Occupations and meanings in oncological palliative care: the case of "Nobreza" in the process of finitude

This study aimed to analyze the role of the Occupational Therapist and to understand the meaning of the occupation for a patient in oncologic palliative care. This is a qualitative research, single case study type carried out with a patient in oncology palliative care, denominated as "Nobreza", hospitalized in a university hospital. The data collection took place with 15 meetings from the instruments: open interview, socioeconomic questionnaire, and occupational therapeutic meetings. The analysis of the data occurred through the thematic analysis of content, and two categories of analysis were generated: 1) Meaning of finitude-involving faith, acceptance of dying and its procedural losses; and, 2) Meanings of occupations learning, perpetuation, and affective exchanges. The possibilities of the Occupational Therapist in palliative care are discussed, from an occupational science perspective. The study brings a reflection that people in cancer palliative care can be accomplished through doing, creating, living, feeling, expressing, and being busy. 

Descriptors: Medical oncology; Palliative care; Occupational therapy.

Este estudio tuvo como objetivo analizar el papel del Terapeuta Ocupacional e comprender el significado de la ocupación para una paciente con cuidados paliativos oncológicos. Trata-se de una pesquisa de abordagem qualitativa, do tipo estudo de caso único realizada com paciente em cuidados paliativos oncológicos, denominada como "Nobreza", internada em hospital universitário. A coleta de dados deu-se com 15 encontros a partir dos instrumentos: entrevista aberta, questionário socioeconômico e encontros terapêuticos ocupacionais. A análise dos dados se deu através da análise temática do conteúdo, o que gerou duas categorias de análise: 1) Significados da finitude-envolvendo fé, aceitação do morrer e suas perdas processuais; e, 2) Significados das ocupações-aprendizado, perpetuação e trocas afetivas. Discutem-se as possibilidades do Terapeuta Ocupacional nos cuidados paliativos, a partir de uma perspectiva da ciência ocupacional. O estudo traz a reflexão, o fato de que, as pessoas em cuidados paliativos oncológicos podem realizar-se por meio do fazer, criar, viver, sentir, expressar, ocupar-se.

Descritores: Oncologia; Cuidados paliativos; Terapia ocupacional.

Este estudio tuvo como objetivo analizar el papel del Terapeuta Ocupacional y comprender el significado de la ocupación para una paciente con cuidados paliativos oncológicos. Se trata de una investigación de abordaje cualitativa, del tipo estudio de caso único realizada con paciente en cuidados paliativos oncológicos, denominada como "Nobreza", internada en hospital universitario. La recolección de datos se hizo con 15 encuentros a partir de los instrumentos: entrevista abierta, cuestionario socioeconómico y encuentros terapéuticos ocupacionales. El análisis de los datos se hizo a través del análisis temático del contenido, lo que generó dos categorías de análisis: 1) Significados de la finitud-implicando fe, aceptación de morir y sus pérdidas procesuales; y 2) Significado de las ocupaciones-aprendizaje, perpetuación e intercambios afectivos. Se discuten las posibilidades del Terapeuta Ocupacional en los cuidados paliativos, a partir de una perspectiva de la ciencia ocupacional. El estudio trae la reflexión, el hecho de que, las personas con cuidados paliativos oncológicos pueden realizarse a través del hacer, crear, vivir, sentir, expresar, ocuparse.

Descritores: Oncología médica; Cuidados paliativos; Terapia ocupacional.

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INTRODUCTION

Cancer is the name for a group with more than 100 diseases that have the disordered growth of cells that invade the tissues and organs as intercession and can spread to other parts of the body1.

There are advances accompanying the treatment of cancer, which involves the use of surgery, radiotherapy, chemotherapy or bone marrow transplantation, in many cases, it is necessary to combine more than one modality. However, according to estimates, the survival rate for neoplasias until 2014 would be 66% in general, which points to the death of a third of cancer patients2.

This reality evidences that people will experience cancer without a curative perspective and, therefore, they will demand care that is not turned to cure, but rather to the quest to reduce emotional conflicts, to adjust their routine according to the difficulties found, to provide continuous attention both to the patient and his relatives, in the search for an improvement in the quality of life that also involves death without great suffering.

