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Experience Report

Occupational therapy in an Intensive Care Unit (ICU): experience report on work with caregivers/family members in a public hospital

Terapia ocupacional em Unidade de Terapia Intensiva (UTI): relato de experiência sobre o trabalho com cuidadores/familiares em um hospital público

Terapia Ocupacional en una unidad de cuidados intensivos (UCI): relato de experiencia sobre el trabajo con cuidadoras/familiares en un hospital público

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Abstract

There is little Latin American literature regarding the practices of occupational therapists in the context of intensive care units. Although it is clear which interventions are mostly carried out, the details of these are not evident, especially the description of the work carried out with caregivers/family members. For this reason, the objective of the article is to describe this process based on one hand, on a committed and therapeutic bond to understand each subject/family in its uniqueness and on the other, on education from the recognition of the diversity of people's knowledge. Therefore, this article reports an experience of what happens in a public hospital in Chile, where there has been work in the discipline for approximately 10 years, considering the particular actions that are carried out jointly with caregivers/family members, highlighting the following two strategies 1) Committed and therapeutic accompaniment initiated from the initial semi-structured interview as the first meeting between the occupational therapist and

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caregivers/family members, and 2) Education as a strategy and space for generating support and explicit mutual knowledge at three specific moments in the process. It is concluded that caregivers/family members are fundamental figures during care in an intensive care unit and it is necessary to reflect on the singularities that exist during the course of the intervention, recognizing their knowledge and stories.

Keywords: Occupational Therapy, Intensive Care Units, Caregivers, Family, Rehabilitation.

Resumo

Há pouca literatura latino-americana sobre as práticas dos terapeutas ocupacionais no contexto das unidades de terapia intensiva. Embora esteja claro quais intervenções são mais realizadas, os detalhes destas não são evidentes, especialmente, a descrição do trabalho realizado com cuidadores/familiares. Por isso, o objetivo do artigo é descrever esse processo a partir, por um lado, de um vínculo comprometido e terapêutico para compreender cada sujeito/família em sua singularidade e, por outro, na educação a partir do reconhecimento da diversidade de conhecimento do povo. Relata-se uma experiência do que acontece em um hospital público no Chile, onde se trabalha na disciplina há aproximadamente 10 anos, considerando as ações particulares que são realizadas em conjunto com cuidadores/familiares, destacando duas estratégias a seguir: 1) Acompanhamento comprometido e terapêutico que começa com a entrevista semiestruturada inicial como primeiro encontro entre terapeutas ocupacionais e cuidadores/familiares e 2) Educação como estratégia e espaço para geração de apoio e conhecimento mútuo explícito no três momentos específicos do processo. Conclui-se que os cuidadores/familiares são figuras fundamentais no cuidado em unidade de terapia intensiva e que é necessário refletir sobre as singularidades existentes no decorrer da intervenção, reconhecendo seus conhecimentos e histórias.

Palavras-chave: Terapia Ocupacional, Unidades de Terapia Intensiva, Cuidadores, Família, Reabilitação.

RESUMEN

Existe escasa literatura latinoamericana con respecto a las prácticas de terapeutas ocupacionales en contextos de unidades de cuidados intensivos. Si bien está claro cuáles son las intervenciones que mayormente se implementan, no es evidente el detalle de éstas, especialmente, la descripción del trabajo realizado con las cuidadoras/familiares. Por esto, el objetivo del artículo es describir este proceso basado, por un lado, en un vínculo comprometido y terapéutico para comprender a cada sujeto/familia en su singularidad y por otro, en la educación desde el reconocimiento de la diversidad de saberes de las personas. Por lo tanto, se describe una experiencia de lo que sucede en un hospital público de Chile, en el que existe un trabajo de la disciplina por aproximadamente 10 años, considerando las acciones particulares que se realizan junto a cuidadoras/familiares, destacando las dos siguientes estrategias 1) El acompañamiento comprometido y terapéutico que comienza con la entrevista semi-estructurada inicial como primer encuentro entre terapeutas ocupacionales y cuidadoras/familiares, y 2) La educación como estrategia y espacio de generación de apoyo y conocimiento mutuo en tres momentos específicos del proceso. Se concluye que las cuidadoras/familiares son figuras fundamentales durante la atención en una unidad de cuidados intensivos y es necesario reflexionar sobre las singularidades que existen durante el transcurso de la intervención reconociendo sus saberes e historias

Palabras Clave: Terapia Ocupacional, Unidad de Cuidados Intensivos, Cuidadores, Familia, Rehabilitación.

