The Perception of Onco-Hematological Patients about Exclusive Palliative Care

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A Percepção dos Pacientes Onco-Hematológicos sobre Cuidado Paliativo Exclusivo

La Percepción de los Pacientes Oncohematológicos sobre Cuidado Paliativo Exclusivo

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ABSTRACT

Introduction: Despite scientific advances and the dissemination of information about cancer, many patients are diagnosed at advanced stages with few chances of cure. Therefore, understanding the patient's perspective is essential to enhance the team's approach when communicating the palliative care proposal. **Objective:** To understand the perception that patients have about exclusive palliative care. **Method:** Qualitative, descriptive study, based on phenomenological analysis. The research was conducted with patients admitted to an oncology-hematology unit, over 18 years old, receiving exclusive palliative care, according to the research question "What is your perception of exclusive palliative care?" **Results:** The study involved ten patients aged 33 to 81 years, with a predominance of females (70%). Five main topics of interest were revealed, including acceptance and transfer to palliative care units. The discussion emphasizes the perception of the illness as something that affects not only the body but also how patients relate to the world. **Conclusion:** Nurses play a crucial role in assisting patients receiving exclusive palliative care, and interdisciplinary communication is important in facing challenges such as lack of knowledge about palliative care and the stigmatization of these units. The research highlights the need for comprehensive, equitable, and humanized approaches to improve the treatment of patients in palliative care, emphasizing the importance of professional training to deal with difficult communications in this context.

Keywords: Palliative Care; Health Communication; Terminal Care; Oncological Nursing.

RESUMO

Introdução: Apesar dos avanços científicos e da disseminação de informações sobre o câncer, muitos pacientes são diagnosticados em estágios avançados, com poucas chances de cura. Portanto, compreender o ponto de vista do paciente é essencial para aprimorar a abordagem da equipe ao comunicar a proposta paliativa. **Objetivo:** Compreender a percepção que os pacientes possuem quanto aos cuidados paliativos exclusivos. **Método:** Estudo qualitativo, descritivo, pautado na análise fenomenológica. A pesquisa foi realizada com pacientes internados em um setor onco-hematológico, maiores de 18 anos, em cuidados paliativos exclusivos, a partir da pergunta norteadora "Qual é a sua percepção sobre cuidados paliativos exclusivos?" **Resultados:** O estudo contou com a participação de dez pacientes com idade entre 33 e 81 anos, havendo predominância do sexo feminino (70%). Revelaram-se cinco tópicos principais de interesse, incluindo aceitação e transferência para unidades de cuidados paliativos. A discussão enfatiza a percepção da doença como algo que afeta não apenas o corpo, mas também a forma como os pacientes se relacionam com o mundo. **Conclusão:** Os enfermeiros possuem um papel crucial na assistência aos pacientes em cuidados paliativos exclusivos, e a comunicação interdisciplinar é importante para enfrentar desafios, como a falta de conhecimento sobre os cuidados paliativos e a estigmatização dessas unidades. A pesquisa destaca a necessidade de abordagens completas, equitativas e humanizadas para melhorar o tratamento dos pacientes em cuidados paliativos, enfatizando a importância da capacitação profissional para lidar com comunicações difíceis nesse contexto.

Palavras-chave: Cuidados Paliativos; Comunicação em Saúde; Assistência Terminal; Enfermagem Oncológica.

RESUMEN

Introducción: A pesar de los avances científicos y la difusión de información sobre el cáncer, muchos pacientes son diagnosticados en etapas avanzadas, con pocas posibilidades de cura. Por lo tanto, comprender la perspectiva del paciente es esencial para mejorar el enfoque del equipo al comunicar la propuesta de cuidados paliativos. **Objetivo:** Comprender la percepción que los pacientes tienen sobre los cuidados paliativos exclusivos. **Método:** Estudio cualitativo, descriptivo, basado en el análisis fenomenológico. La investigación se realizó con pacientes ingresados en una unidad oncohematológica, mayores de 18 años, en cuidados paliativos exclusivos, utilizando la pregunta orientadora "Cuál es su percepción sobre los cuidados paliativos exclusivos?" **Resultados:** El estudio contó con la participación de diez pacientes de entre 33 y 81 años, con predominio de mujeres (70%). Se revelaron cinco temas principales de interés, incluida la aceptación y transferencia a unidades de cuidados paliativos. La discusión enfatiza la percepción de la enfermedad como algo que afecta no solo al cuerpo, sino también a la forma en que los pacientes se relacionan con el mundo. **Conclusión:** Los enfermeros desempeñan un papel crucial en la asistencia a pacientes en cuidados paliativos exclusivos, y la comunicación interdisciplinaria es importante para enfrentar desafíos como la falta de conocimiento sobre los cuidados paliativos y la estigmatización de estas unidades. La investigación resalta la necesidad de enfoques integrales, equitativos y humanizados para mejorar el tratamiento de pacientes en cuidados paliativos, haciendo hincapié en la importancia de la capacitación profesional para manejar comunicaciones difíciles en este contexto.

