



ORIGINAL

Satisfaction and quality of palliative care in patients with neoplasms diseases

Satisfacción y calidad de los cuidados paliativos en pacientes con enfermedades neoplásicas

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ABSTRACT

Introduction: the role of palliative care at the end of life is vital in alleviating suffering through comprehensive assessment and treatment of patients' physical, psychosocial and spiritual symptoms.

Objective: argue the importance of the quality of palliative care in patients with neoplastic diseases.

Method: the research was carried out by collecting information in different scientific article search engines such as PubMed, Google Scholar, Medline, Scielo, Scienca Direct, Elsevier, Medigraphic, ResearchGate. The search strategy was limited to articles ranging from 2019 to 2023, in Spanish and English, about palliative care in patients with oncological diseases and the importance of the satisfaction of users of outpatient services for such purposes. The search terms used in the writing were verified with the MESH and DeCS descriptors, and were: "palliative care", "oncological diseases", "oncological patient", "emotional support".

Development: palliative care improves the quality of life of patients despite the circumstances in which they may find themselves and supports families facing organizational problems associated with the suffering of the imminent loss due to the life-threatening illness of a loved one. Palliative care stands out through the relief of suffering through the early identification, evaluation and precise treatment of physical, psychological and spiritual pain; requires an interdisciplinary approach that involves the patient, family, and community in action; indeed, the practical and philosophical notion of an interdisciplinary team is crucial to providing quality palliative care.

Conclusions: improving the quality of medical services and the preparation of health personnel is vital to provide support in these cases of advanced oncological diseases.

Keywords: Palliative Care; Oncological Diseases; Oncology Patient; Emotional Support.

RESUMEN

Introducción: el papel de los cuidados paliativos al final de la vida es vital para aliviar el sufrimiento mediante la evaluación y el tratamiento integrales de los síntomas físicos, psicosociales y espirituales de los pacientes.

Objetivo: argumentar la importancia de la calidad de los cuidados paliativos en pacientes con enfermedades neoplásicas.

Método: la investigación se realizó mediante una recolección de información en diferentes buscadores de artículos científicos como PubMed, Google Académico, Medline, Scielo, Scienca Direct, Elsevier, Medigraphic, ResearchGate. La estrategia de búsqueda se limitó a los artículos en un rango desde el 2019 hasta el 2023, en idioma español e inglés acerca de los cuidados paliativos en pacientes con enfermedades oncológicas y sobre la importancia de la satisfacción de los usuarios de servicios ambulatorios para tales fines. Los términos de

búsqueda que se utilizaron en la redacción fueron verificados con los descriptores MESH y DeCS, y fueron: “cuidados paliativos”, “enfermedades oncológicas”, “paciente oncológico”, “apoyo emocional”.

Desarrollo: los cuidados paliativos mejoran la calidad de vida de los pacientes a pesar de las circunstancias en que puedan encontrarse y apoyan a las familias que enfrentan problemas de organización asociados con el sufrimiento de la inminente pérdida por la enfermedad potencialmente mortal de un ser querido. Los cuidados paliativos resaltan a través del alivio del sufrimiento mediante la identificación temprana, evaluación y el tratamiento preciso del dolor físico, psicológico y espiritual; requiere un enfoque interdisciplinario que involucre al paciente, la familia y la comunidad en la acción; de hecho, la noción práctica y filosófica de un equipo interdisciplinario es crucial para brindar cuidados paliativos de calidad.

Conclusiones: mejorar la calidad de los servicios médicos y la preparación del personal sanitario es vital para brindar soporte en estos casos de enfermedades oncológicas avanzadas.

Palabras clave: Cuidados Paliativos; Enfermedades Oncológicas; Paciente Oncológico; Apoyo Emocional.

INTRODUCTION

Cancer is one of the leading causes of mortality in the world, so in 2018, there were 18,1 million new cases and 9,5 million deaths from cancer in the world; it is anticipated that by 2040, the number of new cases of cancer per year will increase to 29,5 million and the number of deaths from cancer to 16,4 million. Similarly, the Pan American Health Organization (PAHO) defines cancer as the leading cause of death in Latin America because, in 2018, there were about 3,7 million new cases and an estimated number of deaths of 1,3 million. Look who is the new case 32 % increase by 2030 could reach 15 million cases.⁽¹⁾

The World Health Organization (WHO)⁽¹⁾ reports that cancer is one of the leading causes of death worldwide: almost 10 million deaths and about 20 million cases by 2020, and the number of cases is predicted to increase by 65 % over the next 20 years in low- and middle-income countries, where survival rates are currently the lowest. Likewise, in the Region of the Americas, 4 million people were reported to have been diagnosed with cancer in 2020, and 1,4 million died; approximately 57 % of new cancer cases and 47 % of deaths occur in people 69 years of age or younger when they are in the best stage of their lives.⁽²⁾