Introduction. Experience Scenario

An intensive care unit (ICU) is an organized system for the delivery of care to critically ill people that provides intensive and specialized health care, increased monitoring capacity, and multiple modalities of physiological organ support to sustain life for a period of acute organ failure (Marshall et al., 2017).

People who are in the ICU are subject to various interventions, especially endotracheal intubation and invasive mechanical ventilation, which requires being under sedation and analgesia to tolerate these procedures, coupled with a prolonged stay (Krumholz, 2013). The above has significant consequences for people who find themselves in this situation: experiencing an interruption of normal circadian rhythms, pain and discomfort, delirium, depression, anxiety, inactivity and acquired muscle weakness, among others. Each of these perturbations can negatively affect health and contribute to substantial impairments during the early recovery period and susceptibility to post-intensive care syndrome (Krumholz, 2013). Furthermore, the experience of being in an ICU is a difficult situation for those who are hospitalized and their families, generating negative feelings, which significantly mark their life experiences, especially because there is a loss of independence and autonomy. Furthermore, the presence of invasive procedures, the lack of privacy and separation from the family, cause high levels of anxiety and concern in people hospitalized in said service (Alasad et al., 2015).

Regarding the rehabilitation team, different professionals are involved, including occupational therapists, who are members of the early mobilization/rehabilitation team (Ratcliffe & Williams, 2019). Among the benefits provided, the majority are associated with early mobilization, followed by physical rehabilitation, training in activities of daily living, cognitive stimulation, mental health support and environmental interventions (Costigan et al., 2019). However, despite the aforementioned benefits being described, according to Costigan et al. (2019) in their review, states that there is little research on occupational therapy interventions in this area.

In Chile, there are critical patient units (CPU) in all regions; however, there is no report on the total number of occupational therapists who work in these services, nor the working hours they have. Currently, the National Rehabilitation Plan 2021 – 2030 establishes regulations and technical guidelines to have these positions permanently at CPU (Sociedad Chilena de Medicina Intensiva, 2021), however, regarding the work carried out with caregivers/families, little detailed guidance is indicated.

A Local experience in an ICU of a Public Hospital

In this context, the experience developed over 10 years at the San José Hospital is presented, located in the commune of Independencia in the Metropolitan Region. The CPU has a total of 10 colleagues in the service, being one of the largest teams in our country[1], therefore, it is important to share the experiences developed, to account for what happens in an ICU of a public hospital, highlighting what an institution like this means:

> The contemporary hospital has been going through important challenges imposed by the epidemiological transition and population aging, due to the complexity of the care offered and the increase in survival in the face of technological advances. Thus, the hospital comes to be seen as the place of highly complex care. However, it is important not to forget that the hospital continues to be an important gateway to the system, since it is the space where the lack of access to basic health care, education and social protection is manifested (Galheigo, 2008, p. 25).

The above makes it clear that the actions of occupational therapy team in an ICU need to not only develop intervention strategies and techniques based on technical-scientific knowledge, but also, they must reflect on the historical-social knowledge of the context in which their work is inserted, with the aim of obtaining a greater impact from the actions developed (Santos & Carlo, 2013). In this sense, this knowledge is woven into the social relationships of occupational therapists and hospitalized people and family caregivers[2], since knowing the way in which they experience their daily lives, knowing what their needs are, their aspirations, their networks of support, their closest reality (Núñez, 2019), based on a relationship of trust and empathy, allows them to recognize their particular biographies and trajectories that are often made invisible by the clinical condition, due to sedation and the impossibility of communicating with their families.

