

I fought the good fight. I finished the race. I kept the faith

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Abstract

Palliative care is given by a multiprofessional team to promote the quality of life of patients and their family when facing diseases that threaten the continuity of life. As a part of these teams, occupational therapists develop their actions aiming at the production of meanings and sustaining the lives of patients. From literature on palliative care, occupational therapy and bioethics as the theoretical framework, this article reports the care experience of a patient under palliative care in a hospital context. The objective is to promote occupational therapy as a crucial part of palliative care for cancer patients, considering that, in a context of hardships and limitations caused by advanced stages of this disease, the reported interventions were effective. The patient was able to find a path that provided meaning to their life story.

Keywords: Occupational therapy. Palliative care. Activities of daily living.

Resumo

Combati um bom combate, terminei a corrida, mantive a fé

Cuidados paliativos são fornecidos por uma equipe multiprofissional com o fim de promover a qualidade de vida de sujeitos e familiares que enfrentam doenças que ameaçam a continuidade da vida. Como parte dessa equipe, os terapeutas ocupacionais desenvolvem suas ações visando produzir sentidos e sustentar a motivação dos sujeitos. Tomando como base o referencial teórico sobre assistência paliativa, terapia ocupacional e bioética, este artigo relata uma experiência de cuidado de um sujeito em cuidados paliativos em contexto hospitalar. O objetivo é promover a terapia ocupacional como parte importante dos cuidados paliativos oncológicos, tendo em vista que, num contexto de dificuldades e limitações causadas pela doença avançada, as intervenções relatadas se mostraram eficazes. O sujeito do cuidado pôde encontrar um caminho que conferiu sentido a sua história de vida.

Palavras-chave: Terapia ocupacional. Cuidados paliativos. Atividades cotidianas.

Resumen

Peleé la buena batalla, terminé la carrera y mantuve la fe

Los cuidados paliativos son ofrecidos por un equipo multiprofesional con el objetivo de promover la calidad de vida de los sujetos y sus familias que se enfrentan a enfermedades que amenazan la continuidad de la vida. Como parte de este equipo, los terapeutas ocupacionales desarrollan sus acciones con el objetivo de producir sentidos y mantener la motivación de los sujetos. Con base en el marco teórico sobre asistencia paliativa, terapia ocupacional y bioética, este artículo relata una experiencia de cuidado de un sujeto en cuidados paliativos en un contexto hospitalario. El objetivo es promover la terapia ocupacional como una parte importante de los cuidados paliativos oncológicos, teniendo en vista que, en un contexto de dificultades y limitaciones causadas por la enfermedad avanzada, las intervenciones relatadas demostraron ser eficaces. El sujeto del cuidado pudo encontrar un camino que aportó sentido a su historia de vida.

Palabras clave: Terapia ocupacional. Cuidados paliativos. Actividades cotidianas.

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Palliative care is provided by a multiprofessional team that seeks to promote the quality of life of patients, families and caregivers who face diseases that threaten the continuity of life. Such care is an essential component of comprehensive care and must be part of the health system as a public policy. For the patient's suffering to be relieved, early identification, assessment and treatment of symptoms and physical, psychosocial and spiritual difficulties are necessary¹⁻³.

As part of the multiprofessional team, the occupational therapist is qualified to identify what the individuals recognize as daily needs related to illness. During training, the principles of bioethics are addressed in interface with occupational therapy. Ideally, these principles are internalized by therapists to develop actions in a unique and individualized manner, aiming to produce meanings and sustain their patients' lives⁴⁻⁶.

However, although the training program addresses aspects related to bioethics, studies indicate the occupational therapists' insufficient performance in palliative oncology care and the professionals' unpreparedness when dealing with death⁷⁻⁹. To contribute to the production of knowledge on the topic, this article reports the experience of caring for a patient in oncology palliative care based on the conceptual contribution of bioethics.