In Peru, the National Institute of Neoplastic Diseases (INEN) recorded 2021 an average of 17,500 new cases of cancer among males and females, a figure that increased by 40 % compared to 2020 statistics; most of the patients are from the interior of the country.⁽³⁾

In relation to palliative care in cancer patients, it is a relevant issue for health professionals, especially nurses, who are obliged to provide comprehensive palliative care despite the pandemic by COVID-19; this has limited and has emerged the distancing of health personnel from the patient for care and act under new biosafety protocols, which make their work is seen as less humanized than before the pandemic for fear of contagion by the vulnerability they present. It is estimated that annually, 40 million people need palliative care; 78 % of them live in low and middle-income countries, and currently, worldwide, only 14 % of the people who need palliative care receive it.⁽²⁾

With regard to the quality and satisfaction of patient services in a number of high-income countries, 1 in 10 patients suffer harm while receiving hospital care, and 7 out of every 100 hospitalized patients are expected to contract a healthcare-associated infection; it has been estimated that high-quality health systems could prevent 2,5 million deaths from cardiovascular disease, 900,000 deaths from tuberculosis, 1 million newborn deaths and half of all maternal deaths each year. Globally, the structures essential for quality care need to be improved: 1 in 8 health facilities has no water supply, 1 in 5 has no sanitation, and 1 in 6 has no hand-washing facilities at the point of care. As a result, patients and their families are dissatisfied with the health services provided by health institutions.⁽²⁾

Fusi-schmidhauser et al.⁽⁴⁾ indicate in their research that the most relevant complaints or claims were found in patients who need physical support care, followed by psychological support, social support and spiritual support; while this was happening with the patients in the institutions providing health services, they began to change the strategies of attention to the oncological patient who needed palliative care, the orientations for physical support became virtual and the pharmacological therapies are done via delivery, with indications for their application by the patient himself, the medical attention also became online and the relationship therapies are in the hands of family or private caregivers; emotional assistance to the patient, to the family, practically disappears from the de facto formats, only in the written protocols and recommended for health personnel: but as time went by this distorted the processes and the very structures of corporate action in health institutions, it can be said that this care needs to be reformulated according to the needs and possibilities for the patient to assimilate it.

In Peru, Garcia MT⁽⁵⁾ indicates that patients perceive a regular level of 61,1 % as satisfied with nursing care;

these results indicate the need to continuously assess this indicator, which will help to improve the quality of patient care and the degree of satisfaction. In addition, it indicates that comprehensive care in health services has been affected by the biomedical vision of health, where care is understood based on norms, records, routines, and behavioral patterns, generating in many nurses an overload of work and mechanized tasks, making their work invisible; On the other hand, specialized health institutions hire health personnel to work with little experience, which requires that health professionals, especially nurses, continue to train and qualify to take on the challenge of palliative care for quality care.

Currently, the number of oncological patient problems in hospitalization and consultation services has increased, and this increase in the demand for health services has affected quality indicators. Patients and family members express dissatisfaction about waiting time for hospitalization and consultations; the perceived quality of service has much to do with aspects: care, organization, relationships, and management of the culture of health safety.

Therefore, the quality of service must be improved in order to achieve an important indicator, which is satisfaction on the part of users as a result of the quality of service provided. Likewise, oncology patients state that they perceive dissatisfaction with the services offered in the chemotherapy area, and these manifestations are expressed in the complaint book for reasons such as continuous rotation of human resources, lack of information, inadequate interpersonal relationships with the nursing staff, high demand for health services, among others. Likewise, there may be little social, psychological, and spiritual support, which is considered fundamental; this phenomenon is visible when measuring both variables using a measurement scale that results in a basis for implementing improvement plans and strategies to improve both indicators.

METHOD

The research was carried out by collecting information from different search engines for scientific articles, such as PubMed, Google Scholar, Medline, Scielo, Science Direct, Elsevier, Medigraphic, and ResearchGate. The search strategy was limited to articles in a range from 2019 to 2023, in Spanish and English language, about palliative care in patients with oncologic diseases and the importance of satisfaction of ambulatory service users for such purposes. The search terms used in writing were verified with the descriptors MESH and DeCS and were: “palliative care,” “oncologic diseases,” “oncologic patient,” and “emotional support.”

For inclusion and exclusion, the studies were evaluated according to the PRISMA method guidelines. We included articles such as management and protocol guidelines, randomized controlled trials, field studies, observational design studies, cross-sectional studies, and studies reporting results of the Mediterranean diet in patients with systemic lupus erythematosus. Articles older than five years, studies in any language other than Spanish or English, letters, commentaries and opinions, duplicate studies, and studies that were not relevant to the research topic were excluded.