In this scenario, there is the Palliative Care with principles such as pain relief and other stressors symptoms; reaffirmation of life and perception of death as a natural process; it is not intended to anticipate or delay death; it integrates psychosocial and spiritual aspects to care; it works as a support that assists the patient to live actively until death as well; it provides assistance to families to feel supported throughout the disease process3.

In cancer patients, palliative care treatment focuses on pain relief, which improves sleep and mood, as well as physiological changes such as increased or decreased local blood and lymphatic circulation, as well as feelings of well-being and relief of psychic tension4,5.

As the disease progresses and the responses to curative treatment decrease, palliative care provides social, physical, psychic and spiritual comfort, alleviating suffering and improving the quality of life of patients and family/caregivers6.

It is understood that people experiencing the process of finitude before a disease without therapeutic possibilities of healing, and in an advanced phase can lose the sense of living and accomplishment. Thus, many of them reduce the engagement in occupations, and with that, one of the goals of the Occupational Therapy professional in palliative care is to favor the stay of occupations of these people, as long as it is significant and possible, adapting the performance and/or execution of the tasks to their difficulties.

In a survey conducted in the database of the Virtual Health Library (VHL) Research Portal, in 2014, searching for articles in Portuguese referring to the period of 12 years (2002 to 2013), using as a descriptor “oncologic palliative care”, there were a total of 46 articles included, of which 15 were discarded, since they were repeated, leaving only 31 articles for analysis.

Among the 31 articles, 16 (51.61%), referred to the thematic: (4) vision of the professional in palliative care; (2) bioethics and palliative care; (2) resource used in palliative care; (2) patient expectations in palliative care; (1) palliative care guidelines in Brazil; (2) clinical complications of patients in palliative care (depression and hypodermoclisis); (1) clinical and therapeutic analysis of cancer patients; (1) scientific production in palliative care and (1) behavior of the National Cancer Institute (INCA) in palliative care.

In general, it was verified that only 2 articles of this survey were directly and strictly related to oncologic palliative care. It should be noted that none of them had occupational therapy as an area of knowledge. Most articles belonged to Nursing, 13 (41.93%), the others were divided into Medicine (5), Psychology (2), Physiotherapy (2), Nutrition (4) and Pharmacy (1).

Thus, the Occupational Therapy published little in the period studied, on Palliative Care in the intercession with Oncology. However, it is considered the profession of paramount importance in the area, and that needs to act and produce knowledge in this field, for the propagation of
methods, experiences, and information on occupational issues involving people in cancer palliative care.

The International Society of Occupational Science defines occupation as several daily actions carried out by individuals, families, and communities, who occupy their time and give meaning and purpose to life. Occupations include things that people need, want and expect them to do.

The occupation is conceptualized as groups of activities and tasks of daily life, with value and meaning conferred by individuals and by a culture; it integrates the daily life of the people and the culture to govern it. Occupations can be considered to involve human existence from birth to death and have different meanings and purposes of achievement, which are sources of study and intervention by the Occupational Therapist.

Regarding the meanings of the occupation, Clark, et al. explain that:

“Occupations are meaningful to people because in part they become projects and through them, they can express emotions.”

When studying the meaning of occupation, there is an interest in observing how feelings emerge through everyday occupational experiences and how they are linked to life stories.

Therefore, knowing the meanings of occupations becomes important when Occupational Therapists seek to structure their possibilities of action in several fields, such as palliative care, in which the experiences of occupational involvement go through a process of severe illness and without perspective of modifying therapy of the disease, requiring specialized attention, and to be attentive to the singularities experienced in such a process. One of them is the finitude.

In these singularities, the interest in developing this research, which emerged during the graduation in Occupational Therapy at the University of the State of Pará (UEPA), was discovered from practical curricular experiences in a reference hospital in oncology, and from participation in a group of mourning study, in a university hospital of the city.

It was also instigated to problematize how the occupations in the process of finitude, people with advanced cancer in palliative care are presented, and to know their meanings, besides investigating the role of the occupational therapist in this scenario.

