

Occupations of a young adult under cancer palliative care in the hospital environment**Ocupações de um adulto jovem sob cuidados paliativos oncológicos no contexto hospitalar****Occupaciones de un adulto joven bajo cuidados oncológicos paliativos en el ámbito hospitalario****Emily Maria Lima de Oliveira¹, Luisa Sousa Monteiro Oliveira²****Vanessa do Socorro Mendes da Silva³, Edilson Coelho Sampaio², Victor Augusto Cavaleiro Corrêa²**

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Objective: to understand the occupations of young adults in cancer palliative care at the end of life in a hospital environment. **Methods:** exploratory, descriptive study with a qualitative approach, of the case study type, carried out in the second semester of 2021, with a patient aged between 20 and 40 years, called “*Kindness*”, admitted to an Oncological Hospital. Data collection took place through a semi-structured interview and the data treated by Bardin’s content analysis. **Results:** the following category emerged: *Kindness and her occupational adaptations for social participation*. It was found that the patient presented occupational adaptation strategies for the impacts caused by the illness on her occupations, as well as on occupational disruptions. Among these occupations, social participation stood out. **Conclusion:** it was observed that maintaining meaningful occupations, despite the imminence of death, brought feelings of belonging and “*being alive*”.

Descriptors: Palliative care; Young adult; Occupations

Objetivo: compreender as ocupações de pessoa adulta jovem em cuidados paliativos oncológicos em fim de vida no contexto hospitalar. **Método:** estudo exploratório, descritivo de abordagem qualitativa, do tipo estudo de caso, realizada no segundo semestre de 2021, com paciente na faixa etária dos 20 a 40 anos, denominada “*Gentileza*”, internada em um Hospital Oncológico. A coleta de dados se deu por meio de uma entrevista semi-estruturada e os dados tratados pela análise de conteúdo de Bardin. **Resultados:** emergiu a categoria: *Gentileza e suas adaptações ocupacionais para a participação social*. Verificou-se que a paciente apresentou estratégias de adaptações ocupacionais para os impactos causados pelo adoecimento em suas ocupações, bem como diante às rupturas ocupacionais. Dentre essas ocupações, destacou-se a participação social. **Conclusão:** observou-se que a manutenção de ocupações significativas, apesar da iminência de morte, trouxe sentimentos de pertencimento e de “*estar viva*”.

Descritores: Cuidados paliativos; Adulto jovem; Ocupações.

Objetivo: comprender las ocupaciones de un adulto joven en cuidados paliativos oncológicos al final de la vida en el contexto hospitalario. **Método:** estudio exploratorio, descriptivo, con abordaje cualitativo, de tipo estudio de caso, realizado en el segundo semestre de 2021, con una paciente de 20 a 40 años, llamada “*Gentileza*”, internada en un Hospital Oncológico. La recogida de datos se realizó mediante una entrevista semiestructurada y los datos se trataron mediante el análisis de contenido de Bardin. **Resultados:** emergió la categoría: *Gentileza y sus adaptaciones ocupacionales para la participación social*. Se verificó que la paciente presentó estrategias de adaptaciones ocupacionales a los impactos causados por la enfermedad en sus ocupaciones, así como frente a rupturas ocupacionales. Entre estas ocupaciones, se destacó la participación social. **Conclusión:** se observó que el mantenimiento de ocupaciones significativas, a pesar de la muerte inminente, aportaba sentimientos de pertenencia y de “*estar viva*”.

Descriptor: Cuidados paliativos; Adulto joven; Ocupaciones.

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INTRODUCTION

In the stages of life, there is a variation in determining the characteristics and limits of each stage, at what moment one ends and another begins. The life cycle is divided into eight periods accepted in Western industrial societies. The first is prenatal care (conception to birth), followed by infancy (from birth to 3 years), early childhood (from 3 to 6 years), middle childhood (from 6 years to 11 years), adolescence (from 11 to 20 approximately), young adulthood (from 20 to 40 years old), late adulthood (40 years old 65 years old) and older adulthood (65 years old and older)¹. Each of these periods has typical development in physical, cognitive and psychosocial aspects.

The young adulthood phase, which comprises the ages of 20 to 40 years, is, physically, the period when the body reaches the maximum development, followed by a decline. In addition, lifestyle determines health conditions. Cognitively, young adults reach even more complex capacities and moral judgments, and begin to make educational and professional choices. Personality traits are usually already established, however, this can vary according to life stages and events¹.

In a phase in which the physiological, cognitive, physical and sensory aspects are at peak development, it is expected that only external factors are threatening to health². However, in young adults, cancer is the second leading cause of mortality³.

Cancer is defined as a set of more than 100 diseases, and its main characteristic is disordered cell growth, invading tissues and organs, and tends to spread throughout the body. Cancer cells grow and multiply aggressively and uncontrollably, invading other organs and thus causing functional disorders⁴. It is considered a serious disease and, therefore, during the illness, the person goes through ruptures, role changes, limitations, pain and other symptoms, restrictions on participation in their family and social contexts⁵.

