ORIGINAL ARTICLE

PERCEPTIONS OF PATIENTS UNDERGOING PALLIATIVE CARE ABOUT THE OCCUPATIONAL IMPACTS EXPERIENCED IN CANCER

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Highlights: (1). Occupational repercussions for patients undergoing palliative care involve interruptions and changes in performance. (2). There is a central role in performance focused on activities of daily living, denoting the experience of an occupational imbalance. (3). The occupational repercussions experienced impact aspects such as satisfaction, beliefs and adaptive difficulties, configuring a potential additional element of suffering in the oncological experience.

PRE-PROOF

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PERCEPTIONS OF PATIENTS UNDERGOING PALLIATIVE CARE ABOUT THE OCCUPATIONAL IMPACTS EXPERIENCED IN CANCER

ABSTRACT

Objective: The aim of this study is to describe the main occupational repercussions experienced by people undergoing oncological palliative care and to reflect on the impacts. Method: This is a descriptive, cross-sectional study with a qualitative approach, in which the participants were 6 patients over 18 years of age, diagnosed with cancer and receiving palliative care from a home care service. Data collection used a characterization form and an interview guide, with individual interviews conducted during a single meeting in the patient's home. The data from the interviews were categorized, described, and interpreted based on the fourth edition of the Occupational Therapy Practice Framework: Domain and Process document. Results: The average age of the participants was 56.5 years, with the time since receiving the cancer diagnosis varying between 9 months and 13 years. In most cases, participants had been undergoing palliative care for less than 6 months. Two analytical categories were systematized: 1) Occupational repercussions experienced as a result of cancer, in which both interruptions and changes in performance patterns were observed; 2) Impacts of occupational repercussions: understanding the representations intertwined in the experience of losses, in which implications of occupational modifications associated with aspects of satisfaction, beliefs, and adaptive difficulties linked to the disruption of occupational roles were verified. Conclusion: Considering the repercussions and losses experienced as an aspect of potential additional suffering, it is deemed necessary to incorporate the occupational dimension into care planning, in addition to encouraging further research in this area.

Keywords: palliative care; cancer; daily activities; occupational therapy.

INTRODUCTION

Cancer affects an increasing number of individuals, even with the scientific and technological advances that have significantly improved cancer treatments[1].

According to the International Agency for Research on Cancer (IARC)[2], in collaboration with the Global Cancer Observatory (GCO), on a global level, almost 20 million new cases of cancer were identified in 2022. When considering the estimate for the year 2050, increasing indicators are predicted, with a projection of 35 million new cases diagnosed, considering all age groups and genders.

In the same vein, in Brazil estimates related to mortality from oncological diseases point to an upward growth, with the National Cancer Institute (INCA)[1], in partnership with the Ministry of Health, presenting a forecast of 704 thousand new cases of cancer for the 2023-2025 triennium.

In regard to the care guidelines, the World Health Organization[3] points out that assistance in the oncological context must be supported by basic points that include prevention, diagnosis and treatment, with palliative assistance being part of the recommended care structure. Access to therapies aimed at curing cancer is the right of individuals diagnosed with cancer, and together with disease-modifying treatment, palliative care is recommended[4].

The importance of the current palliative care model is reaffirmed, and proposes that the provision of care measures aimed at alleviating suffering related to the illness process be carried out early, preferably after diagnosis. Cancer affects the body by reducing functionality and restricting activities, impacting human beings in a multidimensional way. Therefore, the care provided by a multidisciplinary team seeks to help the patient live as actively as possible until death[4,5].

An investigation into the association between quality of life and occupation analyzed the skills of activities of daily living (ADLs) of people with advanced cancer, finding a significant association between greater motor capacity in ADLs and better quality of life, reinforcing the close relationship between the two[6]. Another cited study, carried out with occupational therapists, managers, and researchers in the area of Occupational Therapy in palliative care, based on a conceptual mapping of effective therapeutic intervention aimed at occupational repercussions, determined that five aspects are essential: (1) being person-centered; (2) promoting occupational engagement to optimize quality of life; (3) involving the social and relational environment; (4) enabling occupations; and (5) enabling occupational adaptation[7].