DEVELOPMENT

Muñiz-Sobrinó M *et al.*⁽⁶⁾ carried out the study: “Degree of satisfaction of caregivers of patients who have received palliative care in the community setting” with the aim of finding out the degree of satisfaction of caregivers of patients who have received palliative care in the community setting. The sample consisted of 137 patients, 89,2 % of whom were oncology patients and 8,1 % of whom suffered from advanced chronic illnesses. The results reached a medium level, with 67,6 % and 83,3 % of the patients being satisfied with the palliative care received. They concluded that caregiver satisfaction increased when the patient died at home, if the team helped the patient to grieve peacefully, if the relationship was that of children, and when previous instructions were respected, satisfaction was high. However, there were areas for improvement in the approach to grief and symptomatic control.

Burgueño F *et al.*⁽⁷⁾ in Ecuador carried out their study “Perception of the quality of nursing care in oncology patients in Austro Ecuatoriano.” It aimed to determine the perception of the quality of nursing care in oncology patients in Austro Ecuatoriano during 2018; quantitative methodology cross-sectional study, the sample was 216 users attending oncology treatment, its instrument was the questionnaire of Perception of Quality of Nursing Care Quality (CUCACE); The results were 65,3 % have a positive perception of the quality of nursing care, and a correlation with statistical significance was found with the variable age ($p=0,000$) and level of education ($p=0,001$). It was concluded that patients express a degree of positive satisfaction in the attention and care received from the nursing field, specifically those diagnosed with breast cancer and other types of cancer.

Cecilia C *et al.*⁽⁸⁾ in Uruguay carried out a study to determine the degree of satisfaction expressed by the patients who attended the Mastology Teaching and Care Unit of the Hospital de Clínicas and to identify aspects to improve. The results showed a high level of patient satisfaction with the overall care received, with a mean score of 3,26 (95 % CI 3,18-3,34) (range: 1: poor; 5: excellent); this result is independent of age group and type of oncologic treatment received.

However, 38,5 % of working patients think that they were unable to discuss the impact of the disease on

their work (mean 1,82; 95 % CI 1,66-1,97) (range 0: not at all; 3: as much as I wanted) and 27 % of the total respondents think that they could not discuss the impact their disease had on their daily activities (mean 2,13 CI 95 % 2,12 - 2,14) (range: 0: not at all ; 3: if as much as I wanted) nor on their relationships (27; 30 %, mean 2,0 CI 95 % 1,93-2,2) (range: 0: not at all ; 3: if as much as I wanted).⁽⁸⁾

Culquitante KB⁽⁹⁾, in his research on the quality of nursing care and the level of satisfaction of oncology patients in chemotherapy, evidenced that 84,4 % of cancer patients undergoing chemotherapy received good care from nurses. 80,7 % of oncology patients undergoing chemotherapy are satisfied with nursing care. It is concluded that there is a significant relationship ($R^2 = 0,184 < 1$) ($p = 0,00001 < 0,05$) between the quality of nursing care and the level of satisfaction of oncology patients in chemotherapy.

Guillén DY⁽¹⁰⁾ in his study: "Knowledge and attitudes towards palliative care of the terminally ill, among nurses of the health service of the Dos de Mayo National Hospital," Lima, showed that 73 % were familiar with palliative care, 46 % in physical means; 69 % feeding the dying patient; 84 % know how to treat self-esteem; and 67 % feeling; 69 % know about social assistance; and 74 % pointed out the patient's interest in spirituality. It was concluded that most nurses in the medical profession are familiar with palliative care of terminally ill patients.

Also, Flores RE⁽¹¹⁾ states that end-stage patient care is a health problem that is on the rise due to the increase in the prevalence of chronic diseases and aging, with dependence, comorbidity, and fragility, with care needs and, most importantly, palliative care.