The experience of falling ill with cancer is constantly surrounded by negative representations. Since the diagnosis, the patient suffers from impacts that follow them throughout the process of illness, treatment and hospitalization, generating suffering with the evocation of finitude. The changes that occur during this process reverberate directly in daily activities⁶.

A study⁶ carried out with male patients with advanced cancer points out that disease and treatment lead to changes in daily life. With the symptoms caused by cancer, mainly pain and low immunity, people engage less in activities, which may represent, for the patient, the passage from an active life to a passive and useless one.

In the progression and worsening of the disease, the patient reaches a delicate phase when they no longer responds to conventional treatment, changing the therapeutic approach from curative to palliative. It is when death becomes a real and imminent possibility, the moment when distressing symptoms emerge and need to be managed and assisted by the multidisciplinary team⁷.

Palliative care (PC) is presented as an alternative, and its philosophy is to assist people who face chronic degenerative illnesses that threaten the continuity of life, from the moment they are diagnosed until the moment of their death. In PC, patient and family must be seen as the center of treatment, generator of decision-making and care unit⁸.

PC requires management of the associated suffering of patients and family members, who experience the most diverse reactions during the process, such as: fear, anger, disappointment, anxiety, sadness, helplessness and hopelessness⁹.

Adults aged between 20 and 49 years constitute the third group of patients with the greatest need of CP in the world (26%), behind older adults aged 70 years or older (40%), and aged between 50 and 69 years (27%) . Cancer is the leading cause for the need for PC, followed by other diseases such as HIV, tuberculosis and others¹⁰.

It is possible to experience significant occupational losses, such as absence from work, home management activities, occupational routine, occupational roles, thus altering an entire occupational repertoire with meanings¹¹.

Young adults have a different PC approach and unique care needs, which in practice are not adequately assisted¹². Health professionals who work in PC and in other different areas of health should be aware of this public when in conditions of illness that threaten the continuity of life, in addition to their need of training to deal with the most diverse themes that arise during this moment, as this is a group that has social development needs, which has acquired full decision-making capacity and autonomy, and presents behavioral risks¹³.

The cognitive, medical, and psychosocial effects of cancer treatment probably impact these challenges faced by this age group, among them the construction of interpersonal relationships and decisions about education and work, which are so important and emergent¹⁴.

The treatment and symptomatology of cancer generate long periods of hospitalization. A study on the quality of life and perception of the health status of hospitalized people showed that young adults, in the psychological context, were more affected by hospitalization than older people, and that the stressors varied according to age group. For young adults, these factors were related to aspects of social and personal life, such as work, home maintenance and money¹⁵.

The hospital brings losses and mourning related to the lack of health conditions, removal from the routine prior to hospitalization, the family environment, friends and close people, revealing a potential risk for a traumatic occupational experience. So, with the organic, psychic, social and occupational changes, participation and engagement in occupations are impaired¹¹.

Humans are occupational beings, encompassing the need and ability to engage and organize their occupations throughout life. The science of occupation studies individuals and their interactions with their environment and their occupations, taking into account their particularities and experiences¹⁶. Occupation is defined as: the daily work performed by an individual who gets involved from form, function and meaning¹⁷.

It is a science that reveals the complexity and dimensions of human occupations, since they are influenced by several factors, especially: social, cultural and economic factors. The need and meaning attributed to occupations vary and differ according to society or cultural context¹⁸.

In the light of Occupational Science, it is considered that people in oncological palliative care, in the hospital context, have a way of carrying out these occupations, a purpose and a meaning, since there are changes in the occupational routine, in the habits due to the process of hospitalization, occupational roles and significant occupations¹⁹. Thus, this research aimed to understand the occupations of young adults in cancer palliative care at the end of life in the hospital context.

METHODS

This is a qualitative research of the descriptive exploratory type, using the case study as a technical procedure.

The case study is shown as an investigation that seeks to investigate in depth a phenomenon that occurs within a real context, especially when the boundaries between both are not evident. It has variables of interest in addition to data and, as a result, presents multiple sources of evidence, and benefits from the previous development of theoretical propositions to guide data collection and analysis²⁰.

The research took place in a hospital environment, at the Oncology Palliative Care clinics between August and October 2021. The Hospital is a reference in specialized care for cancer patients, meeting demands forwarded by Primary Health Care (PHC), outpatient and hospital, in all of the state of Pará, Brazil, with its total capacity allocated to the Unified Health System (SUS).

In addition, the institution is classified as a Center for High Complexity in Oncology (CACON), is considered a Teaching Hospital by the Brazilian Ministry of Health and offers the Multiprofessional Residency Program in Oncology Health with a focus on Palliative Care since 2012. It has a team multidisciplinary approach for the treatment and performance of procedures made available to the population.