Method

The article presents an experience report with reflections based on the theoretical framework of palliative care in interface with occupational therapy and bioethics. Eli (fictitious name) was a 21-year-old man with advanced leukemia who lived his last days in the hospital. The material that gave rise to the article consists of authors' notes and records of occupational therapeutic visits found on the electronic system of the school hospital where the patient was hospitalized, with data from August and September 2017. The case report was authorized upon clarification of its objectives and the patient and his father signed an informed consent form, a document prepared and standardized by the Teaching and Research Management of the School Hospital of Santa Maria.

First, this article will present the referential of palliative care in interface with occupational therapy and bioethics. Then, interventions and outcome of the case will be reported, based on the literature. Regarding the theoretical frameworks, the authors call attention to the professionals' unpreparedness to deal with their patients' death and the low bibliographic production on the topic, although this number has been increasing⁷⁻⁹. Producing knowledge in this field is therefore fundamental, since from that knowledge the work of occupational therapy in palliative oncology care can expand.

Results: The book of Eli

Eli was a 21-year-old man who worked as a store clerk and lived with his parents. At the age of 15, he was diagnosed with leukemia and has since dreamed of a cure. He was Catholic, wore a scapular around the neck and had the image of Our Lady of Aparecida at the bed headboard. The first contact we had with Eli took place when he was 20 years old. At the time, leukemia was already at an advanced stage and both he and his father – who stayed with him at the hospital – were aware of the prognosis. Due to the progression of the disease, Eli suffered from vision loss; the occupational therapist was then contacted by the unit's staff for follow-up, possible adaptations in the bedroom furniture and carrying out activities of daily living.

Eli remained in the room and, from the first moment, made it clear that vision loss was not a limiting factor in his daily life, as he remembered where the furniture and his belongings were, managing to carry out his daily activities independently. What worried him (and also made him live) was that his girlfriend was six months pregnant, and he was concerned about how to care for his daughter after birth.

Over the course of a month, the occupational therapist performed 15 visits, in which she proposed activities that aimed at thinking about strategies for caring for his daughter. The objective was to encourage the involvement and rescue of significant activities during the hospitalization period, as Eli did not leave the room and spent most of his time in bed.

In this context, some milestones of child neuropsychomotor development were addressed. Eli was informed, for example, that his daughter, even in the mother's womb, could already hear and recognize his voice, which made him very excited. The girlfriend did not usually go to the hospital, at Eli's request, who understood her health situation and did not want to make her apprehensive. However, the couple talked on a daily basis on their cell phones, and Eli started asking his girlfriend to put the phone on her belly so he could talk to his daughter.

During hospitalization, the unit's staff organized a baby shower attended by Eli's girlfriend, mother, mother-in-law and other family members. At the time, the occupational therapist, in addition to participating as a guest, accompanied the patient, describing how the space in which the baby shower took place was organized and decorated and what the gifts were. Interestingly, after the occupational therapist described the environment, Eli's girlfriend also started to detail the gifts as she opened them.

Eli always had a lot of faith in the cure, but he knew the severity of his illness. As time went on, his body gave more striking signs of the nearness of death. As the disease progressed and a cure was no longer possible, the symptoms worsened, and often occupational therapeutic treatments were limited to qualified listening. When the therapist arrived, Eli, who did not like silence, invited her to sit on the bed, next to him, and told life stories, pleasant moments and plans for the future, with the birth of his only daughter. But the patient also expressed his fears... What if he left before his daughter was born?

Thinking about this possibility and considering the established therapeutic bond, the therapist started introducing reminiscent activities in the visits. Eli chose to build what he called a "time capsule," a project that took five visits to be finished. But what was significant to be placed in that time capsule for his daughter?

The first items chosen were music and photos with his girlfriend. This activity reverberated in other moments of Eli's daily life, in addition to occupational therapeutic visits, as it motivated him, during the day, to look for and choose the photos and music he liked most. Although he could no longer see, Eli used his memory to tell the occupational therapist which photos he

wanted to put in the time capsule, published in his profile on a social network. The songs were chosen from Eli's playlist on the cell phone. Both the photos and the songs were saved on a thumb drive and placed in the time capsule.