Palabras clave: Cuidados Paliativos; Comunicación en Salud; Cuidado Terminal; Enfermería Oncológica.

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INTRODUCTION

Cancer is one of the main causes of premature death in many countries with rising incidence due to global demographic and epidemiologic changes as decline of fertility, populational ageing and behavioral and structural changes that increase the disease-associated risk factors[1].

Sickening by cancer determines modifications in many areas of the patients' lives mainly in the family context. After being diagnosed with cancer, many attempt to reorganize all the social demands to minimize their pains and of the persons of their support network. Most of the times, the diagnosis brings uncertainties about what lies ahead, whether it will be painful, long, possibly curable or death[2].

Despite the scientific advances and dissemination of information on cancer, many patients are diagnosed at advanced stages of the disease with few chances of cure. Palliative care (PC) offer a broader perspective to health professionals to act, attempting to improve the quality of life of the patients through relief of pain and suffering caused by cancer progression[2,3]. PC was defined as:

> prevention and relief of suffering of patients and their families, being adults and children, facing physical, psychological, social or spiritual problems associated with life-threatening diseases. Prevention and relief of suffering, early identification and treatment can minimize these problems[4].

Exclusive palliative care (EPC), a modality of treatment aims to relieve the symptoms and improvement of the quality of life of patients with severe and/or advanced diseases[5]. EPC has a multidisciplinary approach with several health professionals offering comfort and support to patients in all their life dimensions, including physical, emotional, social and spiritual aspects[5,6].

It is common that patients feel fear and doubts about PC, especially if they were not duly informed. During an open and true dialogue among the patient and the health care team about the therapeutic proposal, quite often, insufficient communication can aggravate these doubts, preventing the patient to participate of decision-taking about their therapeutic plan[5].

A study concluded that patients coping with oncohematological malignancies usually develop post diagnosis depression, anxiety and stress[7]. The journey of a patient since diagnosis through treatment and the perspective of cure is frequently marked by anguish and suffering but also by hope and persistence. It is plausible to argue that an early approach within a care plan to improve the quality of life and support resilience is essential to help them face the difficulties. However, there are barriers to understand and accept this type of care, especially when the proposal is presented later in an end-of-life context[6,7].

The present study was developed to respond to the research question: "What is the perception onco-hematological patients have of exclusive palliative care?" The objective of the study is to understand the perception patients have on EPC at a national reference cancer institution.

METHOD

Qualitative, descriptive, phenomenological-based study conducted on an onco-hematological unit, currently with 26 active beds, four single bed rooms and eight shared wards.

The study participants were onco-hematology inpatients already referred to PC by a reference cancer treatment institute, aged 18 years or older in the state of Rio de Janeiro. For being a qualitative study, the sample was not pre-determined quantitatively. The number of participants was determined by saturation consisting in collecting data until all important issues are exhausted and become repetitive[8].

Patients in severe health conditions or who did not meet the profile of the target population and patients with cognitive disability or difficulties to communicate were excluded to ensure the quality of the data collected, reliability of the results and cohesive and accurate responses.

Phenomenological interviews with inpatients between August and October 2023 were conducted to evaluate their experiences in regard to the study theme. The interviews occurred in a secluded environment to allow them to express their experiences openly under the purview of the investigator. Patients unable to walk were interviewed at the beds after their consent. The main purpose was their perception of EPC.

Data were analyzed in the perspective of phenomenology in three stages: description of the phenomenon, reduction and comprehension. The first stage consists in describing and reveal the phenomenon lived through oral expression, transcribed as a text to be appraised and understood. The second stage, the reduction, has the objective of defining the essence of the phenomenon described and the last, the phenomenological understanding, simultaneously with the interpretation[9].

The participants consented to join the study voluntarily by signing the informed consent form (ICF), they could leave the study whenever they wished and received an identification code "I" (interviewee) to ensure anonymity. The information collected were used only in the study and will be kept confidential.