The involvement of Occupational Therapy with occupations of people based on the Occupational Science is necessary since the rationale of each knowledge supports the total understanding of the man as occupational being - a perspective adopted in this study.

This study aimed to analyze the role of the Occupational Therapist and understand the significance of the occupation for a patient in oncologic palliative care.

METHODS
This is a qualitative research, of single case study type, having an open interview, questionnaire and occupational therapeutic meetings as an instrument for data collection.

The case study was chosen in this research because it permeates the proposed objectives, aiming at the individual as a single person, respecting his singularities and subjectivities. However, it is worth mentioning that at no time was the scientific rigor required for the validation of the data obtained sought to be simplified.

In case of studies, the focus is on contemporary reality, “how” and “why” questions are requirements of the research problem. It works the subjectivity in the search for scientific knowledge, being a direct observation of the researcher. The case study is characterized by the interest in individual cases and not by the research methods it may cover.

The research was carried out at the Oncology Palliative Care Service (SCPO) of the High Complexity in Oncology Care Unit (UNACON) of the João de Barros Barreto University Hospital (HUJBB) in Belém do Pará, Brazil.

It was constituted through the follow-up of a patient admitted to the clinic of infectious diseases or DIP (infectious and parasitic
In this methodological proposal, there was no delimited planning, since the interventions happened from the explicit necessity of the participant in each research meeting that lasted around 60 to 120 minutes.

Data collection was held in one month. The records were done in field diaries referring to the facts considered relevant to the study and the impressions through the stages and experiences during the data collection.

Recordings and photographs were used to record the meetings and productions. Consultations to the participant's medical records also occurred for the knowledge and clarifications regarding the clinical case.

The triangulation of the data was obtained through interviews, questionnaire, and occupational therapy meetings. This phase of the research preceded the analysis of data and allowed the organization of the sources of evidence. Data analysis followed the steps: data ordering, data classification, and final analysis.

RESULTS
From the analysis, it was possible to create categories of analysis that elucidated the understanding of the meanings that the patient gave to the occupations in the process of death and dying: Meanings of finitude - Spirituality in the process of finitude, acceptance of death and total pain; Meanings of the occupation - Learning, ways to perpetuate and space for affective exchanges.

Meanings of finitude: spirituality in the process of finitude, acceptance of death and total pain.
The apprehension of the dimension about how Nobreza faced the process experienced was revealed:

"Everything in my life was God's purpose, and I understand that if I am here it is because God wants it. It is the beginning of the preparation for something God is calling me. Only He saves. I am going to a space that God has reserved for me. I am being renewed and prepared. Now it's a new day, new things are happening, now I'm having the opportunity to do what God wanted for me, and I'm getting ready for it. Only God knows the things, the time, and I'm waiting, the disposition, preparing myself psychologically, mentally for what would happen. "He allowed me to be here."

The development of the meetings was in accordance with the availability, motivation, and interest of Nobreza to develop or close each meeting, respecting her involvement and clinical conditions that were determinant for the research.
Another meaning provided by Nobreza to finitude involving the concept of total pain may be considered the last meeting with her, in which her son stated that the mother said the desire to die soon.

Thus, Nobreza was questioned about the reasons for this desire. In response, she stared, expressed her denial, but did not respond verbally, she was silent. She was asked about some pain, and she replied: “No ... I do not know what I’m feeling ... It hurts everything ... “.

Meanings of the occupation: learning, ways to perpetuate and space for affective exchanges

In the first meeting, when she was asked about how she would like to be busy, Nobreza questioned:

*What kind of thing? What do you have there? After clarifying, she said: I can teach you the crafts, which I did ... Would you have it there?*

After the production of necklaces of this meeting, being the production of elected crafts, available in figures I and II, we inquire about the meaning of carrying out such occupation. And then, as she always did, Nobreza looked thoughtfully at what she did and replied,

It was good ... I was a hippie and a homeless person, I did this... (Notalgia feeling).

The demonstration of satisfaction in performing this occupation - noting that making crafts characterized the occupational therapeutic meetings with Nobreza - the pleasure she felt, and how she was doing well was made explicit in short but self-explanatory sentences at different times, such as when she asked us if we would meet each other the next day, because she had missed the meeting in the weekend. And on another day, when she said:

“I missed you yesterday ... “.