As for Palliative Care clinics, the cancer hospital in question was one of the first public hospitals in Brazil and the first in the Brazilian Northern region to offer the service, which had existed for almost 20 years, inspired by the work carried out by the National Cancer Institute. It has two Oncology Palliative Care clinics (CCPO 1 and CCPO 2), with a total of eighteen beds. They offer active and integral assistance through a multidisciplinary team, and also have the Home Care Service, which guarantees the continuity of the team's assistance to the patient outside the hospital environment.

The study was based on the follow-up of a female person, admitted to the Palliative Oncological Care clinic 2 (CCPO 2). The patient was identified as "*Kindness*", and she received this identification for her remarkable gentleness during the days she was under care.

The Palliative Performance Scale (PPS) score was applied; this scale is one of the tools used to quickly describe the patient's functional level and define prognosis²¹.

In total, there were eight meetings, including the day on which the interview was carried out, and they took place in August 2021. The study also had a field diary for notes on the consultations.

The research was submitted and approved by the Ethics Committee for Research on Human Beings in accordance with Resolution No. 466 of the Brazilian National Health Council (CNS) as Approval No. 4,789,220 and signature of the Free Informed Consent Form (FICF).

After accepting and signing the FICF, a semi-structured interview was carried out, divided into two moments: 1 - referring to sociodemographic data and 2 - referring to questions about occupations:

- *"Tell me how your life has been so far."*;
- *"Describe me what your occupations were like before you were hospitalized."*;
- *"What are the purposes of these occupations?"*;
- *"What are their meanings?"*;
- *"How is your life going at this time of hospitalization?"*;
- *"Describe me how your occupations are at this moment in life."*;
- *"What are the purposes of these occupations?"*;
- *"What are their meanings?"*; and

- "Would you like to add anything else?".

The responses were audio recorded, transcribed and analyzed using Bardin's content analysis method, which consists of techniques to analyze communications, with different forms and adaptations, in order to meet the demands of communications²².

Content analysis has three phases: pre-analysis, material exploration and treatment of results, inference and interpretation. The pre-analysis consists of organizing the material and aims to structure the ideas, identify and organize what is relevant to be used²². In this phase it is necessary to carry out: "skim" reading, choosing the documents, formulating hypotheses and objectives, referencing the indexes and elaborating the indicators, and preparing the material. The material exploration phase is the phase in which the researcher codes and categorizes the material. And then, it is about the results and interpretation, so that the researcher condenses the data provided by the analysis²².

RESULTS

Kindness' case

"*Kindness*" was 40 years old, had completed higher education, worked as a cook, divorced, Catholic, mother of a 15-year-old boy, who received the pseudonym "*Affection*". Prior to the illness, she lived in the state of Santa Catarina, Brazil, and returned to the municipality of Ananindeua, in the metropolitan region of Belém, Pará, Brazil, to live with her parents and son. She was diagnosed with gastric cancer, carcinoma type, with metastasis to the intestine. On the Palliative Performance Scale (PPS) score, she reached 20%;

"*Kindness*" worked in the kitchen of a restaurant, and also made sweets and snacks to supplement her income. When she was young, she dreamed of being a stewardess, but due to some interventions from her father, she decided to follow other paths, which in her father's opinion could bring a faster financial return, and which was in accordance with the socioeconomic reality of her family. The suggestion was for the an course in Data Processing, and *Kindness* did so; and only from then on, she opted for something that made more sense to her as a profession.

Kindness was a communicative, pleasant person, with easy speech and interaction; she liked to talk, to be around people. So, she chose to work with social events, more specifically as a ceremonialist. She also improved her knowledge about food, which was said to be very passionate about, being a great enthusiast since childhood and companion of her mother and her aunt in the kitchen, where she observed and learned everything that was in this universe.

At the age of twenty-four, she became the mother of “*Affection*”, while she was building her professional career, in the middle of a postgraduate course that she did not wish to interrupting, and thus continued to walk the path she had chosen. Her son was her faithful companion, and she was with *Kindness* at all times.

Before realizing she was ill, she lived in Santa Catarina, with her son, and worked in a local restaurant. *Kindness* mentioned that she was never afraid of change, that she felt adventurous and was always willing to change, as long as her son was with her, the only possibility of making her stop was if her son could not accompany her. Their relationship was supported by mutual respect, and whenever she spoke about her son, she emphasized how present and caring he was. In one of the meetings, she reported that she used to tell him “*the one who has Affection, has everything*”.