Although it is not configured as a simplified process – as it encompasses a subjective experience, loaded with personal, cultural and social values –, the analysis of the way in which individuals understand and articulate their occupations, motivations and inherent meanings is fundamental to obtain a deeper understanding of the human being[8], which indicates that the exploration of such aspects are relevant as a research axis for the provision of care practices that come improve the desired holistic care.

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Considering the multidimensionality of suffering, which can be physical, psycho-emotional, social, and spiritual in nature, this study focuses on exploring aspects linked to the occupational dimension of suffering, with the objective of describing the main occupational repercussions experienced by people undergoing oncological palliative care.

METHOD

This is a descriptive, cross-sectional study with a qualitative approach, carried out in a Home Care Service (HCS) of a public hospital that is a reference in oncology in the state of Pará, Brazil.

The inclusion criteria were patients aged 18 years or over, diagnosed with any type of cancer, undergoing palliative care, who expressed interest in participating in the research. Patients who were hospitalized at the time of data collection or who presented cognitive changes that made it impossible to respond in a structured manner were excluded.

The research instruments involved a sociodemographic and clinical characterization form and an interview guide, both developed by the researchers. The characterization form covered information such as name, date of birth, education, profession, marital status, telephone number, diagnosis, information on symptoms, length of follow-up by the HCS, type of treatments performed, as well as the Palliative Performance Scale (PPS)[9] score, which evaluates the patient's functional performance in palliative care.

The interview guide involved questions focused on occupations, before and after the illness, factors associated with possible changes that occurred with the illness and treatment process, as well as meanings attributed to occupational changes.

The instruments were evaluated by two judges, characterized as occupational therapists with experience in palliative care and home care. After analytical feedback from the judges, a pilot test was carried out. Such procedures highlighted the need for adjustments associated with simplifying questions, changing terminologies and modifying the ordering of questions to better achieve the outlined objectives.

The research was disseminated by a HCS professional to patients registered with the service and, based on the expression of interest, the researcher made telephone contact with the patient to schedule an interview. Data were collected from September to November 2022,

with the interviews carried out in a single meeting and individually, at the participant's home. The number of participants was defined based on convenience criteria, limited to patients assisted by the HCS who met the inclusion criteria and expressed availability within the schedule established for the research.

The information in the participant's characterization form was systematized in a descriptive way supported by simple quantifications. Data from the interviews were categorized, described and interpreted based on the American Occupational Therapy Association (AOTA) document known as: The Occupational Therapy Practice Framework: Domain and Process 4th Edition[10].

This study complied with the precepts of Resolution No. 466, of December 12, 2012 and Resolution No. 510, of April 7, 2016 of the National Health Council in accordance with the standards for Research Involving Human Beings. The research subjects were duly informed about all aspects of the research through the Free and Informed Consent Form (ICF), which explained the objectives, method and data collection procedures. The ICF was read to the participants of this research, in accordance with the precepts of the Declaration of Helsinki and the Nuremberg Code. The study was approved by the Human Research Ethics Committee of the Federal University of São Carlos according to ruling no. 5,469,642.

RESULTS

The participation of 6 patients in palliative care (4 women and 2 men) followed by the HCS of a reference oncology hospital in the northern region of the country was obtained.

Regarding the sociodemographic profile, the average age of the participants was 56.5 years old, with the youngest age being 39 years old and the oldest being 82 years old. Regarding marital status, 4 participants stated that they were married, 1 was widowed and 1 was divorced. Regarding education, 3 participants stated that they had incomplete primary education, 1 had incomplete secondary education, 1 had completed secondary education and 1 had completed higher education. In regard to religion, almost all participants reported being evangelical (n=5), one was Catholic. Four of the participants stated that they were retired.

Regarding the clinical profile, there was a diversity of oncological diagnoses (stomach cancer, breast cancer, cervical cancer, sigmoid colon cancer, and two diagnoses of prostate cancer). The time since receiving the oncological diagnosis varied between 9 months

and 13 years, however, in most cases, the participants had been undergoing palliative care for less than 6 months, with functional status ranging from 30 to 60 in the Palliative Performance Scale classification, a factor indicative of functional aspects involving impairments, at different levels, in mobility, in the performance of routine activities and self-care.

The content of the interviews gave rise to two analytical categories known as: "Occupational repercussions experienced as a result of illness and/or cancer treatment" and "Impacts of occupational repercussions: understanding the representations intertwined in the experience of loss", which are detailed below.

