Utilization of the International Classification of Functioning, Disability and Health in Patients with Advanced Cancer Under Palliative Care

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Utilização da Classificação Internacional de Funcionalidade, Incapacidade e Saúde em Pacientes com Câncer Avançado em Cuidados Paliativos

Uso de la Clasificación Internacional de Funcionamiento, Discapacidad y Salud en pacientes con Cáncer Avanzado en Cuidados Paliativos

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ABSTRACT

Introduction: The principles and guidelines that govern palliative care state that a comprehensive assessment of the patient is essential and that, in addition, it is important to perceive the individual in all its dimensions. Corroborating the principles of palliative care, the International Classification of Functioning, Disability and Health (ICF) is an instrument that enables a biopsychosocial approach. **Objective:** To evaluate the functionality, symptoms and social and environmental aspects of cancer patients under palliative care utilizing an ICF-based checklist. **Method:** Quantitative, observational and cross-sectional study. The 14 categories ICF-based checklist was previously developed by the investigators having as reference the main assessment instruments commonly adopted in palliative care. Patients admitted to a palliative care ward, diagnosed with cancer and with PPS (Palliative Performance Scale) scores greater than or equal to 30% were submitted to an assessment based on the aforementioned checklist. **Results:** There were 21 patients with different cancer diagnoses that participated in the study. More than 50% of the patients reported mild, moderate, severe, or total disability in seven categories of the components activity and participation. For two categories of the body function component, more than 50% of the patients reported mild, moderate, severe or complete disability. **Conclusion:** The ICF-based checklist can provide an assessment that considers the different dimensions of health, from a physical, biological and psychosocial perspective.

Key words: palliative care; International Classification of Functioning, Disability and Health; neoplasms.

RESUMO

Introdução: Os princípios e diretrizes que regem os cuidados paliativos afirmam que é imprescindível a avaliação abrangente do paciente e que, além disso, é importante perceber o indivíduo em todas as suas dimensões. Corroborando esses princípios, a Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) é um instrumento que possibilita uma abordagem biopsicossocial. **Objetivo:** Avaliar a funcionalidade, os sintomas e os aspectos sociais e ambientais de pacientes oncológicos sob cuidados paliativos a partir de um *checklist* baseado na CIF. **Método:** Estudo quantitativo, observacional e transversal. Um *checklist* baseado na CIF com 14 categorias foi desenvolvido pelos pesquisadores previamente tendo como referência os principais instrumentos de avaliação comumente utilizados em cuidados paliativos. Pacientes internados em uma enfermaria de cuidados paliativos, diagnosticados com câncer e com escores de PPS (*Palliative Performace Scale*) igual ou superior a 30% foram submetidos à avaliação a partir do *checklist* baseado na CIF. **Resultados:** Participaram do estudo 21 pacientes com diferentes diagnósticos de câncer. Mais de 50% dos pacientes relataram dificuldade ligeira, moderada, grave ou completa em sete categorias do componente atividade e participação. No componente funções do corpo, mais de 50% dos pacientes relataram deficiência ligeira, moderada, grave ou completa em duas categorias. **Conclusão:** O *checklist* baseado na CIF pode proporcionar uma avaliação que considera as diferentes dimensões de saúde, sob um olhar físico, biológico e psicossocial.

Palavras-chave: cuidados paliativos; Classificação Internacional de Funcionalidade, Incapacidade e Saúde; neoplasias.

RESUMEN

Introducción: Los principios y directrices que rigen los cuidados paliativos establecen que es fundamental una valoración integral del paciente y que, además, es importante percibir al individuo en todas sus dimensiones. Corroborando los principios de los cuidados paliativos, la Clasificación Internacional de Funcionamiento, Discapacidad y Salud (CIF) es un instrumento que posibilita un enfoque biopsicosocial. **Objetivo:** Evaluar la funcionalidad, los síntomas y los aspectos sociales y ambientales de pacientes con cáncer en cuidados paliativos mediante una lista de verificación basada en la CIF. **Método:** Estudio cuantitativo, observacional y transversal. La lista de verificación basada en la CIF con 14 categorías fue desarrollada previamente por los investigadores teniendo como referencia a los principales instrumentos de evaluación comúnmente utilizados en cuidados paliativos. Los pacientes ingresados en una sala de cuidados paliativos, diagnosticados de cáncer y con puntajes PPS (*Palliative Performance Scale*) mayores o iguales al 30% fueron sometidos a una evaluación según en la lista de verificación basada en la CIF. **Resultados:** Participaron en el estudio 21 pacientes con diferentes diagnósticos de cáncer. Más del 50% de los pacientes reportaron dificultad leve, moderada, severa o completa en siete categorías del componente de actividad y participación. En el componente de funciones corporales, más del 50% de los pacientes reportaron deficiencia leve, moderada, severa o completa en dos categorías. **Conclusión:** La lista de verificación basada en la CIF puede proporcionar una evaluación que considere las diferentes dimensiones de la salud, desde un punto de vista físico, biológico y psicosocial.