During one of her outings for dinner with her son in May 2020, in celebration of Mother's Day, to carry out one of her most significant occupations, the gastric cancer presented, at first, with a malaise. After performing some tests, a carcinoma was found. From then on, *Kindness* and *Affection* returned to their hometown, in Ananindeua, in the metropolitan region of Belém, in the state of Pará, Brazil, after a period away from other family members and friends, to start the treatment and thus have the closest support from everyone:

[...], I arrived from Santa Catarina on the 15th of August last year, almost a year ago. And when I got here, I said to my mother like 'look, I need an urgent endoscopy, I'm going to Belém for the exam, to take care of myself. I'm not going to Belém, [pause], for a vacation, I took forty days off at work, mom, to take care of myself.

At this moment, it is possible to notice a change and occupational rupture of personal and professional projects regarding the work activity, since before the illness, the participant lived in another state, working as a cook.

The first hospitalization occurred for the attempt of surgical treatment, however, given the tumor extension, it was not possible to obtain success in the procedure. *Kindness* was discharged with a referral for palliative chemotherapy and symptom control.

During this period, she stayed at her parents' house in the care of the family, however, with the progression of the disease and functional decline, she had to modify and adapt to the new care routine. Among these modifications, changes in the space where she lived to better meet the demands as they appeared.

In the most significant changes, the way of eating stands out, which became different from their understanding of their own body and illness:

My breakfast was just some porridge, milk with mashed biscuits in it, you know? Half a fruit, then a break, and let it sink, [...].

I ate, then I waited for the food to come back... am I going to defecate? Am I not? So then I could take a shower.

For having a health condition that threatened the continuity of her life, feelings of belonging were a way of experiencing the feeling of being alive. This was possible by spending these moments at home with family and friends. The occupational adaptations carried out in the routine favored the engagement in meaningful occupations, in particular, social participation. And so, the possibility of experiencing the illness process in an active and present way:

I wanted contact, and I wanted people to reach out and people to talk and everything.

My mother came from the kitchen: 'wow, today I wanted to make that mashed potatoes your son likes'. Then I would answer: 'do it, mom, he'll like it...' Then she would say: 'no, but I want the mashed potatoes you make, the ones he likes, that doesn't have the 'little lumps', that is smoother, how do you do it?'. Do you know? So, like, she came, [...], then, I said to her: 'Mom, this is the amount of potato, this is you how you mash them, like this, like this, [...].

And the most interesting thing is that my family has this feeling... it stuck. I mean: if she can no longer come here and sit in the kitchen, at least to see what we brought from the supermarket, we go with her first to decide what she wants, right? Different like that... I think it's a way for her to feel alive.

When asked about the meanings attributed to social participation and interaction:

This is a contact, right? What is important for a living being, right? Look, leaving the room, no longer having a television in the room, [...], and I watched the news with my father, I preferred to be with him.

So, this question of touching, of being there, look, seeing the color of the clothes that that person is wearing, discussing an issue, it's different from just listening.

During the interview, she tells an episode referring to the commemorative date of Mother's Day, in which she had the idea of producing small "kits" for orders, not only for financial support, but because the month and date were significant. Aware of the functional limitations, she followed through with the idea, but she had the help of family members to make it possible, and she organized it herself by adapting the steps of the occupation:

I was so well, that I received two orders of two cod soufflés, and I made that cod soufflé, like, [...], standing up, and it seemed like I had nothing, you know? I did it in my time, right? I organized everything, we made a list, we planned it well, [...], let's start this way so we don't get tired. We're going to need it, buy it in advance.

Kindness demonstrated her inclination to engage in meaningful occupations, always bringing the feeling of "being alive". At home, care was carried out mainly by her mother and sister, but the father and son were always close by helping with whatever was needed. The other family members and friends helped to provide support in case of hospitalizations, visits for exams and visits.

The son was present at different times, and *Kindness* considered it necessary for him to participate in good or bad phases of this process. Her only requirement is that her and her son not share the same room at night, so that sleepless nights would not interfere with his school performance. The night before her return to the hospital, *Affection*, without knowing it, asked to sleep in the same room with his mother. On the way to the hospital, on a call to the father, she passed on some health care that was part of his son's routine and that should be followed during her absence.

In less than a year, *Kindness* returned to the hospital. This time, she was admitted to the Palliative Care clinic. Even though her body was weak, she believed it was possible to revert the situation and return to chemotherapy, supported by her spirituality and, mainly, by her religiosity kept through habits and rituals created after the illness, along with the family, before being hospitalized, praying every day during the afternoon, at 3 pm. In one of her reports, she had ambiguous feelings about this new moment, and brought up spirituality as a coping mechanism:

[...], *I can say that it has been a decadence since May, like... Hm-huh. doyou understand? And I kept my spirit high. There, in terms of matter, it was decadence.*

Even if there was no cure, at that moment the most important thing was to live and enjoy each day. In itself, what was sought was to have the symptoms minimally controlled to live in the most active way possible, and thus be with the one you loved. She 'embraced' the prognosis, and took care of what was possible for her. It wasn't a possibility to reject or ignore what was going on, but assuming a position of passivity and seeing the days go by without her getting involved in every minute wasn't a possibility either. She sometimes referred to cancer, saying that "*it*" didn't like certain foods and she needed to respect it, and created strategies to make it possible.