Category 1 - Occupational repercussions experienced as a result of illness and/or cancer treatment

The participants expressed that they noticed, from the illness and cancer treatment, repercussions in their occupations. Such modifications were reported regarding both interruptions and changes to assisted occupational performance.

It was found that there was a tendency towards a total interruption of instrumental activities of daily living (IADLs) focused on aspects of setting up and managing a residence (e.g., cleaning the house, washing clothes), preparing meals and housework, mobility in the community, as well as occupations related to work and education (Table 1).

Table 1 - Interrupted occupations.

Interrupted Occupations	Excerpts from the participants' remarks
IADLs	[...] I liked doing my things, cleaning my house, cooking [...] but now I can't do it. I still can't do it (Subj.1). I did the housework, right? [...] when I walked (Subj.2). [...] even more so since I'm at home, I like cleaning the house, sweeping, making food, washing clothes. So, these household chores bother me a lot, because now I can't do them (Subj.3). [...] I can't do it alone, I can't get up and go to the kitchen, no. Last year I still managed, I still did it, I made my own food, but now [...] (Subj.4). For example, here [...] in this case, they helped me, they helped me get out of here so I could go to the hospital, many times it's difficult, you see how difficult it is, the terrain there [...] is not level [...] the terrain is uneven, it's very difficult for me to get there (Subj.4). It changed from when I could go back, right? And then I could go to the junction, to the bottom and now I won't go. Nothing, I'm not even going there anymore. That means it really changed, right? Right here at home. I don't go because I'm afraid, if I fall, slip and fall I won't get up (Subj.5).
Work	I was a construction foreman [...] then after I got sick, that's it, I stopped [...] in general, whatever construction work I did. I did civil construction, naval construction, I worked with all types: civil, naval. Then I stopped. I can't handle anything else! (Subj.5). [...] and my work, you know, which is what I really liked doing, waking up at 5:30 am to go to work, and that's what I miss (Subj.3).
Education	When I fell ill I was going to take the ENEM (University entrance exam) for law [...] I really had to stop, because, you know, when you want to study, you can't just do it at home via the internet, you often have to go out (Subj.4).

Source: The authors

In addition to occupational interruptions, the perceived repercussions were also associated with changes in performance, that is, occupations that were previously carried out independently began to be carried out in an assisted manner. Transformations in the patients were also observed, specifically in the affected body functions, manifested by a fear of falls and their progressive mobility deficit. Along with this, the influence of the context -

environmental factors - revealed itself as an aspect of significant interference: physical barriers in the home (uneven terrain, mentioned by Sub4), act as obstacles that enhance limitations to participation and promote dependence on third parties, revealing that the physical environment can restrict performance and intensify the occupational suffering of patients in palliative care.

It was observed that having the help (partial or total) of family caregivers was a condition imposed by the illness and/or treatment on the participants as a way of enabling the continuity of activities of daily living, such as eating, dressing, bathing, functional mobility, performing personal hygiene and personal care (Table 2).

Table 2 - Needs for assistance in ADLs.

Type of Assistance in ADLs	**Excerpts from participants' remarks**
Human assistance	Taking a shower, now that I'm able to take a shower alone, but it's still with her (daughter's) help (Subj.1). I dress myself, the only thing he helps me with, for example, is the diaper: I hold the leg here, then he puts the diaper on and I dress myself, you know? (Subj.4). Well, it's getting difficult, I sit on the toilet and pull, right? I was going to fall inside the bowl and fell to the floor. I sat on the floor. And then there was no one to lift me up, I was just sitting there (Subj.5). I have to sit on the toilet, he (husband) gives me a bath sitting there on the toilet. I'm not in a position to stand up alone, I can't bathe myself (Subj.6). So, I don't normally take my shower like I used to, I have to adapt by having my daughter there, going with me, a chair nearby so that if I get sick, I sit on the chair, understand? [...] and then, when it comes to dressing, I depend on them (daughters), you know? Getting dressed, fixing my hair, I depend on them (Subj.3). [...] I can't walk [...] taking a shower is no longer in the bathroom, (it's) in bed. Lunch in bed. I change in bed (Subj.2).
Assistance through assistive devices	[...] I adapted with the cane [...] it helps me (Subj.4). But now I've got a wheelchair, I got a wheelchair and I just need to get a little better to be able to go out (Subj.3).

