering the above, it is possible to conclude from the particular realities studied that the humanization of care is part of the focus of occupational therapy interventions. However, it is limited due to institutional factors such as the health institutions where the courses are given at the end of life, including the vision that the health teams have about the person on the brink of death.

In this sense, a reduced vision of the person, which focuses on the disease, is a great obstacle to providing comfort and carrying out an intervention based on humanizing practices. This is also seen at a structural level, starting from the absence of clear public policies in this regard, to the hospital environment, where the social paradigm that conceives care in this context regulates it, based on the fact that it is a sick person, beyond being a person.

For this reason, it becomes a challenge both at the social level and at the educational level in the health area to acquire knowledge regarding humanizing practices based on the rights of people, for their subsequent implementation, because this is what finally determines the look that the health professional directs towards the person. In this case, is undergoing an end-of-life process, which can often favor or not a good death.

In this search to humanize care, is where occupational therapy has been positioned as a key discipline, generating changes in the perspectives within the teams, advancing towards hospital intervention processes that provide an accompanied death, in comfort, and in the most humane and dignified way possible. Notwithstanding the foregoing, this search has been complexed for the group of occupational therapists due to the need to validate disciplinary knowledge.

Despite the difficulties in the search to humanize care, the versatility of occupational therapy professionals and their look based on the person has allowed them to function as a gear within the health teams, which mobilizes them around the person as a human and as an occupational being, in whom it makes sense to intervene to provide a better process at the end of his life, understanding the discipline of occupational therapy as essential within these spaces.

All of the above makes us reflect on the political role and the ethical and social commitment that we have as professionals in terms of decision-making within the team, (beyond the therapeutic links that are built during interventions with older people in the process of end-of-life). Are the various perspectives considered when defining a

client's course of treatment? Or is it rather a process in which, for example, the vision of an occupational therapist or the patient and the family would not fit?

Although the professional in charge of the decisions is indeed a doctor, it is at least possible to ask if a different vision, a complementary look, means better ensuring the dignity of the elderly in their end-of-life processes. The recent entry into force of Law 21,375 (Chile, 2021a), undoubtedly represents an important challenge, especially in terms of its concrete implementation, through public policies, which have the challenge of collecting a comprehensive, broad vision, holistic and human on end-of-life processes, adjusting to current paradigms such as those raised by the participants in this research.

Limitations and Projections

The "snowball" strategy for obtaining participants is identified as a limitation of the study due that most of the interviews were carried out with professionals who work mainly in the central area of the country so there are other realities in Chile not considered in this study.

Another limitation is the scant information, policies, and research available on the topic addressed in Chile, preventing contextualization of the current situation within the country.

All these accounts for projections in the area aimed at promoting this line of research, investigating or deepening the end-of-life process at the national level, from occupational therapy, or the perspective of health teams, contrasting actions by the level of care or type of establishment (public/private).

In addition, it would be interesting to know and explore the approach from a transdisciplinary perspective, which considers experiences, training, and other elements that contribute and highlight actions that are being carried out and have not yet materialized in publications, or that denote the need to articulate others at a structural level to generate changes aimed at improving the approach to health at this stage of life, from a holistic perspective and based on the respect and promotion of human rights.

References

Alvarado, A., & Salazar, A. (2014). Análisis del concepto de envejecimiento. *Gerokomos*, *25*(2), 57-62.

Arantzamendi, M., Lopez-Dicastillo, O., Robinson, C., & Carrasco, J. M. (2017). Investigación cualitativa en cuidados paliativos. Un recorrido por los enfoques más habituales. *Medicina Paliativa*, *24*(4), 219-226.

Betancourt, G. (2014). Limitación del esfuerzo terapéutico y principios bioéticos en la toma de decisiones. *Revista Humanidades Médicas*, *14*(2), 407-422.

Briceño, C. (2011). Reflexiones en torno al razonamiento bioético en cuidados paliativos. *Revista Chilena de Terapia Ocupacional*, *11*(2), 34-46.

Briceño, C. (2017). *Necesidades de cuidados al fin de la vida en personas mayores con dependencia por condiciones crónicas desde la perspectiva de los cuidadores informales y profesionales de la salud: un reto a nuestro actual sistema sanitario* (Tesis de maestría). Universidad de Chile, Santiago.

Carsi, E., & Nicora, Y. (2011). Ocupación en el final de la vida. *MedPal, Interdisciplina y Domicilio*, *3*(4), 25-26.

Cea, M. (1996). *Metodología cuantitativa: estrategias y técnicas de investigación social*. Madrid: Síntesis Sociología.

Celis, F., Gálvez, C., Moretti, C., Navarrete, E., Rovegno, M., & Torrent, V. (2014). Terapia ocupacional y paciente crítico. *Revista Chilena de Terapia Ocupacional*, *14*(1), 101-110.