Palabras clave: cuidados paliativos; Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud; neoplasias.

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INTRODUCTION

Palliative care is defined as a modality of care whose purpose is to prevent and alleviate suffering through early recognition, evaluation and treatment of pain and other physical, psychosocial, and spiritual problems. Its ultimate goal is to improve the quality of life of patients who face problems related to life-threatening diseases as well as their families[1]. In the field of oncology, palliative care plays an important role in the management of the patient's total symptoms and in providing quality of life[2].

Principles and guidelines for quality palliative care include comprehensive assessment that emphasizes patient and family involvement, communication, management, and continuity of care[3]. It is also important to consider the perception of the individual in all its completeness, including physical, functional well-being and psychosocial and spiritual aspects in their care. For this, an interdisciplinary team is essential[4].

The monitoring of the evolution of the disease is considered an important factor for palliative care, allowing decision-making, visualization of the prognosis and prevention of adverse effects associated with functional decline. Thus, functional assessment is an essential tool to guide care[5]. The instruments commonly used in palliative care to assess the degree of capacity and functional dependence are the *Karnofsky Performance Scale* (KPS) or the *Palliative Performance Scale* (PPS)[6].

In this perspective, the International Classification of Functioning, Disability and Health (ICF) is an instrument that aims to assess the influence of the health situation on functionality, environment, work, family, and community social life[7]. And, similar to what is foreseen in the principles of palliative care, the ICF proposes a biopsychosocial approach that includes the physical and social levels in health, going beyond the exclusive biomedical model, evolving to a three-dimensional care: biomedical, psychological and social[8].

The ICF reflects the concept that health problems affect many areas of an individual's life and describes the level of need within the domains of disability, activity and participation; it also includes the impact of the environment and denotes a social and individual perspective and may provide an adequate framework to explore the functional difficulties experienced by people with incurable cancer[9].

The ICF consists of two parts, each with two components: the first refers to functionality and disability and has as components the functions, body structures and activity and participation; and the second relates to contextual factors and includes environmental and personal factors. Each component can be described in positive or negative terms[10]. Body functions refer to the physiological aspects of organ systems; body structures address the anatomical regions of the body; activity is the performance of a task by an individual; participation is involvement in a life situation; contextual factors indicate the individual's history and lifestyle, while environmental factors include the physical and social environment in which people live[11].

Each ICF category should be assigned a qualifier that expresses the influence of the health condition on that specific factor, according to the guidance of the World Health Organization (WHO). The qualifier scale ranges from 0 to 4, considering the severity of the impairment[12].

The ICF is a complex instrument that contemplates a large number of aspects, thus, the who recommends the use of ICF *core sets* or *checklists* that bring together the categories that represent the functionality of people with specific health conditions, that is, one should pay attention only to those categories that are typical and significant for a given disease instead of evaluating the 1,454 aspects of the ICF[13].

A study by Giardini et al.[14] with patients admitted to a palliative care unit concluded that the ICF structure can be extended to palliative care because, by integrating the standard functional assessment, it allows the identification of two levels of intervention: one that directly affects the patient's activity and participation, and another related to barriers and facilitators, that is, caregivers and environmental factors.

Given the above, the questioning of research on functionality by levels of activity and participation, symptoms according to body functions and social and environmental factors of patients with advanced cancer in palliative care arose from the use of a *checklist* based on the ICF.

Although the use of ICF as an assessment tool in cancer patients under palliative care has already been addressed in some studies, few have integrated body functions and social and environmental aspects into the functionality of these patients, which is why this study and the use of ICF to provide a more detailed and comprehensive classification of health states were justified.