Source: The authors.

Category 2 - Impacts of occupational repercussions: understanding the representations intertwined in the experience of loss

The representations analyzed in the verbal remarks of the participants indicated that, based on the illness and the significant occupational repercussions caused, there is an understanding that this process impacts on the level of patient satisfaction, permeates aspects of beliefs, as well as impacting on the loss of occupational roles that deal with identity, which consequently leads to an adaptive difficulty (Table 3).

Table 3 - Dimensions impacted by occupational repercussions.

Impacts	Excerpts from participants' remarks
Satisfaction	I'm not satisfied at all [...] I can't do anything alone (Subj.6). I'm not satisfied, because every day that passes it gets worse, right? And I'm feeling like this: look, if I want to put the coffee on to drink, I can't reach the container because my hand won't close any more than this (shows his hand). All of this is illness. I never wanted this, it means I can't close my hand and put it round the bowl. Sometimes I call her (partner) to make me coffee. She takes it and pours the coffee and sugars it and then I'm bothering the person, right, pouring a coffee, bothering them, right? But I can't do anything (Subj.5).
Occupational roles and adaptive processes	I was sad, right? Because I would like to still be doing something and painting my house was left undone. I didn't get to paint it. It's because I was a hard-working guy, very hard-working! Even too much! And then, I stopped. Imagine when a person is a worker and is left empty. Standing still. It makes everything complicated (Subj.5). This assessment, it's like this [...] to tell the truth, it's a little cruel because we're not prepared, right? Falling ill and [...] You're never ready, prepared, right? For [...] I think that psychologically, human beings are not prepared to fall ill. Human beings are prepared to... reach old age, they know they will reach old age, but they want to show their ability in old age, you know? They want to die without illness, but unfortunately [...] For me it was terrible. I didn't feel good about it, no. It's complicated, sometimes even explaining it is a bit harsh, it gets to be harsh [...] (Subj.4). After I discovered the disease, I stopped doing many things, the things I liked to do, I stopped doing. I liked... I sold food, I sold snacks, I did my own thing, I didn't stop. Now I can't do any of that anymore. (Subj.1).

Belief system	[...] I think it's a God thing. Putting myself through this, an ordeal, to see how my faith is, because I talk so much about faith, I talk so much about [...] does it mean "pay lip service"? So I think it's a trial from God and that God doesn't want evil for anyone (Subj.3). It's me being closer to God, understand? [...] of God and my daughter (referring to the oncological experience) (Subj.2).

Source: The authors.

As evidenced by the excerpts shown in table 3, two of the participants reported that the dependence on family caregivers to carry out their occupations caused losses in satisfaction related to the way in which their respective occupations are carried out. The reason for dissatisfaction was associated with the perception of functional difficulties, and through the remarks, it was seen that changes in motor performance competence are elements that are difficult for such participants to accept.

Three of the participants, when reporting on the occupational repercussions experienced during the illness, referred to suffering related to the interruption of significant occupations they carried out during their lives, as well as the loss of occupational roles and the difficulty of adapting to this new condition.

Two of the participants, when discussing the transformations caused by a disease such as cancer and its treatment, also mentioned a redefinition of this stage of life symbolized by the (re)connection with aspects of their values, beliefs and spirituality, presenting a perception of the current experience as a situation of approaching a superior divinity or a test of faith.

DISCUSSION

The data obtained in this study showed that, faced with illness and cancer treatment, patients had repercussions on their occupations, such as interruptions in significant occupations, loss of occupational roles and adaptive difficulties. In this sense, it is important to highlight that limitations in the occupational repertoire can contribute to the feeling of non-existence of work and negatively impact the quality of life of individuals.

The occupational repercussions observed in this study indicated a tendency towards complete interruption of instrumental activities of daily living related to setting up and

managing a residence (for example, cleaning the house, washing clothes), preparing meals and housework, mobility in the community, as well as occupations associated with work and education. Participants reported having a routine centered on activities of daily living (eating, bathing, dressing, performing personal hygiene), highlighting the presence of an imbalance in the occupational repertoire mobilized by the illness and treatment process.