Who are the caregivers with whom the occupational therapists team interact in ICU contexts?

According to Law No. 21.380, which regulates the rights and duties of people in relation to actions related to their health care, the role of caregiver is defined:

> [...] Caregiver will be understood as any person who, free of charge or remunerated, provides assistance or care, temporary or permanent, for the performance of activities of daily living, to people with disabilities or dependency, whether they are or not united by kinship ties (Artículo 5° quáter. Ley 21.380, 2021).

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[1] It should be noted that, in 2012, there was only one occupational therapist working a 9-hour day from Monday to Friday (44 hours in total) at UPC.

[2] Regarding personal care and assistance for people in a situation of dependency or vulnerability, it is usually carried out by the person's family and/or close network, with a marked feminization of this activity, carried out by mothers, sisters, daughters, grandmothers, among others. For this reason, we will talk about caregivers in the text

The differentiated burden in the distribution of the role of caregivers between men and women and the presence of the female gender in care is a fact, as shown in the II National Disability Study (Servicio Nacional de la Discapacidad, 2022) which indicates that care is provided by a network family member (in 82,1% of cases), specifically women (70%), mainly daughter or spouse. The above is observed in our unit, where it is mostly women who interact with the ICU health team. At the same time, they state that they are responsible for other tasks, such as caring for a family member with a disability, domestic tasks, informal paid work, among others. Feminized care produces inequity because the main caregivers are usually women with low income, unemployed or precarious jobs, low educational level, being direct relatives, who live with the person they care for, and not only care for, but also support and help other women in care (Vaquiro Rodríguez & Stiepovich Bertoni, 2010). This is due to the high cost of formal care and the relevance of women in Latin American society, observing a lack of alternative structures provided by the State (Centro Estudios de Vejez y Envejecimiento UC, 2015).

In the context of our hospital, the first approaches occur in person or by telephone. The caregivers/family members express difficulties in certain unmet needs that affect their health and well-being, similar to those described by Sevin et al. (2021), among them: lack of support in the face of high acute stress, little validation, without spaces for catharsis, lack of spiritual support and little information of what happens in the life of the hospitalized person. Doubts are also expressed regarding the quality/frequency of the care to be provided immediately and in the future, since caregivers who are in the public health context must comply with a high workload of paid and/or unpaid work that provides little time to perform this role, determining:

> They have to resort to the help of relatives, neighbors and community organizations generally run by themselves. Although these inequalities are not new, they have worsened. What has been called "crisis of social reproduction" is occurring, which consists of a crisis in people's living conditions, with difficulties and deficiencies not only in the conditions in which they care for and are cared for, but also in decent housing, drinking water, electricity, public health and education services, among many others (Nin, 2021, p. 331).

Therefore, in this scenario, providing support to the caregiver/family member from the first moment in an ICU hospital context is essential to provide support and containment in the face of a high degree of concern and uncertainty about the health-disease process and functional-life prognosis of his family member. It is essential to reflect on the intervention strategies to use in this process, which are set out below.

A. The experience of therapeutic and committed accompaniment

Most people upon entering the ICU find an unknown scenario: they are on invasive mechanical ventilation, sedation, and with an orotracheal tube, limiting the connection with the environment and verbal language (Karlsen et al., 2019), affecting the autonomy and independence of the hospitalized person in this invasive and often dehumanizing context: the individual is observed and identified from biomedical characteristics such as bed number, pathology and medical resolution, relegating identity and personal aspects. Therefore, it is essential to humanize care, to know not only the clinical history but also the biography and historicity of the individuals, which is constructed through the caregivers/family members, who provide valuable information on this aspect. In this context, the type of relationship established will be essential under the circumstances indicated above.