The interviews were recorded and stored in a device controlled by the investigators. After the transcription, the audio was permanently deleted. Electronic safety measures were implemented, including antimalware to protect the data.

The risks of the study are the emotional discomfort of the patient while reporting their experiences lived in the hospital. The interview was immediately interrupted if the patient felt some kind of uneasiness and this fact would be promptly discussed.

The Ethics Committee approved the study, report number 6176757 (CAAE (submission for ethical review): 70123923.0.0000.5274) in compliance with Directive number 466[10] dated December 12, 2012 of the National Health Council.

RESULTS AND DISCUSSION

Between September and October 2023, the interviews conducted revealed a significant perspective of the level of knowledge patients had on EPC. Ten patients aged 33-81 years old mostly females (70%) joined the study.

The majority were single (50%), followed by married (30%) and widow/er (20%), who completed high school (50%) and were employed (Table 1).

The synthesis of the meanings presented shows an understanding of a very sensitive period for health professionals, patients and their families when the diagnosis of neoplasm is confirmed, regardless of the disease stage. It is when crucial information about the treatment, prognosis, adjustments of daily routine, body changes and other aspects are shared. The relevance of this communication is usually associated with dismal news, depending on the emotional toll on the involved[11].

The interactions among the patients' physical, psychological, social or economic needs were highlighted. In this scenario, it is important to acknowledge that these needs relate among themselves, revealing connections among psychological suffering, access to a qualified health network and the patients' socioeconomic context, critical elements for a comprehensive and effective approach to cancer treatment[3,6].

The topics extracted from the interviews with the patients when their knowledge about EPC were discussed are presented in Table 2. These five elements were developed from the responses to the research question. The participants were identified with the letter 'I' as interviewee followed by a numerical code based on their age in ascending order.

Table 1. Demographic characteristics of the study participants, RJ, Brazil, 2023

Variables	n	%
Sex		
Male	3	30
Female	7	70
Marital status		
Single	5	50
Married	3	30
Widow/er	2	20
Education		
Complete elementary school	1	10
Incomplete elementary school	3	30
Complete high school	5	50
Incomplete high school	0	0
University	1	10
Work status		
Retired	2	20
Unemployed/housewife	2	20
Employed	6	60

Table 2. Topics collected from the interviews

Topics	Interviewees (I)	%
Patients introduced in the context of palliative care	I1; I5; I7	30
Patients who were not approached about palliative care	I2; I3; I4; I6; I8; I9; I10	70
Patients who did not accept palliative care	I3; I7	20
Patients who accepted palliative care	I1; I5	20
Perceptions about the transference to the palliative care unit	I4; I6; I7; I8	40

Five main topics of interests have emerged from the results. Initially, 30% of the patients were dully introduced to the context of PC after the physician informed the course of the treatment. A considerable portion (70%) were unaware of PC, in addition, 20% of the patients, after receiving the news they would be submitted to EPC, did not accept, while other 20% accepted. At last, 40% shared their perceptions about the possibility of transference to the PC unit.

As aforementioned, 70% were unaware about PC, this conduct is relevant to ensure quality of life, comfort and dignity in end-of-life. Trained PC health professionals should have specific skills to deal with complex issues as sensitive communication, shared decision-taking and advanced care plans.

How dismal news are communicated can impact the evolution of the disease and the life of the persons involved, affecting psychological aspects and acceptance of EPC like happened with 20% of the patients who did not accept PC after talking with the professional.

A significant proportion of the interviewees shared their perceptions about the transference to a PC unit. Fear, uncertainties and misconceptions as “a route to death” come together with the communication of the transference. The narratives below express the interviewees view as soon as they knew they would be transferred to the palliative care unit.

> We don’t want to die, have to accept, but that’s ok (I6).
>
> (..) go where? INCA IV? Palliative? No way! Have you already thrown the towel?
> For two days I was thinking: I’m going to die. Things I ever thought in two years. This is not good (I4).

Communication is an essential tool to comfort the patients in terminal stage. An effective communication or its lack tend to increase discomfort and harm the trust on health professionals[5].

The application of the phenomenological analysis allowed the identification of the categories representing key-aspects of the experiences lived by patients in PC. The categories identified are:

Unawareness of palliative care: poor communication of dismal news

In the phenomenological perspective, communication can stimulate personal transformation, rooted on the experience of the own body. The body reflects the perception and is the source of the transcendence, allowing to retrieve the past and create a vision of the future, ultimately leading to a renewed self at each new experience[12].