The second item chosen was a letter to his daughter, written during a visit. Eli was suggested to record the letter on audio or, if he felt more comfortable, to narrate what he would like to say for the therapist to write it. Eli chose the second option. In the letter, written in the first person and addressed to the daughter, Eli referred to him and his girlfriend as "daddy and mom."

The letter begins introducing him and his girlfriend to the daughter. In the sequence, he tells of the gifts his daughter has already received, the baby shower that took place that week - "her first little party" - and how much he and his girlfriend are people who fought for their dreams and always liked to help others. In the letter, Eli points out that at that time he was hospitalized, undergoing health treatment, but would be fine when his daughter arrived. At one point he says: "The world outside is not easy, but know that with each new day we can do something to make it better." Finally, Eli introduces family members and godparents and wishes the daughter to be an "honest and sincere person, and never spare efforts to help people, whether they are family members or not."

The letter was signed by Eli, with an end note saying that it was written with the help of the occupational therapist. Subsequently, the letter was typed, again signed by Eli and placed in the time capsule (a wooden case with a key). On the day that the final version was delivered and read, Eli remembered something he had heard in the movie "The book of Eli" and that he would like to add to the letter: I fought the good fight. I finished the race. I kept the faith. Eli told family members that the time capsule should stay with them and be delivered to his daughter on her 15th birthday. Eli died days after finishing his capsule.

Discussion

Palliative care emerged in the 1960s, in the United Kingdom, with Cicely Saunders' work dedicated to individuals with advanced cancer. Saunders, who had a humanistic background and became a doctor,

studied cancer pain and created the concept of “total pain,” which states that a person suffers, in addition to physical impacts, with the emotional, social and spiritual implications of life-threatening diseases. In 1967, Cicely Saunders founded St. Christopher’s Hospice, a milestone in the consolidation and dissemination of palliative care worldwide^{1,2}.

Besides patient care, the St. Christopher’s Hospice included teaching and research practices. The institution received professionals from several countries, mainly from the United States and Canada, who brought the practice of palliative care to their places of origin. In the mid-1970s, palliative care was widespread in the USA by Elizabeth Kübler-Ross, and a hospice was founded in the country. Since then, this specialized type of care has spread to several countries^{1,10}.

In 1990, following a meeting of cancer and palliative care specialists from several countries, the World Health Organization (WHO) published its first definition of palliative care, recognizing and recommending it as a health priority. In 2002, the concept was revised and extended to other chronic diseases, such as AIDS and heart, kidney, degenerative and neurological diseases. Two years later, a new WHO document was issued, *Palliative care: the solid facts*, which recommended the inclusion of palliative care in the treatment of all chronic diseases^{1,11}.

The Ministry of Health (MS) has been formally consolidating palliative care in Brazil’s health system through ordinances and documents from the Ministry itself and from the National Health Surveillance Agency¹². Ordinance 874 GM/MS, of May 16, 2013, establishes the National Policy for the Prevention and Control of Cancer in the Health Care Network for People with Chronic Diseases within the scope of the Unified Health System. In it, article 13 stands out, establishing that: *Preventive care, early detection, diagnosis, treatment and palliative care are part of comprehensive care, which must be offered in a timely manner, allowing continuity of care*¹³.

The Brazilian National Cancer Institute (Inca) argues that active treatment and palliative care are not mutually exclusive. The institution proposes that palliative care should be applied in the course of the disease, together with active cancer treatment, gradually increasing if a cure is no longer possible. Despite the therapeutic

advances in recent years, the survival rate indicates that approximately one third of people with cancer will experience it without a cure prospect. It is necessary to relieve the suffering and reduce the emotional conflicts of these patients and family members, ensuring physical, psychological, spiritual and social comfort^{6,14}.