The research enabled the perception and approximation of another meaning given to the occupations that Nobreza performed: to pass on what she knew, her experiences and abilities:

*I want to teach people to leave something here, a teaching, a learning, so when you teach someone, you will remember me. It’s so good when you can tell people what you know, and not save it for yourself.*

At that moment she was teaching us to make handicrafts with seeds, as shown in Figure III.
These reports emphasize another meaning of the occupations chosen by Nobreza during the research: learning since through her knowledge in manual activities he began to find in this opportunity the possibility of passing on techniques, forms of work and commercialization of the products. Therefore, taking care of teaching the researchers how to make and market costume jewelry and handicrafts was configured as a significant occupation for Nobreza.

Nobreza also informed her desire to create a foundation to teach people: “Industrial Foundation Confection of Art”.

In the relationship of being perpetuated, Nobreza still chose to present people she considered important. She reported her desire to make a present for the doctor accompanying her, for the caregiver of the patient in the bed that shared the ward with her, and for us researchers, as in Figures IV and V.

It is observed that, although Nobreza did not have complete independence (as for bathing, personal hygiene), she was autonomous, evident in the orders that directed to the son, demanding to be attended. She was surprised when this did not happen: “My love! I’m talking to you! Take my diaper, get it ready, put it up here... You would not obey me, do as I say...”


**DISCUSSION**

From the report, it is observed that Nobreza is anchored in spirituality to reveal meanings provided to her process of finitude, in which she is supported in a divine force and sought to accept her situation by claiming that it was God who wanted her in the hospital. She withdrew all judgment about her life and all that she had lived and from that moment she wanted to feel a new person, realizing and
accepting the will of God in her life. It was expressed that the meaning of her existence and the circumstances she experienced was permeated by divine interventions involving spirituality.

In turn, spirituality is to move towards a final meaning, an ontological transcendence, that is, it is related to questions related to the end of life, its meaning and relationships with the sacred and the transcendent. Spirituality is part of human nature, and it should be revealed by experience and individual discoveries. It is different for each individual and may appear as a purpose of life, connection with a force, something greater, self-knowledge, and it may or may not be linked to religion and its practices.

In this sense the meanings of finitude for Nobreza also involved the experience of acceptance of death, directly related to her spirituality, as she expressed in reports that she was hospitalized by the will of God, or when she said that all that happened was by “His” will, being there was part of a purpose for which she was subject to follow, therefore, she accepted to experience it.

According to the literature of the stages of death, acceptance is the one in which the patient begins to accept his situation and his destiny. Thus, Nobreza was in this period, because the verbal expression of her health condition, the revelation about accepting the divine designs for her life, the perception of being hospitalized, being attended by the palliative care service and aware of her diagnoses and prognosis, characterize the acceptance of death.

A survey conducted with elderly women on cancer palliative care confirms that acceptance of the death and dying process, as well as the need and desire to share experiences about what they experience, is explicit in the conditions of disease progression.

Total pain is characterized as the set of factors that define the suffering of the patient, being physical, represented by pain and other symptoms referring to the body; psychic, referring to the loss of autonomy, anxiety, anticipatory mourning; social, related to dependence, social isolation, family and economic issues; besides religious and spiritual aspects.

In this sense, it is understood that Nobreza perceived the increasing progression of her illness, which aggravates each day with greater weakness and less functionality, making her give up or convinced that to go home would not be possible anymore. These perceptions in some way conferred on her experiences of pain that went beyond the physical realm of; for example, oncological pain and reached the psychic, social and spiritual sphere, culminating in the verbalization that her pain was widespread.

Pain and suffering need priority in the hierarchy of health care system, and care means support for the condition of the other, and it is an affirmation of the interest in their well-being and the commitment to do everything possible for the situation. To care for the other is to give him “time”, attention or something that can contribute to making the situation less painful and inhuman. Therefore, caring should take precedence over healing.

It is believed that the research and its interventions became vehicles of care for Nobreza since it enabled reflections on her experiences through the questions raised, as well as, through the occupational therapeutic meetings that fomented the freedom of choice in what engagement in significant occupations for the participant.