During the ten days she spent hospitalized at the Palliative Care clinic, she brought lightness and serenity, showing herself calm and transforming the environment for her and the companions, giving new meaning to the space in her own way through her way of seeing each day as a opportunity to continue living.

Always very communicative and in the exercise of her autonomy, she is active throughout the process of procedures, medications and clinical conduct. She pays attention to each team visit and to the rotation schedule that she lovingly built with her friends and family to help with care.

Kindness had a care network within the hospital, of family members and friends, with a total of five people, who were organized in a rotation scheme, with the aim of minimizing the

overload with that care. She assumed this attitude of also taking care of the people around her, moreover, this organization was done by herself, seeking to respect the availability of each one.

It was clear how much her life and existence reverberated in everyone who met her. The exchanges carried out with companions during the meetings showed how she was special and loved. She was always kind to herself, to others, to the disease.

Kindness passed away two days after the interview for this research, on a Friday, at 7 am. The cousin who accompanied her during that moment when she passed, and who coincidentally was in the first days of the first hospitalization, mentioned that minutes before leaving, she said goodbye saying: “*That’s enough for me, [...].*”

From the reports, observations and field diary, the category was built: *Kindness and her occupational adaptations for social participation*.

DISCUSSION

Kindness and her occupational adaptations for social participation

The diagnosis of cancer offers unique representations in a person's life, as it is a disease that has biological and physiological complexities, in addition to being progressive and serious. Due to the associated stigmas, the diagnosed person lives the imminence of death, with reflections about dying and finitude²³. These reflections can generate suffering of a spiritual nature, anguish, fear, and the most diverse feelings regarding the loss of health that are different for each of the individuals who experience this experience²³.

In the case of a chronic disease, at a given moment, cancer can progress to PC, and throughout it all, between treatments, procedures, hospitalization, functional losses, there are also leaves of absence and loss of significant occupations.

In the reports, it was possible to notice that one of the occupational changes that occurred in the face of the illness was the way of eating. With the diagnosis, she chose to change her diet in order to allow digestion of food and remain satisfied. Even though there was a desire for other things that could harm her, she respected her own body and care for her diet.

Kindness referred to trying to know the limits of her body and what could be consumed, the speed at which she should eat and when she should stop. The occupational routine related to food became different, and the patient tried to deal with it in an appropriate and responsible way.

Because her diagnosis was of gastric cancer, and because she had a very affectionate and organic relationship with food and nutrition, she made changes in the occupational way of

carrying it out, whether in the amount of food ingested, or the speed at which she ate, or the types foods she consumed.

The science of occupation studies the involvement of man in meaningful occupations, and this as an occupational being²⁴. The occupations are part of everyday life, and are performed by an individual who gets involved based on a form, function and meaning¹⁶. The occupational form is the characteristics of each occupation, the selection and choice of execution of one type or another, defined solely by the person who performs it, within the representations that he or she assigns¹⁶.

Occupations are defined by the American Occupation Therapy Association²⁵ as activities that people engage in throughout their lives, in their daily lives, that represent some meaning and that from their involvement can bring quality of life, health, well-being, life purpose and social participation²⁵.

Occupation is a fundamental human need, to which people attribute meanings and adapt by learning to deal with new circumstances²⁶. The Structure of Occupational Therapy practice: domain and process²⁷, divides occupations into nine, namely: activities of daily living (ADLs); instrumental activities of daily living (IADLs); health management; rest and sleep; education; work; playing; and social participation.

In *Kindness's* case, losses and occupational changes occurred from the moment she received the diagnosis, in which she chose to leave the city where she lived and her professional career to start cancer treatment. Therefore, the first impact on her occupations, as a young adult in the productive phase, was at work. In this phase, young adults are focused on progressing within the field of work, with a view to reaching a desired place in the career they have chosen, and this process was interrupted by illness, treatment and hospitalization²⁸.

Occupational rupture occurs when there is a disturbance in the quantity and/or quality of a person's occupations due to a significant event in life, which may be due to illness, and interfere with emotional and social functioning²⁹. It should be said that the purpose of the return was to support family and friends.

Occupational disruptions from illness at a productive age, modified their social functioning, through which social participation began to have a new form, senses and meanings. Even though this break occurred in their professional plans and broke with personal and even social expectations, there was adaptation, since, in addition to professional roles assuming a certain importance in the lives of young adults, relationships are also important for a sense of belonging³⁰.

Social participation consists of getting involved in activities that include interaction with other people, or even, inserting yourself in daily activities and assuming social roles valued by a person or sociocultural context³¹.

Occupational adaptation is a social process that takes place over time, so that, involving an individual's conscious choice based on the influence of social relationships and relationships that people have with their environments, to modify and discover new ways of doing it³².