An essential component of comprehensive health care, palliative care is a basic human right, especially at the end of life. It must be offered by multiprofessional teams and integrate the health system as a public policy, at different levels of care^{2,3}. Based on the WHO definition, Byock¹⁵ highlights the principles of palliative care:

Death must be understood as a natural process, part of life, and quality of life is the main clinical objective; palliative care does not anticipate death, nor does it prolong the process of dying; the family must be cared for with as much dedication as the patient. Patient and family members form the so-called care unit; symptom control is a fundamental goal of care. Symptoms should be routinely assessed and effectively managed; decisions about medical treatments must be made ethically; patients and families are entitled to accurate information about their condition and treatment options; decisions must be made in a shared manner, respecting ethnic and cultural values (...). The experience of falling ill must be understood globally and, therefore, spiritual aspects are also incorporated in the provision of care; assistance does not end with the patient’s death, but extends to supporting the family’s grief, for as long as necessary.

In addition to these guiding principles, the WHO recommends that palliative treatment should start as early as possible, preferably along with curative treatment, making every effort to understand and control symptoms. This approach can prevent and relieve suffering due to physical, psychosocial and spiritual discomfort caused by the disease and the proximity of death³.

The concept of palliative care has expanded and can be adapted to different regional realities, to the resources available in health care services and to the epidemiological profile of the population served. Palliative care, as it considers that the individual is composed of many dimensions, corroborates the National Humanization Policy (PNH), launched in 2003, whose guiding

principles are the valuation of the subjective and social dimension and the strengthening of multidisciplinary team work¹⁶.

Occupational therapy, palliative care and bioethics

Occupational therapists' training seeks to qualify them for multidisciplinary team work, preparing the professionals to identify needs related to the occupation of each individual and relate them to the process of life and illness. Thus, these professionals provide individualized and singular assistance to sustain life and produce meanings for their patients^{5,6}.

In palliative care, the occupational therapist seeks meaningful activities, involving the patient and their family members, creating possibilities for communication and the exercise of creativity and enriching daily life with sensory and cognitive stimuli. It is also the occupational therapist's role to provide guidance on comfort measures and symptom control, train the patient to perform activities of daily living – optimizing functionality for autonomy and independence for as long as possible – and provide support and listening to family members and caregivers, regardless of the stage of the disease^{5,17}. The profession is anchored in occupational science, which has as its principle the idea that every human being, living in their social, cultural and political context, has the right to occupational justice, that is, to participate in society through the occupation that is significant and more relevant to them^{4,18,19}.

Occupational therapists should assess their patients as the protagonists of these assessments, respecting them and valuing their autonomy, to jointly build a therapeutic plan that considers the needs centered on the occupational desires of each individual. It means that respect, autonomy and professional ethics are principles inserted in the occupational therapist's training. Such principles are not emphasized only in the topics related to bioethics, but are part of all spheres of knowledge and professional performance^{4,11}.

Autonomy is a fundamental concept for occupational therapists. Thus, the relationship established in the therapeutic process must focus on the patient, strengthening their role. As Ballarin

and collaborators point out²⁰, having autonomy as a principle implies understanding the individuals assisted, considering their culture, context, ideas, values and beliefs, and respecting their freedom of choice with regard to their treatment.

According to Armitage and Crowther²¹, care for terminally ill patients, occupational therapists must be able to observe, listen and work with each patient individually, identifying previous occupational roles and values. The performance objective is to improve these patients' quality of life, preserving their autonomy in decision making, even in the process of finitude²¹. Thus, considering that the objective of occupational theory is to guarantee autonomy and promote occupational justice, its encounter with the principles of bioethics (autonomy, beneficence, nonmaleficence and justice) is quite fertile^{4,11}.

The time capsule of Eli

From the first moment, Eli made it clear that vision loss was not a limiting factor for performing daily activities related to self-care (personal hygiene, dressing, eating and mobility). His focus of concern was on how to care for his soon to be born daughter. Thus, although the occupational therapist's interventions have turned to reminiscences, this has not limited the possibilities of acting in palliative care.

Subjects in the final stages of life experience common situations, but express them in different ways, according to each personal and socio-cultural context. This variety of experiences creates a series of challenges for occupational therapists. One of these challenges is to accept that some projects agreed upon with the patient can be frustrated by innumerable variables over which there is no control. For example, due to use of medications or the evolution of the clinical condition, the patient may show weakness or indisposition to carry out the idealized project. At this point, the professional must understand the complexities that involve the finitude of life and remember the principle of non-maleficence^{4,11}.