According to Merleau-Ponty, communication plays a key role in constructing our reality and understanding ourselves and the other. Each gesture and expression mirror the totality of the corporeal expression, revealing feelings. Merleau-Ponty[9] believes language is an ambiguous and spontaneous gesture able to fill in gaps and dissipate opacities, drawing attention to the wholeness of the existence. Even communication failures can provide a vision of the facticity of the human being and of the world.

The study was developed in an oncological reference hospital and teaching institution with high turnover of professionals, mainly residents, which makes the creation of bonds among professionals and patients, difficult, especially while communicating dismal diagnoses. Not always the same professional communicates the disease is not treatable or curable, a challenging task for those who tell the news and those who receive it, mainly in palliative care.

Patient-centered communication is essential to offer high quality treatment, regardless of who the communicator is[2]. At a teaching hospital, professionals in formation face challenges, especially dealing with patients with advanced cancer. Many need to improve their communication skills of diagnoses or news that affect the course of the treatment. The following narrative is an example:

> My physician has ever broached the theme. He prescribed chemo, medication, tests. But a resident steps in, he doesn’t know what the hospital has to offer. What I was able to understand is that there was nothing else to be done [...] They should know what to offer the patient (I4).

During the interview, the interviewees were uncomfortable or doubtful while responding to the main question. Some patients were outraged with lack of humanization when they were informed about the inexistence of an effective cancer treatment. Others less educated were confused when they heard physicians talking about EPC. Despite having received information about the treatment, they did not fully understand the meaning and impact on the fight against the disease.

> Nobody explained me. Sometimes, they say they will prescribe a medication, but they don’t say which (I6).

The perception of the disease: difficult coping with signs and symptoms that appeared during palliative care

It seems unquestionable that emotional issues are intrinsically connected with physical problems of the patients. While talking with the patients, even if they did not verbalize their feelings, they expressed anguish, doubts, uncertainties on their faces and bodies, revealing concerns on how their lives would be after knowing their cases were uncurable.

Coping with the disease and daily changes of the symptoms bring a great psychological impact in patients in EPC, affecting their personal relations and interactions with the health team. Some patients expressed discomfort while discussing their health condition, showing outrage regarding their hospital experience as seen in the following narratives:

> Palliative? Don't know these stories the health team talks about. I know nothing of this... (I7).
>
> I feel lost. It is all over again, it seems I'm going back (I9).

In this phase, the symptoms reflect an intense and persistent suffering, encompassing an array of groups involving nausea, nutritional imbalance due to failure to meet what the body needs (cachexia, thinning), fatigue, anxiety, ineffective breathing pattern, and ineffective thermoregulation (cold and clammy skin, cyanosis, sweating, extremities with poor circulation)[13].

The perception of the disease and of the body highlights that it is not a mere object, but a mean to perceive and relate with the world. Corporeity plays a central role in expressing and interpreting these signs, bringing comfort while sharing anguishes and fears. Merleau-Ponty's phenomenological perspective highlights the importance of understanding these complexes experiences beyond a purely clinical analysis[14].

It is essential to prepare oneself emotionally and carefully plan the approach to patients about EPC before initiating any action to prevent discomfort. In addition to psychological intervention and preparation to deal with the symptoms, it is crucial that the professionals develop communication strategies to cope with suffering and support the patients in end-of-life process.

It corroborates Merleau-Ponty who sees the body not only physically, the body is its own subject and the individual is a being in the world within its sociocultural context. Therefore, the communication of aspects of the physical health is within the context of the identity of the subject and its commitment with the world[15].

Quality of life as a priority

The concept of quality of life is "the perception of the individual's position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"[16].

There are two different dimensions of the concept of quality of life: objective and subjective. The objectivity addresses the position of the individuals and their interaction in the society while subjectivity consists in understanding their physical, emotional, social and spiritual conditions[17].

In the context of the patients in oncologic treatment, the pursue for quality of life amidst the disease-imposed challenges is somewhat idealized. The great wish of the individuals is to enjoy the family, friends and beloved ones for more time as the present study has clearly concluded. They also attempt to reach periods of mental and physical well-being and leisure, practice of physical activities and a full life in society.

> What I really wish is to get out of here and be with my family. I miss doing things I did before I got ill (I3).