The family proved to be one of the main points of support, and who most favored occupational adaptations for participation. The family ties built throughout life favored following the paths of loss at that moment in life, even though the process of caring for a loved one in the final stage of life is complex, when accompanying the person who falls ill and the impacts of the illness on the day to day and other spheres of life. And they still need to deal with the possible loss of affective ties and manage their own suffering. Family members were able to think of these modifications to insert her into the environment.

Relationships with family and friends proved to be very important during the period of illness. A study with young adults aged between 19 and 24 years, after cancer treatment, showed how much relationships can be modified during cancer treatment, and how this condition is significant for this stage of development³². For *Kindness*, this contact was fundamental.

A study³⁰ revealed the loss of significant social, occupational and professional roles, in addition to the social isolation to which they are subjected. For *Kindness*, despite these obstacles, it was possible to observe situations of re-signification, based on occupational adaptations carried out on a daily basis, resulting in new ways of occupying oneself, which can make the experience of occupational engagement something powerful to help in the process of living so actively as possible while going through the process of finitude.

The occupation of being a 'Mother', perceived during the meetings as one of the most significant, was also modified by the illness. It is known that changes in occupations are something recurrent in people's lives after the diagnosis of cancer. As these are occupational roles that require mobility and interaction in a social context, they are often difficult to maintain or rescue³³. However, it did not become unfeasible to be exercised by *Kindness*, happening as a daily and important exercise, to remain a mother.

With the new hospitalization and the consequent interruption of chemotherapy, her great concern and one of the main factors that caused her suffering, came from the vivid presence of the idea of dying. This imminent death can generate suffering and spiritual crisis, thus, it becomes essential to be addressed as a health aspect within palliative care³⁴.

Spirituality is the way human beings seek to find meaning in their own existence and life. It is the unique and individual experience of each one with the sacred³⁵.

In a study based on Martin Heidegger's ideas, there is talk about how the experience of life and its meaning revolves around how much the individual gets involved with the environment, and this can take the form of engagement in meaningful occupations³⁶.

Occupations are presented as a therapeutic possibility for people who experience occupational interruptions, since they give meaning to human existence³⁶. Faced with an illness that threatens the continuity of life, in which patients seek to regain control of their own lives and find meaning, engaging in meaningful occupations and finding ways to make this possible is a possibility to ensure that patients can achieve comfort and well-being, and to deal with all the possible sufferings that go through the final phase.

In the case of *Kindness* and her family, it is possible to see the inclination to maintain and adapt occupations in the face of functional decline, and the impacts that this has on their experience of existing in a context where the loss of functionality and consequently the ability to carry out their tasks, which hinders their involvement in the world and reduces or transforms the meanings³⁶.

Therefore, adaptations in these occupations are necessary for the maintenance of significant occupations and, thus, the purpose of existing, since involvement in occupations assumes the role of bringing meaning to human existence.

CONCLUSION

It was identified that there are changes in the occupational universe in the person diagnosed with a progressive and incurable disease, among them changes, ruptures and occupational adaptations. Occupations have changed, giving way to other occupational forms. Among these occupations, for the participant of this research, social participation stands out.

It was revealed, from occupational adaptations in the environment in which the person is inserted, after contact with ruptures, that one can modify the meanings and give meaning to one's life, minimizing possible existential suffering, fear of death, psychic suffering and feeling of uselessness. In addition, the importance of relationships with family, friends and other peers to face this process, making the experience lighter.

The limitations found in this study are related to the difficulty of having access to the theoretical framework that addresses the audience of young adults in palliative care, which emphasize the losses and impacts that the illness can generate in their occupations and specific roles in this phase of human development. Also, because it is a case study, generalizations are

difficult, but possibly the data collected can serve as a basis for other studies that also include quantitative data, notably in young adults with cancer.

Despite this, in the aspect of Occupational Therapy in Palliative Care, there is an interpretation based on a case in a young adult, which can be a trigger for other investigations that expand the understanding of the practice in people with cancer in a hospital situation.