The majority of people hospitalized in the ICU come from different sociodemographic contexts: commune, socioeconomic situation, and social security, among others. The same occurs with their personal contexts: underlying diseases, age range, heterogeneous medical diagnosis, networks, among others (Ruiz et al., 2016; Ramos et al., 2023). Therefore, knowing these singularities define the steps to follow in the evaluation and intervention (not ignoring the clinical aspects of the health-disease process of each person of course), since carrying out a practice that is committed and situated in each individual it is possible to move away from an interventional practice directed and carried out through standardized acts and procedures. For example, in one week it is common to evaluate a person over 80 years of age who lives alone, with a history of mild cognitive impairment, who is hospitalized for a hip fracture and, on the other hand, a 19-year-old person who lives with her parents and sisters, who has just had a traffic accident on the way to university. The above requires us not to homogenize the intervention processes, since they are decisive in approaching the caregivers/family members, and understanding how they experience this sudden and complex stress. Building the bond with the family is part of the occupational therapist's care with the hospitalized person and must provide a space for mutual learning about the process of being hospitalized in an ICU.

The inaugural point is the construction of a therapeutic bond that involves a relational process, defined as:

> [...] an emotional experience that is co-created, that occurs and passes between two subjectivities. Therefore, it progresses as a network of affective and value expressions (explicit or implicit, central or peripheral) that are part of the communicative action. Their expressions allow us to account for the quality and trajectory of this connection and at the same time, they create it at every moment of the interaction (Molina et al., 2013, p. 16).

It is a response to a critical moment in the biographical trajectory of a family, where active listening and dialogue are key aspects for a situated communicative action that allows knowing the stories of both the Occupational therapist and the family member and enabling a space to gradually build a committed bond. This will be the basis of the therapist-caregiver interpersonal relationship, which reflects an ethically non-neutral attitude, which contributes to facilitating and reestablishing the family member's ability to trust, establishing a genuine relationship in the face of the events that are presented. The emotions of hate, love and sadness in these very critical and highly uncertain circumstances are accepted not only as part of this relationship, but as a bond between human beings (Lira et al., 1989).

Now in practice, the approach is done through the initial semi-structured interview, which opens up listening, not as a one-way interrogation, but providing the opportunity to talk with the caregivers/family members. Dialogue is established as a socializing means with the objective of achieving authentic communication and meet between people (Freire, 1975).

Regarding the interview, 3 moments are considered, which allow us to understand it as a process and not just the application of a data collection technique. These moments are detailed below:

1. **Verify the history of the hospitalized person** (see Table 1) to facilitate decision-making by the health team (whether by telephone or in person). For example: if the hospitalized person has a history of major cognitive impairment, it is crucial to corroborate this information with the person closest to them and know where this diagnosis was made, when and by which specialist. If reliable, specify through specific guidelines the stage in which he/she is located and his/her functional status. This allows a biographical overview of significant aspects of the people's lives, as well as the understanding of the magnitude of some difficulties that he or she may present.

Table 1. Semi-structured-initial interview applied by occupational therapy.

1. **General background**
Name
Age
Hospital and intensive care unit admission date
Residence commune
Family Telephone Number
2. Previous medical history
Comorbidities
Medication (type/dosage)
Corroborate diagnoses of chronic diseases (e.g. major cognitive impairment, osteoarthritis, etc.)
3. Biographical background
Scholarship (years)
Reading-writing
Previous paid/unpaid work
Technical aids for everyday use (type of cane, type of wheelchair, glasses, dental plate, hearing aids, etc.)
4. Family context
Previous cohabitation (number, relationship)
Establish prior support network
Previous housing (house, apartment, street location)
Place in the home where this room
5. Previous functionality
Apply standardized functionality guidelines in basic and instrumental activities of daily living
Establish magnitude and clear detail of dependency in daily activities
6. Relevant aspects of his biographical career
Interests, music, hobbies, etc.
7. Comprehensive geriatric assessment in older people