Handicraft was her former occupation of labor, and she mentioned that she had been the source of income for her family for many years, and she encouraged the construction of her own house.

After explaining her interest in dealing with handicraft activities, the resources were available for this purpose. It was verified that when coming in contact with the tools and materials of the crafts, Nobreza showed in every detail how memories were being rescued in that contemplation, a nostalgia of the times in which she made handicrafts and marketed them.

In this experience, it was explicit that occupations are forms of enrichment of the human being, devices that enhance participation and social inclusion, demanding
capacities, materials and establishing internal mechanisms for their performance\textsuperscript{18}. They also provide new experiences, based on the memories that the subject reveals when she comes into contact with the actions, relationships, tools and materials that may involve an occupation, or in the execution of the occupation, enabling new ways of perceiving it.

Being aware of a person's needs in their process of finitude, and the meanings they assign to their life and their occupations, are important factors in palliative care, since occupations are routine and familiar things that individuals are involved and even do the end of life, they reflect the unique characteristics of each person, since occupations fill their time and give them meaning\textsuperscript{19}.

When assigning "nostalgia" as a meaning for the making of costume jewelry, Nobreza allowed us to consider this affirmation as the rescue of several moments throughout her life, as for example: memories of periods that involved the whole process aimed at the occupation of labor as an artisan; purchase of materials; confection and sale; and, the relationships that established between being a craftsman and living in street situation.

In this sense, engaging in jewelry making could express the occupational involvement of Nobreza, with an occupation full of meanings and at the same time not only characterized as the occupation of work but somehow, told and expressed who was and what made throughout her existence, generating in it the feeling of well-being.

From an occupational perspective, feelings of well-being originate from the things people do, providing a sense of vitality, purpose, satisfaction, and fulfillment\textsuperscript{18}. That is, well-being comes from the moment in which the person performs a certain occupation that brings him, for example, personal satisfaction, and sense of life, leading to the encounter of good feelings, such as nostalgia.

The involvement of Nobreza with the proposals of the research and interventions was significant, since knowing that she missed the meetings confirmed that in some way, the proposal was making a difference in the period of hospitalization, consequently, in the process of being in oncological palliative care.

The ability to develop meaningful occupations is associated with increased well-being and these tasks must meet the basic needs, such as social and personal\textsuperscript{21}.

However, for a job of this size, the patient establishes the objectives and priorities in his process of finitude, thus, the professional's function is to enable him or her to accompany him or her to achieve the identified goals\textsuperscript{22}, priorities that can change drastically with time, and it is up to the professional to be aware of such changes and at the same time sensitive to relate the needs of these people to the possibilities of effective fulfillment.

The occupations are forms of enrichment of the human being, devices that potentiate the participation and social inclusion, demanding capacities, materials and establishing internal mechanisms for its performance\textsuperscript{23}. They provide new experiences, starting from the memories that the subject creates when he comes in contact with the material, enabling new perceptions about the experience.

Occupations are tasks aimed at goals that will normally extend over time, having to mean for performance, and involving multiple tasks. Also, occupation is the principal means that people develop and express their personal identities\textsuperscript{24}.

A new meaning is signified to be busy in the making and teaching of handicrafts, which was to be perpetuated, to want to leave something of himself, his mark, besides the teachings, that would be a way to materialize by doing, because although people die, they are perpetuated through their actions and ideas\textsuperscript{25}.

Providing significant people in palliative care are also ways that reveal farewells, at this juncture, occupations such as making gifts occurred in research in which an elderly woman in palliative care also presented the team that accompanied her during hospitalization, moments before discharge, expressed that all his thanks were in that gift in the form of love\textsuperscript{14}. 
The meaning of the experiences can also be influenced by innate conditions of the person that impel him to certain styles of occupations and not to others, and that can be related to previously constructed meanings throughout his life cycle.

Thus, the experience of perpetuation can be related to the opening of occupational possibilities that could involve, for example, leisure and/or social participation for Nobreza and that gave her senses and meanings related to the condition of proximity with the finitude. In this conjuncture, the gifts become forms of recognizing the game as non-extendable and being able to find ways to experience it with affection for those who remained.