REFERENCES

1. Papalia DE, Olds SW, Feldman RD. Desenvolvimento humano. 8. ed. Porto Alegre: Artmed; 2006. 873p.
2. Papalia DE, Olds SW, Feldman RD. Desenvolvimento humano. 12. ed. Porto Alegre: Artmed; 2013. 800p.
3. Instituto Nacional de Câncer José Alencar Gomes da Silva. Coordenação de Prevenção e Vigilância. Incidência, mortalidade e morbidade hospitalar por câncer em crianças, adolescentes e adultos jovens no Brasil: informações dos registros de câncer e do sistema de mortalidade [Internet]. Rio de Janeiro: INCA; 2016 [cited in 01 Oct 2020]. 412 p. Available from: https://www.inca.gov.br/sites/ufu.sti.inca.local/files//media/document//incidencia_mortalidade_morbidade.pdf
4. Instituto Nacional de Câncer José Alencar Gomes da Silva. ABC do câncer: abordagens básicas para o controle do câncer [Internet]. 6. ed. rev. e atual. Rio de Janeiro: INCA; 2020 [cited in 5 Oct 2020]. 114 p. Available from: https://www.inca.gov.br/sites/ufu.sti.inca.local/files//media/document/livro_abc_6ed_0.pdf
5. Othero MB, Ayres JRCM. Resgate biográfico como estratégia de assistência a pacientes com condições neurológicas muito graves. Rev Ter Ocup. [Internet]. 2014 [cited in 5 Oct 2020]; 25(1):80-6. DOI: <https://doi.org/10.11606/issn.2238-6149.v25i1p80-87>
6. Reis CGC, Olesiak LR, Quintana AM, Farias CP. Repercussões profissionais e cotidianas do adoecimento em pacientes do sexo masculino com câncer avançado. Psicol Pesq. [Internet]. 2018 [cited in 5 Oct 2020]; 12(1):1-11. DOI: [10.24879/2018001200100315](https://doi.org/10.24879/2018001200100315)
7. Epelman CL. End-of-life management in pediatric cancer. Curr Oncol Rep. [Internet]. 2012 [cited in 5 Oct 2020]; 14:191-6. DOI: <https://doi.org/10.1007/s11912-012-0218-z>
8. De Carlo MMRP. Fundamentação e processos da terapia ocupacional em contextos hospitalares e cuidados paliativos. In: De Carlo MMRP, Kudo A, organizadores. Terapia ocupacional em contexto hospitalar e cuidados paliativos. São Paulo: Payá; 2018. p. 1-32.
9. Rezende G, Gomes CA, Rugno FC, Carvalho RC, De Carlo MMRP. Sobrecarga de cuidadores de pessoas em cuidados paliativos: revisão integrativa da literatura. Medicina (Ribeirão Preto) [Internet]. 2016 [cited in 5 Oct 2020]; 49(4):344-54. DOI: <https://doi.org/10.11606/issn.2176-7262.v49i4p344-354>
10. World Health Organization. Worldwide Palliative Care Alliance. Global atlas of palliative care [Internet]. 2nd. ed. Geneva: WHO; 2020 [cited in 5 Oct 2020]. 120 p. Available from: <https://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>
11. Frizzo HCF, Corrêa VAC. Perda e luto no contexto hospitalar e cuidados paliativos. In: De Carlo MMP, Kudo, organizadores. Terapia ocupacional em contexto hospitalar e cuidados paliativos. São Paulo: Payá; 2018. p. 387-98.
12. Lippe M, Linton B, Jones B. Utilizing a collaborative learning activity to sensitize interprofessional students to palliative care scopes of practice with adolescent and young adults. J Interprof Care [Internet]. 2018 [cited in 5 Oct 2020]; 33(2):267-9. DOI: <https://doi.org/10.1080/13561820.2018.1538108>