2. **Identify the caregiver's situation and degrees of well-being/discomfort.** The anguish of not knowing what happened to cause the person to be in a serious condition requires resolving initial doubts, among them: (1) is my family member conscious or asleep? (2) Can I bring or do something that will support his current health process? (3) Do you have rehabilitation experience with people who have the same characteristics as my family member? How do they continue in the short and long-term future? The previous concerns arise from the initial interview and when an answer is found, they have a considerable impact on the reduction of anxiety. In fact, information about the state of the individual's health process is one of the greatest concerns regardless of the education or culture of the family members (Kynoch et al., 2016), which implies locating oneself, being relevant and promoting permanent communication.
3. **Spaces for expression, relief and breath.** The caregiver/family member's need to be able to relate her fears, feelings, worries and concerns about how to cope with this complex moment is part of the bond. Here the therapeutic use of the self is used as an intervention strategy, describing it as the intentional use of the professional's own personality, perceptions, introspection and judgment as part of the therapeutic process, including active listening, conveyance of needs, accompaniment, comfort, confrontation, validation of emotions, positive reinforcement and use of silence (León et al., 2022; Pérez Riffo, 2013).

B. Education as a strategy and space for mutual knowledge

Education does not consist of a mere transmission of knowledge, but rather the continuous construction of a shared and dialogued reality, above all, in educational work with caregivers/relatives of people in a life-threatening state, such as the ICU, since it favors the reduction of stress in them, providing a humanizing environment within the hospital system:

> Being hospitalized generates an incisive rupture in the daily lives of individuals, but, in general, it is understood that the individual himself needs to elaborate and overcome the conflicts generated by this condition; there is an undervaluation of the hospital routine as a generator of stress, which ends up aggravating the clinical condition of the individual. Concerning the restructuring of that individual's daily life and proposing hospital humanization actions are also actions that can be carried out by the occupational therapist, together with the team (Santos & Carlo, 2013, p. 100).

In this context, from the ecology of knowledge, an exchange of reciprocal knowledge occurs, of a scientific and popular nature, as well as lack of knowledge of each subject, thus generating an enriching intersubjective process in which knowledge is learned and unlearned (Santos, 2010). A clear example is when a hospitalized person is in a context of superficial sedation in the ICU with little connection to the environment, requiring constant stimulation to increase alertness. Under these circumstances, daily stimulation without biographical information has no impact on his state of consciousness. At that moment, the caregiver/relative says "it would help my mother a lot to hear her dog's barking, since they are together all day and she adopted him as a puppy," giving space to the spiritual dimension, which takes and collects the beliefs and customs rooted in our culture positively affecting the intervention with the person. Therefore, in this case of knowledge exchange, the pragmatic content of education is dialogic and, at the same time, problematizing, promoting horizontal relationships and mutual delivery of knowledge (Freire, 1975).

Now, this dialogic process with the family occurs in 3 significant moments in the ICU:

1. **Education about the UCI context.** The objective is to understand what being in an ICU entails in detail, since it is common for the family not to have knowledge about the context in which the hospitalized person is (Naef et al., 2022). Different family members may have different participation needs and preferences influenced by their previous experiences, knowledge, physical and mental health, and socioeconomic status (Xyrichis et al., 2021), determining how vital it is to explain and make the understanding of this context more tolerable.
2. **Periodic communication about the rehabilitation process of people in the ICU**. Because the majority of hospitalized people cannot communicate verbally or give an opinion about the health care received, it is usually the caregiver/family member who has to evaluate the care their family members receive from the ICU team. Therefore, the objective is to express clearly and frequently the rehabilitation milestones that people are achieving, since it allows us to understand their progress. It is worth highlighting the relevance of using language according to the knowledge and history of the caregiver, as an example: "after three weeks I can tolerate five minutes sitting on the edge of the bed with the assistance of a person", "after several days he is no longer agitated or confused, he is calm, he is even oriented, he knows where he is." The above makes the exchange of speech a clear and effective communication (Ito & Tsubaki, 2023).
3. **Family education at the edge of the bed.** The bed becomes the setting to promote the rehabilitation process through active interaction with the hospitalized person and their caregivers/family members. During visiting hours, education is carried out on actions that the caregiver can carry out that support treatment goals. (see Table 2). The relevant thing here is to highlight the situatedness of this, since depending on the biography and interests expressed by the caregiver, intervention strategies can be chosen that use elements of everyday life: significant biographical moments ("talk to him about his job, when he was traveling north driving his truck"), ways of relating ("he likes to be talked to slowly", "perhaps today he is not in optimal health conditions so it will not be possible to visit him or touch him"), delivery of recent significant information ("tell him that his sister, whom he takes care of, is now with his other brother and is very well taken care of"), specific tastes ("he really likes folk music, if you play that specific musical band he calms down"). These antecedents mark an intervention situated thanks to the knowledge of the caregiver/family member.