Thus, this research aimed to evaluate the functionality, symptoms and social and environmental aspects of cancer patients under palliative care using an ICF-based *checklist*.

METHOD

Quantitative, observational, and cross-sectional study conducted in a palliative care unit.

The study included patients with advanced cancer admitted to a palliative care ward, regardless of the type and location of the cancer, without a proposal for disease-modifying treatment, who underwent or not previous cancer treatments and with a PPS score greater than or equal to 30%. Patients under 18 years of age, with cognitive alterations and/or psychiatric disorders, non-contacting or with progressive neuromuscular diseases did not participate in the study.

Initially, the medical records of patients admitted to the palliative care ward were analyzed to evaluate the inclusion of participants in the study. Subsequently, the selected patients were evaluated using the PPS, an instrument that was developed in 1996 by *Victoria Hospice*, in Canada, with the objective of performing the functional evaluation of the patient and understanding the evolution of the disease. The scale has 11 levels, from zero to 100, divided into intervals of ten; in 100%, the patient's functionality is preserved, 0% means death[15]. Patients with PPS scores greater than 30% and who met the inclusion and exclusion criteria were submitted to the Informed Consent Form (ICF). After reading and adhering to the term, information was collected from the participants to characterize the sample and evaluate functionality, symptoms and social and environmental aspects from a *checklist* based on the ICF.

The information for the characterization of the sample was obtained from the previous reading of the medical records. The evaluation based on the ICF-based *checklist* was carried out by a structured interview in the palliative care unit, carried out by the same researcher, and in an individualized manner. In the activity and participation and body functions component, each category was transformed into a question in which the patient reported the absence or presence of mild, moderate, severe, or complete difficulty and disability. In the environmental factor's component, it was asked whether the family and individual attitudes of family members facilitated or acted as an obstacle in care.

The ICF-based *checklist* was previously developed by the researchers of this study, with reference to the main assessment instruments commonly used in palliative care. After a survey and bibliographic research, the following instruments were evidenced: KPS[16], Katz Index[17], Lawton & Brody Index[5], *Rapid Disability Rating Scale* (RDRS)[18], *Health Assessment Questionnaire* (Haq)[19], Functional Independence Measure (MIF)[5]; Edmonton Symptom Assessment Scale (ESAS)[20]; *European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire* (EORTC QLQ-C30)[19] and *World Health Organization Quality of Life Instrument* (WHOQOL-BREF)[21]. From the analysis of these instruments, it was observed that the most evaluated aspects in palliative care regarding functionality were ambulation, postural transfers, self-care, and instrumental activities of daily living (IADL). In terms of signs and symptoms, pain, nausea, depression, anxiety, and shortness of breath were seen. And, with reference to social and environmental aspects, social and spiritual life were considered. After collecting these data, these aspects were researched within the components of the ICF, and an evaluation form was created.

The sampling was by convenience, and the medical records of patients hospitalized from August to November 2021 were analyzed. These were also inspected daily to assess the possibility of including a new participant in the study.

The data were stored and organized in a spreadsheet in the *Microsoft Excel 2016* program and, subsequently, the descriptive analysis of the characteristics of the sample and the results obtained was performed, using mean, median and absolute and relative frequencies.

This research project was approved by the Research Ethics Committee of the Instituto de Medicina Integral Professor Fernando Figueira (IMIP) under opinion number 4846565 (CAAE: 49236821.8.0000.5201), in compliance with Resolution nº. 466/12[22] of the National Health Council for research with human beings.

RESULTS

Twenty-one patients diagnosed with cancer and in palliative care were included in the study. The mean age of the participants was 59 years (range 42 to 84 years), 52.38% female and 47.62% male. Regarding PPS scores, the maximum value found among patients was 60% and the lowest 30%, with a median of 30%.

Table 1 describes the main diagnosis of the study participants. The other characteristics such as: location of metastases, complications associated with cancer, other comorbidities and previous treatments are shown in Table 2. Tables 3, 4 and 5 list the results found in the components activity and participation, body functions and environmental factors, respectively.