Chile. Ministerio de Salud – MINSAL. (2017). *Guía de práctica clínica alivio del dolor por cáncer avanzadas y cuidados paliativos*. Santiago: MINSAL. Recuperado el 22 de diciembre de 2022, de https://diprece.minsal.cl/wrdprss_minsal/wp-content/uploads/2018/02/Resumen-ejecutivo_Alivio-del-Dolor_2017.pdf

Chile. Ministerio de Salud – MINSAL. (2021a, 21 de octubre). Ley 21735 de 21 de octobre de 2021. Consagra los cuidados paliativos y los derechos de las personas que padecen enfermedades terminales o graves. *Biblioteca del Congreso Nacional de Chile,* Santiago. Recuperado el 22 de diciembre de 2022, de https://www.bcn.cl/leychile/navegar?i=1166846&f=2022-03-21

Chile. Ministerio de Salud – MINSAL. (2021b). *Plan nacional de salud integral para personas mayores y su plan de acción 2020-2030*. Santiago: MINSAL. Recuperado el 22 de diciembre de 2022, de https://diprece.minsal.cl/wp-content/uploads/2021/09/Plan-Nacional-de-Salud-Integral-para-Personas-Mayores_v2.pdf

Chow, J. K., & Pickens, N. D. (2020). Measuring the efficacy of occupational therapy in end-of-life care: a scoping review. *The American Journal of Occupational Therapy*, *74*(1), 1-14. http://dx.doi.org/10.5014/ajot.2020.033340.

Díaz, V., Ruiz, M., Flórez, C., Urrea, Y., Córdoba, V., Arbeláez, C., & Rodríguez, D. (2013). Impacto familiar del diagnóstico de muerte inminente. *Revista de Psicologia Universidad de Antioquia*, *5*(2), 81-94.

Dueñas, O., Riaño, G., Palacios, M., & Sierra, J. (2011). *Derechos humanos y políticas públicas para el adulto mayor: situación en Colombia y referencias iberoamericanas*. Bogotá: Editorial Universidad del Rosario.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107-115. http://dx.doi.org/10.1111/j.1365-2648.2007.04569.x.

Faria, N. C., & Carlo, M. M. R. P. (2015). Atuação da terapia ocupacional com mulheres com câncer de mama em cuidados paliativos. *Revista de Terapia Ocupacional da Universidade de São Paulo*, *26*(3), 418-427.

Forero, C. I. A., Molina, M. A. M., Benítez, P. B., Alvarez, G. P., Wilches, K. V. E., & Muñoz, A. C. P. (2014). *Adultos mayores privados de la libertad en Colombia*. Bogotá: Editorial Universidad del Rosario/Instituto Rosarista de Acción Social Concepción del Adulto Mayor. Concepción del adulto mayor, pp. 60-98.

Fuster, D. (2019). Investigación cualitativa: método fenomenológico hermenéutico. *Propósitos y Representaciones*, *7*(1), 201-229.

García-Schinzari, N. R., Sposito, A. M. P., & Pfeifer, L. I. (2013). Cuidados paliativos junto a crianças e adolescentes hospitalizados com câncer: o papel da terapia ocupacional. *Revista Brasileira de Cancerologia*, *59*(2), 239-247.

Gempeler, F. (2015). Derecho a morir dignamente. *Universitas Medica*, *56*(2), 178-185.

Gómez, J., & Catalá, T. (2010). La terapia ocupacional en la atención al final de la vida. *TOG (A Coruña)*, *7*(6), 145-160.

González, F., Massad, F., Lavanderos, F., Albala, C., Sánchez, H., Fuentes, A., Lera, L., Cea, X., Salas, F., Bravo, D., Castillo, E., & Quijada, S. (2010). *Estudio nacional de dependencia en las personas mayores*. Santiago: Servicio Nacional del Adulto Mayor.

Hawley, P. H. (2014). The bow tie model of 21st century palliative care. *Journal of Pain and Symptom Management*, *47*(1), 2-5.

Hernández, R., Fernández, C., & Batista, M. (2014). *Metodología de la investigación*. Ciudad de México: Interamericana Editores.

Hui, D., Nooruddin, Z., Didwaniya, N., Dev, R., Cruz, M., Kim, S. H., Kwon, J. H., Hutchins, R., Liem, C., & Bruera, E. (2014). Concepts and definitions for "actively dying," "end of life,"

"terminally ill," "terminal care," and "transition of care": a systematic review. *Journal of Pain and Symptom Management*, *47*(1), 77-89.