Table 2. Description of bedside intervention strategies for caregivers/family members.

Strategies	**Description**
Support for training in activities of daily living	Facilitate the execution of basic daily living activities, mainly personal hygiene, since it is one of the first activities that people in the ICU can carry out
Support for cognitive stimulation	Reality-oriented therapy in conjunction with reminiscence requires significant time to generate an impact on orientation and relationship with the environment. Through reading significant texts, describing photographs, listening to private audios saved on the family member's cell phone, among others, allows to facilitate the active work of cognitive functions
Emotional support and containment	During their stay in the ICU, people experience feelings of sadness and anguish that sometimes require containment, support and closeness with a caregiver/family member in order to reduce emotional lability.
Spiritual support	A significant percentage of the population of hospitalized people are believers in different religions, so praying together with his family is an important calming point in the acute context in which he is.
Support with communication elements	Having devices, such as cell phones, whiteboards, notebooks and tablets, allows you to increase communication with the environment and express your concerns.

Source: Own elaboration.

In summary, when engaging in an educational process, in this particular context, both types of knowledge must be given equal relevance in the dialogue. In fact, from the ecology of knowledge the variety of knowledge is contemplated and how they relate to each other, opposing the logic of the monoculture of scientific knowledge, identifying other knowledge and criteria of rigor and validity that operate in a credible way in social practices that metonymic reason declares non-existent (Meneses et al., 2019). Seeking credibility for non-scientific knowledge does not imply discrediting scientific knowledge, rather it implies using it in a broader context of dialogue with other knowledge (Santos, 2010) as occurs in an ICU. Another fundamental aspect is to emphasize that not only the occupational therapist participates in the educational work, but also the entire ICU health team in an articulated manner, discussing together about how to carry out the process with responsibility, consistency and effectiveness.

Learning and final reflections

Life trajectories are radically interrupted when hospitalized in an ICU, the feelings of caregivers/family members become a prevailing need to attend to a situation as pressing as being at life risk and with a prognosis of substantial mortality. Due to the above, discussing the intervention strategies to use in this context becomes an immutable constant. As mentioned in this article, the majority of hospitalized people have different sociodemographic and biographical contexts, so the singularities of each person define the path to follow, and leads us to not homogenize the intervention processes, but to locate them within a therapeutic and committed linking process that allows generating the necessary conditions for a respectful dialogue and exchange of knowledge and experiences, work that is often made invisible in working with caregivers/family members. On repeated occasions these actions are observed in isolation, through a vertical relationship and little interpersonal interaction. Based on the above, restructuring the daily life of each individual and proposing humanization actions are tasks that promote stress reduction and relief for people involved in rehabilitation processes in an ICU.

Occupational therapists who work in public health care for a significant population in our country that has an infinite diversity of health-disease dimensions. This entails having updated and numerous scientific knowledge that must be complemented at the same time and with equal significance as the knowledge based on the narratives and historicity of each person. The emotional, socioeconomic and historical burden of each individual is visualized in our practice, ignoring it or not taking it into account limits our actions. In this way, it is important to reflect that the hospital is not only a sectorized place in the health network, but also a place that is part of the daily processes of our society, a gateway to multiple realities and where spaces of connection and constant education are generated.

In conclusion, for professionals who develop this hospital area and for hospital institutions that still do not have clarity about the role of the profession in this field, it is vital to present this type of experiences and their value within the health care and attention network. Furthermore, include the work that can be done with caregivers/family members through a therapeutic-educational relationship, promotes intervention strategies specific to the context of public service, enabling the hospital to be a space for the recognition of collective knowledge of those who attend an ICU.

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Author's Contributions

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