On the other hand, the occupational experiences of work through the handicraft and that were somehow rescued by Nobreza in this study became forms of the perpetuation of her life, in the opportunity to show, as the labor involved for many years, opportunity to relive some experiences, even if hospitalized.

Nobreza could have been involved in a range of other occupations since there was such freedom in research. However, the same freedom was the propeller of a style of occupational involvement aimed at dealing with handicrafts in their different forms, and in doing opted to pass on their knowledge, to give people and to generate personal satisfaction for the feelings she has received.

These experiences were possible even Nobreza experiencing palliative care and in the process of hospitalization, which is related in an important way to one of the principles of palliative care that is to provide the patient, to live as actively as possible until their departure.

Even with a diversity of definitions to the term occupation, it is possible to observe that living is a continuous occupation. By objectively understanding, or not, the meanings of their occupations, the human being lives in an incessant search for new doings.

According to the Science of Occupation - an academic subject with the purpose of studying man as an occupational being:

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*Occupation is characterized by all daily activities that can be culturally recognized and that fill people’s time.*

Occupations are fundamental to the individual’s identity and sense of competence, occurring in contexts and influenced by the interaction between client factors (values, belief, spirituality, body functions and structure), performance (motor of process, performance skills and social interaction) and areas of performance.

In this sense, it is considered important to understand the science of occupation and its perspectives, as it allows the occupational therapist to enhance the knowledge about the vision of man as an occupational being, expanding his understanding of how man seeks to be busy.

From this, he builds his life, projects, and possibilities of performance, as well as, it allows to problematize the intercessions that can be made in human life in the face of the different circumstances: birth, illness, the cycle of human life, including dying.

As occurred in the study with Nobreza, in which the occupational therapeutic meetings evidenced the recovery of feelings and values, for example, when she talked about her former occupation, the craft, and her mood changed. There was great satisfaction in commenting on the subject, her creations and experiencing it again.

The role of the occupational therapist in addressing a cancer patient should consider all of their feelings, thoughts, and life goals. He needs to understand the patient in the broad and real sense of the word and to take care of him with wholeness.

In patients on cancer palliative care, these perspectives become even more significant as the threshold of living is coming to its end: death.

Considering that Occupational Therapy is supposed to understand this integrality of the subject, Palliative Care requires the development of studies with this view, since this reality involves the singularity of the individual who is in the process of finitude, and he needs to know and explicit wishes and needs, which also involve the field of occupations.
The occupational therapist provides the person in palliative care with the maximization of self-control, as well as the possibility of adjusting to the situation and the environment, assisting the patient in the establishment and prioritization of life goals, to maintain the identity of being productive and active, competent in functional performance and participation when making decisions.

It is very difficult for the person who is in the process of dying to have possibilities to solve the issues of life. Thus, the occupational therapist in palliative care helps the person in creating opportunities for the planning of death as well as in the patient and family relationship preparing them for departure.

In this research, the differentiated look, the exposure of feelings was evidenced by the occupations through the making of handicrafts.

Experiences with Nobreza do not limit the interventional possibilities of the Occupational Therapist in Palliative Care, since the meetings could directly support other occupations by providing for the execution or the training, for example, daily life activities (bathing, personal hygiene, dressing (caring for others, managing communication, financial, maintaining health), provided that it was within the scope of performance and desires of Nobreza, which is not revealed in the meetings with her.

Occupational Therapy anchored in the perspective of Occupational Science can analyze how human beings understand their occupations, the motivations, and meanings for it, which involves the existential and cultural understanding. It is a delicate work because it is a personal experience revealed from the reflection on participation in certain occupations.

CONCLUSÃO
When the look of the Occupational Therapist’s clinical practice based on Occupational Science in this study was based, the meaning of the occupation was valued, and allowed to understand the relevance of the proposals and paths adopted, revealing in the hall of significant occupations.

In the experience with Nobreza, such occupations could and did need to be rescued, unveiled and proportioned before their condition of serious illness and without the perspective of curative treatment, giving and teaching.

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