The evaluation of the effects of oncologic treatment on the health-related quality of life (HRQoL) of patients diagnosed with cancer can be a valuable tool for the multiprofessional team, especially the nursing team. It can guide the planning of targeted interventions to minimize potential adverse effects[18].

Introduce comfort strategies aligned with the patients reported needs is essential to stimulate a feeling of empowerment and encouragement to make personal decisions[18,19]. Whereas the interviewees narratives, the nursing team is essential to develop and promote the well-being and self-care of patients in EPC not only intervening on the symptoms caused by the disease but increasing the feeling of well-being.

The stigmatization of the palliative care unit among the patients

The communication of dismal news is permeated by feelings that reveal denial, depression or acceptance. It is possible to notice, while following up inpatients receiving this news during their process, is the necessity to offer support, listen, understand their emotional manifestations and help them to go through this phase[11].

The patients keep themselves secluded and silent, do not wish to approach the subject or ask the nurse team about the current status of the disease because they are expecting to hear something different. The interviewees, despite being aware of the disease status, think only in the finitude of the life after receiving the news they would be transferred to PC.

Clarify that modalities to ensure the quality of life and symptoms relief will be offered in PC, but without curative therapies, avoiding the patient to feel abandoned and causing less suffering. It is necessary to dedicate time and space for the patient and the family to accept consciously and calmly the transition to PC[6,15].

I6 attempted to pull away from the subject as the narrative revealed. Even aware of his/her condition, the family assumes the responsibility of not discussing the matter.

> If anyone discussed this type of care with me, I haven't noticed. I'm not saying they did. Have to tell the truth. When you asked me, in fact, I thought it was this that happened (I6).
>
> But how have you figured it out it was this? (Investigator).
> I guessed by the word (I6).
>
> Have your children and sisters discussed this with you? (Investigator).
> No! Never. I never knew what they talked with the doctor. I guess they tried to spare me, you see? (I6).

It is clear that communicate the proximity of finitude, based on these brief narratives, even if it is not possible to preview it with some certainty, is making the individual to look into his/her own existence. Most of the times, it is the beginning of a reflection since the beginning until the present "end" that was not planned but now should be and that quite often, is the contrary of what was desired so far. It takes time to elaborate and accept the circumstance.

The professionals should understand the human complexity, including the emotional phases as depression, anger and denial. Empathy should be the main resource of nurses while providing care. This implies in understanding the other in their complex and deep needs, especially in crucial moments of the life.

CONCLUSION

Despite scientific advances of the treatments and improved dissemination of information on cancer, many patients are still diagnosed at advanced stages of the disease with scarce perspectives of cure. In this scenario, PC emerge as a new approach for health professionals to ensure the patients a better quality of life.

The study has shown that nurse professionals play a key role in caring for patients in EPC. When conducted within the principles of universality, wholeness, equanimity and humanization, it brings palpable benefits to treat these individuals who frequently have to cope with considerable debilitation due to the disease progression. In the perspective of Merleau-Ponty phenomenology, highlighting the interconnection between the individual and the world, can influence the nurse team to understand the conception of the patient, improving the efficacy of the established therapeutic relation.

The results indicated that the complexity of the communication of dismal news in PC requires interdisciplinary work, not only by the physician. As patients with advanced cancer present physical, emotional and social issues, bringing a complexity into their vision of being in the world, it is essential that the professionals offer a holistic assistance, positively contributing to the end-of-life process.

A clear and effective communication demystifying cancer and PC, as the current study concluded, stimulates the observation of this individual beyond their debilitated bodies, allowing to see them as human beings, with wishes, meanings and capacity to attribute new feelings to their own existence and how they see and place themselves in face of the world.

The study limitations are the small number of interviewees and data collected from a single unit, despite the problematic being found in the whole hospital. Patients demands in EPC were substantial but few were in physical and psychological conditions to provide information. Even with these limitations, it is important to highlight that the relevance and reliability of the study were not compromised.

Although PC is widely known today with several studies attempting to improve the holistic vision, there is still a gap in health professionals preparation to deal with dismal news and face complex situation in the hospital environment. However, it is important to promote training of these professionals to positively change the care provided to these patients.

CONTRIBUTIONS

Paulo Sérgio Lima Donza contributed substantially to the study design, acquisition, analysis and interpretation of the data, wording and critical review. Marlise Barros de Medeiros contributed substantially to the acquisition, analysis and interpretation of the data, wording and critical review. Both authors approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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