Occupational imbalance can be defined as the construction of activities in an individual's routine that do not meet their physiological, emotional or social demands, contributing to exposure to potential risks to health and well-being[11]. To promote occupational balance, it is essential to develop satisfactory personal occupational projects and guarantee access to the human, technological, physical and social resources necessary for participation, which involves a diversity of occupations, time management skills and respect for autonomy, guaranteeing freedom of choice according to the importance attributed to each occupation[11,12].

It is identified in the literature that, faced with the threat to health and the proximity of finitude, patients want to remain involved in choices, in meaningful occupations and close to their surroundings, as such aspects allow them a minimum sense of control and preservation of dignity. It is considered that occupations carry identity characteristics, with the need to receive assistance for occupational performance being a factor that reflects on self-perception of functional incapacity, expressing a negative impact on life satisfaction[13].

People with advanced cancer present problems related to performance and involvement in daily occupations, indicating the need for palliative rehabilitation services[6].

When considering, for example, data on participants' functional status between 30 and 60 in the PPS classification, limitations can be seen, at different levels, for walking, work, hobbies, domestic work, self-care activities and eating. Such data indicate that coping with cancer, regardless of age, requires dealing with constant changes in participation in occupations and functional status[14]. Therefore, preventing occupational disabilities and reducing functional losses are possible objectives when considering early rehabilitation actions (pre-qualification)[15].

In addition, considering the implementation of palliative care from the moment the life-threatening disease is diagnosed is another possible and recommended strategy. The beneficial effects already scientifically demonstrated on quality of life and survival,

especially with regard to engagement in meaningful activities, can minimize the harmful effects of treatment[16].

It is noteworthy that the impossibility of involvement in day-to-day occupations tends to cause suffering, thus enabling this engagement tends to be a source of relief, pleasure and well-being. However, the importance of occupation in the context of palliative care is undervalued, and occupational therapists, professionals with expertise to work on such problems, are still little recognized as fundamental health professionals in the palliative care team[16,17].

During illness, valued occupations undergo changes, with, at first, a predominance of occupations aimed at affirming life (maintaining a routine as close as possible to normal, favorite hobbies, productive activities and ADLs) and later, at preparing for death (life review, writing in a diary, legacy activities, last wishes and choices for the end of life, in addition to promoting comfort through relaxation strategies, energy conservation, simplification of activities and distraction for managing symptoms). It is noteworthy that the course of the disease leads to fluctuations in the clinical picture and patients' needs, resulting in changes in the occupations valued by patients depending on the stage of illness. In this sense, occupational therapists play a fundamental role in helping people to participate in their desired occupations, even in the face of limitations imposed by the disease[17,18].

It is reinforced that it is essential to identify specific demands regarding the most important occupations, graduating the intervention when necessary, given the challenges imposed by cancer symptoms, and it is essential to overcome the challenges associated with providing greater occupational participation for patients in the context of their process of living and dying[7].

Considering that we are occupational beings, and that to this end, our occupations express characteristics of our being, as well as our occupations having a direct relationship with health and well-being[10], it is evident that repercussions on occupations brought on by the experience of life-threatening illnesses are a potential source of suffering. In view of the above, it is important to remember that preventing and alleviating suffering is a precept of palliative care, and for this reason, the presence of occupational therapists in palliative care teams is necessary.

Limitation of the study

The limitations of this study refer to the small number of participants and its geographical location restricted to a single home care service, which prevents the generalization of the findings considering the cultural plurality existing in different regions of the country and structural specificities of each service.

FINAL CONSIDERATIONS

The findings of this study enabled the description of occupational repercussions experienced by patients in oncology palliative care, which involved occupational disruptions of IADLs, work and education and changes in ADL performance standards.

Such repercussions present themselves as a potential element of suffering, impacting the subjects' levels of life satisfaction, the structure of beliefs and the adaptive processes necessary in the face of the loss of occupational roles.

This configuration denotes the need to guarantee the incorporation of the occupational dimension in care planning, to provide support actions that involve restorations, adaptations and comfort to the patient in the face of functional and occupational losses experienced according to the phase of illness, providing well-being and preservation of autonomy.

The importance of studies that reproduce evidence on the best intervention practices focused on occupational losses presented by patients is highlighted, since it is a way to improve assistance in palliative care and allow quality of life until the very last moment.

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Tatiana Barbieri Bombarda:	Conceptualization, Formal Analysis, Methodology, Supervision, Data presentation design, Writing of original manuscript, Writing - review and editing.
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