13. Humphrey L, Dell ML. Identifying the unique aspects of adolescent and young adult palliative care: a case study to propel programmatic changes in pediatric hospitals. *Semin Pediatr Neurol*. [Internet]. 2015 [cited in 5 Oct 2020]; 22(3):166-71. DOI: <https://doi.org/10.1016/j.spen.2015.05.006>
14. Penn A, Kuperberg A. Psychosocial support in adolescents and young adults with cancer. *Cancer J*. [Internet]. 2018 [cited in 5 Oct 2020]; 24(6):321-7. DOI: <https://doi.org/10.1097/PP0.0000000000000339>
15. Martins LK, Carvalho ARS, Oliveira JLC, Santos RP, Lordani TVA. Qualidade de vida e percepção do estado de saúde entre indivíduos hospitalizados. *Esc Anna Nery Rev Enferm*. [Internet]. 2020 [cited in 5 Oct 2020]; 24(4):e20200065. DOI: <https://doi.org/10.1590/2177-9465-EAN-2020-0065>
16. Yerxa EJ. Occupational science: a new source of power for participants in occupational therapy. *J Occup Sci*. [Internet]. 1993 [cited in 5 Oct 2020]; 1(1):3-9. DOI: <https://doi.org/10.1080/14427591.1993.9686373>
17. Espinosa IM, Gómez PS. Ocupaciones de tiempo libre: una aproximación desde la perspectiva de los ciclos vitales, desarrollo y necesidades humanas. *Rev Chil Ter Ocup*. [Internet]. 2006 [cited in 5 Oct 2020]; 22(2):259-65. DOI: <https://doi.org/10.5354/0719-5346.2010.110>
18. Jasmin E. Des sciences sociales à l'ergothérapie: mieux comprendre la société et la culture pour mieux agir comme spécialiste en habilitation à l'occupation. Quebec: Les Presses de l'Université du Québec; 2019. 352 p.
19. Rugno F, Bombarda T, De Carlo MMRP. Terapia ocupacional e cuidados paliativos oncológicos. In: De Carlo MMRP, Kudo, organizadores. *Terapia ocupacional em contexto hospitalar e cuidados paliativos*. São Paulo: Payá; 2018, p. 213-22.
20. Yin R. Estudo de caso: planejamento e métodos. 5. ed. São Paulo: Bookman; 2015. 271 p.
21. Victoria Hospice Society. Palliative Performance Scale (PPSv2) [Internet]. Columbia: VHS; 2004 [acesso em 31 dez 2021]. 3 p. Available from: http://www.npcrc.org/files/news/palliative_performance_scale_PPSv2.pdf
22. Bardin L. *Análise de Conteúdo*. São Paulo: LDA; 2016. 275p.
23. Chagas ACN, Oliveira LSM, Silva VSM, Corrêa VAC. Sobre os propósitos das ocupações de pessoas em cuidados paliativos oncológicos em um contexto hospitalar. *Rev Fam, Ciclos Vida Saúde Contexto Soc*. [Internet]. 2021 [acesso em 31 dez 2021] 9(Supl 1):190-201. DOI: <https://doi.org/10.18554/refacs.v9i0.430>
24. Palma O, Soto X, Barría C, Vucero X, Mella D, Santana Y, et al., Estudio cualitativo del proceso de adaptación e inclusión de un grupo de estudiantes de educación superior con discapacidad de la universidad de magallanes. *Magallania* [Internet]. 2016 [cited in 31 Dec 2021]; 44(2):131-58. DOI: <http://dx.doi.org/10.4067/S0718-22442016000200007>
25. American Occupational Therapy Association. Estrutura da prática em terapia ocupacional: domínio e processo. 4. ed. *Rev Ter Ocup*. [Internet]. 2020 [cited in 5 Oct 2020] 26(N Esp):1-49. DOI: <http://dx.doi.org/10.11606/issn.2238-6149.v26iespp1-4926>.
26. Caixeirinho JRM, Almeida CP, Quaresma CRP. Occupational participation and institutionalized elderly people. *J Occup Sci*. [Internet]. 2018 [cited in 31 Dec 2021]; 25(3):383-92. DOI: <https://doi.org/10.1080/14427591.2018.1465453>
27. American Occupational Therapy Association. Estrutura da prática em terapia ocupacional: domínio e processo. *Am J Occup Ther*. [Internet]. 2020 [cited in 31 Dec 2021]; 74(SUPPL 2): 1-49. DOI: <https://doi.org/10.5014/ajot.2020.74S2001>
28. Institute of Medicine. Identifying and addressing the needs of adolescents and young adults with cancer: workshop summary [Internet]. Washington, DC: The National Academies Press; 2015 [cited in 31 Dec 2020]. DOI: <https://doi.org/10.17226/18547>
29. Nizzero A, Cote P, Cramm H. Occupational disruption: a scoping review. *J Occup Sci*. [Internet]. 2021 [cited in 31 Dec 2021]; 24(2):114-27. DOI:

<https://doi.org/10.1080/14427591.2017.1306791>

30. Wallys A, Meredith P, Stanley M. Living beyond cancer: adolescent and young adult perspectives on choice of and participation in meaningful occupational roles. *Br J Occup Ther.* [Internet]. 2021 [cited in 31 Dec 2021]; 84(10):628-36. DOI:

<https://doi.org/10.1177/03080226209606>

31. Bedell GM. Measurement of social participation. In: Anderson V, Beauchamp MH, organizadores. *Developmental social neuroscience and childhood brain insult: theory and practice.* New York: Guilford Press; 2012. p. 184-206.

32. Nayar S, Stanley M. Occupational adaptation as a social process in everyday life. *J Occup Sci.* [Internet]. 2014 [cited in 31 Dec 2021]; 22(1):26-38. DOI:

<https://doi.org/10.1080/14427591.2014.882251>

33. Calice GB, Canosa HG, Chiba T. Processo ativo de morte: definição e manejo de sintomas. In: Castilho RK, Silva VCS, Pinto CS, organizadores. *Manual de Cuidados Paliativos.* 3. ed. Rio de Janeiro: Atheneu; 2021, p. 515-9.

34. Saporetto LA. Espiritualidade nos cuidados paliativos. In: Castilho RK, Silva VCS, Pinto CS, organizadores. *Manual de Cuidados Paliativos.* 3. ed. Rio de Janeiro: Atheneu; 2021. p. 531-4.

35. Koenig H. *Handbook of religion and health: a century of research reviewed.* Oxford: University Press; 2001. 724 p.

36. Larivière N, Quintin J. Heidegger and human occupation: an existential perspective. *J Occup Sci.* [Internet]. 2021 [cited in 31 Dec 2021]; 1-11. DOI:

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