DISCUSSION

The present study was conducted with the purpose of investigating the functionality, symptoms and psychosocial aspects of cancer patients in palliative care. The checklist used consisted of a *checklist* based on the ICF. Providing a more diverse assessment, the ICF maintains some aspects of daily life, values personal dignity and the family role. The integrated use of this instrument can enable a global assessment, highlight difficulties and confirm the importance of an interdisciplinary approach

Table 1. Clinical diagnosis of study participants

Diagnostics	n	%
Anal canal cancer	1	4.76
Cervical cancer	3	14.29
Endometrial cancer	2	9.52
Pancreatic and spleen cancer	1	4.76
Prostate cancer	4	19.05
Lung cancer	4	19.05
High rectal cancer	2	9.52
Gastric Cancer	3	14.29
Unresectable abdominal tumor, liposarcoma and schwannoma	1	4.76

Table 2. Characteristics of study participants

Features	n	%
•Metastases location		
Liver	2	7.41
Bone	4	14,81
Peritoneum;	4	14,81
Lung	3	11.11
•Adrenal	1	3.70
Inferior rectus	1	3.70
Central Nervous System	2	7.41
bladder	1	3.70
No information in the medical record	9	33.33
Complications associated with cancer		
Enterocutaneous fistula	1	4.76
Intestinal obstruction.	2	9.52
Vocal cord paralysis	1	4.76
Plegia, anemia, melena and fecal incontinence	1	4.76
Spinal cord compression syndrome	1	4.76
Pyloric syndrome and partial dehiscence	1	4.76
Without complications	14	66,67
Primary tumor treatments		
Surgical	3	12.50
Chemotherapy	8	33.33
Radiotherapy	2	8:33
Hormone therapy	1	4.17
No information in the medical record	10	41.67

Table 3. Results obtained from the activity and participation component

Categories	n	%
d4500 Walking short distances		
not at all	2	9.52
mild or moderate difficulty	9	42.86
severe or complete difficulty	10	47.62
d4103 Sitting		
not at all	4	19.05
mild or moderate difficulty	6	28.57
severe or complete difficulty	11	52.38
d104 Standing up		
no difficulty	5	23.81
mild or moderate difficulty	4	19.05
severe or complete difficulty	12	57.14
d540 Dress up		
not at all	2	9.52
mild or moderate difficulty	6	28.57
severe or complete difficulty	13	61.91
d510 Washing		
not at all	2	9.52
mild or moderate difficulty	4	19.05
severe or complete difficulty	15	71.43
FAMILY LIFE		
not at all	14	66,67
mild or moderate difficulty	4	19.05
severe or complete difficulty	3	14.28
Intimate Relationships		
complete difficulty	21	100
d930 Religion and spiritual life		
not at all	9	42,85
mild or moderate difficulty	7	33.34
severe or complete difficulty	5	23.81

in patients at the end of life[1]. It is important to consider that palliative care has as its premise a conception of care that supports the multidimensional understanding of health, with attention to the physical, emotional, social, pain and suffering dimensions[2].

Although the ICF presents an evaluation proposal similar to that proposed by the principles of palliative care, few studies were found that used ICF in cancer patients under palliative care. The integrative review carried out by Sanvezzo et al.[5], which aimed to identify tools to assess the functionality of the elderly in palliative care, cited instruments such as KPS, PPS, Katz Index and FIM.

In this study, in the activity and participation component, patients presented the severe or complete difficulty qualifier

Table 4. Results obtained from the body functions component

Categories	n	%
b280 Feeling of pain		
no disability	6	28.57
mild or moderate disability	5	23.81
severe or complete disability	10	47.62
b5350 Feeling nauseous		
no disability	11	52.38
mild or moderate disability	4	19.05
severe or complete disability	6	28.57
b460 Sensations associated with cardiovascular and respiratory functions		
no disability	13	61,90
mild or moderate disability	5	23.81
severe or complete disability	3	14.29
Emotional Functions		
no disability	9	42.86
mild or moderate disability	6	28.57
severe or complete disability	5	23.81
unspecified	1	4.76

Table 5. Results obtained from the environmental factors component

Categories	n	%
e310 Close family		
no facilitator	3	14.29
unobstructed	18	85.71
e410 Individual attitudes of family members		
no facilitator	2	9.52
unobstructed	19	90.48

more frequently in the following categories: walking short distances (47.62%), sitting (52.38%), standing (57.14%), dressing (61.91%) and washing (71.43%). The cross-sectional study by Giardini et al.[23] evaluated 32 patients with cancer in palliative care who were hospitalized and observed that 50% of the patients presented a slightly impaired qualifier in the activity and participation component but did not specify in which categories.