Leiva, A., Troncoso-Pantoja, C., Martínez-Sanguinetti, M., Nazar, G., Concha-Cisternas, Y., Martorell, M., Ramírez-Alarcón, K., Petermann-Rocha, F., Cigarroa, I., Díaz, X., & Celis-Morales, C. (2020). Older people in Chile: the new social, economic and health challenge for the 21st century. *Revista Medica de Chile*, *148*(6), 799-809. http://dx.doi.org/10.4067/S0034-98872020000600799.

Maglio, I., Wierzba, S., Belli, L., & Somers, M. (2016). El derecho en los finales de la vida y el concepto de muerte digna. *Revista Americana de Medicina Respiratoria*, *16*(1), 71-77.

Marín, A. (2018). Percepción de los profesionales de enfermería acerca del proceso final de vida en el ámbito hospitalario. *NURE Investigación: Revista Científica de Enfermería*, *15*(95), 1-10.

Martinez, N. (2020). *Las personas mayores ante la muerte: implicaciones educativas* (Tesis de doctorado). Universidad de Granada, Granada.

Merchán, E., & Cifuentes, R. (2011). Teorías psicosociales del envejecimiento. In C. Nuin Orrio (Coord.), *Enfermería de la persona mayor* (pp. 27-33). Madrid: Editorial Universitaria Ramón Areces.

Organización Mundial de la Salud – OMS. (2022, 1 de octubre). *Envejecimiento y salud*. Recuperado el 22 de diciembre de 2022, de https://www.who.int/es/news-room/fact-sheets/detail/ageing-and-health

Organización Panamericana de la Salud – OPS. (2020). *Las funciones esenciales de la salud pública en las Américas. Una renovación para el siglo XXI. Marco conceptual y descripción*. Washington: OPS.

Queiroz, M. E. G. (2012). Atenção em cuidados paliativos. *Cadernos de Terapia Ocupacional da UFSCar*, *20*(2), 203-205.

Rojas, V. (2019). Humanización de los cuidados intensivos. *Revista Médica Clínica Las Condes*, *30*(2), 120-125.

Sanchís, L. (2018). *Afrontamiento del miedo a la muerte* (Tesis de doctorado). Universidad Complutense de Madrid, Madrid.

Superintendencia de Salud. (2006). *Perfil epidemiológico del adulto mayor en Chile*. Santiago: Superintendencia de Salud, Departamento de Estudios y Desarrollo. Recuperado el 22 de diciembre de 2022, de https://www.supersalud.gob.cl/documentacion/666/articles-4020_recurso_1.pdf

Superintendencia de Salud. (2019). *Hospitalización social en adultos mayores en el sistema de salud de Chile*. Santiago: Superintendencia de Salud, Departamento de Estudios y Desarrollo. Recuperado el 22 de diciembre de 2022, de https://www.supersalud.gob.cl/documentacion/666/articles-19660_recurso_1.pdf

Talbot-Coulombe, C., & Guay, M. (2020). Occupational therapy training on palliative and end-of-life care: scoping review. *British Journal of Occupational Therapy*, *83*(10), 609-619. http://dx.doi.org/10.1177/03080226209269355.

Trevisan, A. R., Reksua, S., Almeida, W. D., & Camargo, M. J. G. (2019). A intervenção do terapeuta ocupacional junto às pessoas-hospitalizadas: adotando a abordagem dos cuidados paliativos. *Cadernos Brasileiros de Terapia Ocupacional*, *27*(1), 105-117.

Viviens, R. (2012). *Terapia ocupacional y cuidados paliativos*. Zaragoza: Universidad de Zaragoza.

World Federation of Occupational Therapists – WFOT. (2016). *Declaración de posicionamiento: terapia ocupacional en cuidados en el fin de vida*. Londres: WFOT.

Author's Contributions

Natalia Paz Castillo-Núñez, principal investigator, research design, analysis, review, research process guide, text writing, full-text review, editing. Gisele Romina López Contreras, ethical aspects of research, fieldwork, content analysis, text writing, analysis and organization

of sources, review of results. Diego Alonso Márquez Rojas, fieldwork, content analysis, discussion, conclusions, text writing, analysis and organization of sources, review of results. Valeria Liliana Vargas Silva, fieldwork, content analysis, discussion, conclusions, text writing, review and summary of results, review discussion, and conclusions. Nicole Vannesa Villavicencio Garrido, fieldwork, content analysis, discussion, conclusions, text writing, review and synthesis of results, discussion, and conclusions. Cristóbal Javier Catalán-Águila, project design, guide in initial stages, ethical aspects, discussion writing, full-text review. All authors approved the final version of the text.

Funding Source

Internationalization program of the Master in Occupation and Occupational Therapy degree, Faculy of Medicine, University of Chile – Santiago, Chile.

Corresponding author
Cristóbal Javier Catalán-Águila
e-mail: cristobalcatalana@uchile.cl

Section editor
Prof. Dr. Daniela Testa