With the creation of the time capsule, the occupational therapist was able to openly address Eli's plans and understand his wishes. In addition, the patient's father has always accompanied the visits,

being aware of what was being done. Although he did not openly intervene or participate in the construction of the capsule, he observed everything. In this situation, it may be that the process of mourning was anticipated, at the same time that the father became aware of all the son's plans.

The terminal patient does not always have the possibility to resolve their pending issues, whether financial, family or emotional. Hence the importance of the strategy adopted, which, through human activity, created possibilities for communication. There was a purpose in what was being done, and both Eli and his father had the opportunity to share memories and fulfill their last wishes, seeking to make the inevitable departure more pleasant.

Another bioethical reflection that involves the daily practice of occupational therapists refers to autonomy. In the case of Eli, it was possible to work with his autonomy, desires and choices due to the strong therapeutic bond that was created. However, professionals can often be frustrated with the refusal of care. In this case, therapists should try to get closer to the patient and gradually establish bonds, strengthening the trust for listening and the joint elaboration of projects. If the refusal persists and the professional's attempts are exhausted, the patient's freedom of choice must be respected^{4,11}.

Palliative care patients tend to reflect on the use of time, on the way they dealt with their affective relationships during life, on the interruption of their occupational roles and on deprivations resulting from long periods of hospitalization and physical weakness²². Therefore, considering that *there is no cure, there is no guarantee, there is fragility, helplessness and loneliness*²³, listening is essential in the care for an individual with an advanced disease.

In hospital, outpatient or home care, the occupational therapist applies strategies to prevent the patient from being trapped in impossibility. Through human activity, the professional seeks gaps in life, power and creation, discovering links between past, present and future, for until the last moment, life cannot lose its meaning. This intervention is essential because, based on the patient's history, desires, meanings and needs, the therapist can expand the possibilities of daily practice, understanding activities as sources of

experience and stimulating the creation of projects of life, closure and farewell^{6,17,22}.

Due to the complexity of comprehensive assistance for individuals in palliative care, the work of different professionals is necessary. Therefore, although this article presents exclusively the contributions of occupational therapy, it is highlighted that Eli was cared for by an entire multidisciplinary team. Only integrated work is able to build a meaningful path for the patient, considering their existence in all cycles, from birth to death^{6,24}.

Final considerations

Interventions in occupational therapeutic care enabled reflections and memories that gave Eli's life meaning and purpose until the last moment. The experience made the effectiveness of the proposed activities evident, which gave the patient resilience to face what seems to be beyond human comprehension. In this way, Eli inscribed his uniqueness in space-time by creating a link between past, present and future, perpetuating himself in the lives of those he loved so much.

Creating the time capsule and choosing the elements that constituted it seems to have been a way for Eli to leave something of himself in the world and materialize his love. At first, this creation may seem macabre, but it is essential to highlight that the therapist's visits throughout the project were never sad. On the contrary, the meetings were marked by good memories, stories and hope. This is because, although Eli, his father and the occupational therapist knew that it was a farewell, at that moment they were not talking about illness or death, but about life.

In conclusion, the strategy adopted allowed the occupational therapist to make her contribution to palliative care. Even in a context of difficulties and limitations brought about by the advanced disease, the interventions proved to be effective in pointing out a path capable of giving meaning and (re)constructing Eli's life story, as well as suggesting projects for the future of those who remained after his departure. Having clearly understood her object of intervention (human occupation), the therapist was able to identify dimensions that

go beyond physical condition (in this case, visual impairment and leukemia).

When the occupational therapists base their actions on interdisciplinary theoretical references (such as bioethics) and focus on patient care, they are able to carry out their work according


to the purposes of the profession. Solidarity, respect, equity, commitment and responsibility are concepts that permeate the practice of therapists who assist patients in palliative care. Maintaining daily reflections on these concepts is essential for these professionals' work.

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