The reduction in functional capacity in cancer patients is attributed to muscle weakness, a consequence of the increase in the rate of energy expenditure and the protein degradation process, in addition to the decrease in protein synthesis and increase in lipolysis[24]. Loss of functionality is one of the main signs used in prognosis in palliative care[6].

The study by Monaco et al.[25], which aimed to explore the internal needs of palliative care patients living in a *hospice*, found that human relationships represented a fundamental key at the end of patients' lives, especially family relationships. Although the patients had everything in the *hospice*, their main thoughts were always focused on human relationships[25]. In the present study, most patients reported no difficulty in the family relationships category (66.67%).

In this study, 100% of patients reported complete difficulty in the intimate relationships category. The presence of the disease can affect the patient's intimacy in a wide variety of ways, including costly physical symptoms, overwhelming levels of stress and tension, treatments that complicate physical intimacy, and impaired functional ability[26]. Kelemen et al.[27] verified the concerns of hospitalized palliative care patients regarding intimate relationships and showed that relationships strengthened during the course of the disease, while sexual activity was negatively affected.

In the religion and spiritual life category, more than 50% of patients reported mild or moderate difficulty (33.34%) and severe or complete difficulty (23.81%). Spiritual care is an essential intrinsic component of palliative care, and there is growing evidence that end-of-life spiritual care is important for patients and that they want health professionals to pay attention to this aspect[28].

In this study, in the body functions component, it was found that patients reported severe or complete deficiency (47.62%) and mild or moderate deficiency (23.81%) in the pain sensation category, and no deficiency in the nausea sensation category (52.38%) and sensations associated with cardiovascular and respiratory functions (61.90%). Pain management can be difficult because it is dynamic, complex, and multidimensional. Pain in cancer can be associated with other symptoms such as fatigue, insomnia, inactivity, mood and interpersonal relationships[29]. The good management of symptoms in oncology is associated with improved quality of life of the patient and the family and may offer advantages in relation to survival[30]. Li et al.[31] investigated the severity of symptoms of 386 patients with advanced cancer using ESAS and the End-of-Life/ Quality-of-Life Measure (QUAL-E), observing that tiredness, sleep, and appetite were often classified as more severe, while pain and tiredness were pointed out as the most bothersome.

Cicely Saunders, considered a pioneer in palliative care, provided reflections on the multidimensionality of symptoms, covering not only physical symptoms, but also mental suffering, the social and biographical context of the patient and their emotional difficulties [32]. In this study, patients reported mild or moderate disability

(28.57%) and severe or complete disability (23.81%) in the emotional functions category.

Giardini et al.[14] verified the role of the caregiver as a modulator of disability in patients with advanced cancer. In this study, 50 patients admitted to a palliative care unit prepared a self-report on quality and were assessed with an ICF checklist. This research concluded that even patients confined to bed and dependent on others had reduced disability thanks to the role of the caregiver[14]. Family caregivers play an integral role in the care and support of cancer patients. They can assume various responsibilities during the patient's disease trajectory, providing physical, emotional, social, spiritual and support benefits[33]. In this study, 85.71% and 90.48% of patients reported no obstacles from family members and individual attitudes of these family members in the care process, respectively.

From a biopsychosocial context, the ICF enabled a multimodal assessment of the main deficiencies and difficulties of patients in palliative care. However, this study presented as a limitation the small number of participants due to the low turnover of patients in the unit where the research was carried out. Thus, additional studies are needed in order to evaluate the applicability of ICF in patients under palliative care.

CONCLUSION

Cancer patients in palliative care had mild, moderate, severe or complete difficulty in the activity component and participation in the categories: walking short distances, sitting, standing, dressing, washing, religion and spiritual life, and intimate relationships; and mild, moderate, severe or complete disability in the pain sensation and emotional functions category of the body functions component. ICF can be a versatile multidimensional assessment tool in cancer patients in palliative care.

CONTRIBUTIONS

All authors contributed substantially in the design and/or planning of the study; in the collection, analysis and interpretation of data; in the writing and critical review; and approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

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