On the other hand, *oncology patient satisfaction* with the quality of palliative care is defined as a subjective perception or representation of the processes that take place during patient care. This perception or social representation of the care received is a product of the way we understand a process that occurs in the human body (the disease) and is experienced physically and mentally. Body and mind are two parts of the same whole.^(12,13)

For Salazar M⁽¹⁴⁾, there is a tool such as SERVQUAL (Quality Service) which is used to determine the level of satisfaction with the quality of service provided to users, customers, patients, beneficiaries and their perceptions of the service provided by an organization, and can be a measure of the quality of service. It is divided into one dimension:

The dimension of satisfaction with the service received refers to the security and trust generated by the attitude of the personnel who provide the health service, demonstrating knowledge, privacy, courtesy, ability to communicate, and inspire confidence in the patient in all aspects, respecting his or her culture and customs. In addition, the user's perception of how the user perceives that the organization complies with the delivery of the health service offered. Quality depends on the user's perspective. Therefore, quality is considered to exceed the user's expectations in a way that meets the needs of the user. Medical support services.⁽¹⁴⁾

These are units producing health services that operate independently or within an inpatient or outpatient facility, as appropriate, that provide complementary or auxiliary services to medical care, the purpose of which is to assist in the diagnosis and treatment of clinical problems: external user; a person who comes to a health facility to receive continuous and quality health care, in the context of family, in relation to the quality of palliative care, palliative care is conceptualized as active and holistic care for patients of all ages with intense health-related suffering due to severe illnesses and, especially, in those who are in their last days of life. This definition is particularly important because it orients the corporate actions of the institutions toward improving the quality of life of patients, relatives, and caregivers.⁽¹⁵⁾

The variable quality of palliative care in the practice of oncology patients requires support services in a timely and continuous manner, making the patient feel satisfied with the services provided. There are cases of oncology patients who, due to their condition of dependency, can rarely maintain the comfort and hygiene they need, and health personnel are reluctant to change the patient's position, to clean their mouth or wash their hands and face, mainly for fear of being infected by intrahospital nurses.⁽¹⁶⁾

Health personnel are rarely willing to monitor or follow up on the palliative care needed by the oncology patient. On the other hand, Salazar M⁽¹⁴⁾ defines palliative care as having the objective of improving the quality of life of oncology patients and their families when they are facing life-threatening situations such as cancer:

Dimension 1 Physical support

It aims to help the patient to be oriented to follow their therapies in a normal and safe way and to count on specialized medical care to help them relax in the midst of the pain and discomfort generated by their health situation. One of the most useful ways to help the development of palliative care is to monitor the existence of programs on the care they can and should physically receive. This can be interpreted as efforts to improve the quality of life of oncology patients.⁽¹⁵⁾

Dimension 2 Psychological support

It focuses on the mind, as the mind depends on the body to receive information from patients and their immediate care, including the preparation of behavior creatively and harmoniously, including cognitive aspects that lead to perceiving, thinking, knowing, understanding, and problem-solving. This approach, which may

seem like a lack of empathy, is very important for the people around the patient and the patient himself to accept his reality and what may happen to his life so that the psychological traumas left by his illness and possible death have less impact on people's lives.⁽¹⁷⁾

Helping someone psychologically helps to strengthen a person's ability to cope with adverse situations in their life. It brings benefits such as improving their well-being, as well as providing them with tools to better cope with future conflicts. Receiving psychological support involves working with a mental health professional to cope with the challenges that come with a cancer diagnosis. Counseling can help you understand your feelings and reactions and provide a safe place to talk about your concerns.⁽¹⁷⁾ This health professional is also responsible for conducting campaigns to promote healthier lifestyles and awareness campaigns.⁽¹⁸⁾

Dimension 3 Social support

It indicates that the oncology patient always needs help with greater economic efforts to deal with a disease that requires a highly specialized treatment at a high cost to the oncology patient.⁽¹⁵⁾ Also, the social support generated by his behavior is conflicting expressions, unjustified anxieties, and even economic order, which leads to distorting the behaviors in front of others.⁽¹⁹⁾

Dimension 4 Spiritual support

It is defined as the form or expression of the influence of religion in social phenomena. It is a kind of spiritual need that is born in the idea that the history of his life and the life of others is a kind of plan inspired and arranged by God; others think that it is a matter of religious faith inculcated socially and culturally before he even has use of reason.⁽¹⁶⁾ Spiritual support has become a factor of adhesion and personal devotion; through it, a more dignified treatment is finally sought; that is, spiritual support works on the meaning of life and death, leading to a better understanding of what happens with the patient and his surroundings.⁽²⁰⁾

Palliative care is a fundamental and inherent activity that establishes a deep and meaningful relationship with the patient until death; being necessary for this profession to integrate the two dimensions of care immersed in the culture (collective and individual practices) and the other in the moral which gives a value to care, a good that gives legitimacy to act. The oncological phenomena of care and its theoretical components will give a coherent and consistent sense of nursing as a human science.⁽²¹⁾

The current concept of quality in the context of health care needs to have a multidimensional perspective that encompasses all the groups involved in care, professionals, users, and administration, with the objective that all aim to achieve the ideal of integrated care. The aspects of the principles of ethics, technique, scientific knowledge, and interpersonal relations are dimensions of quality, which is a set of factors that are necessary to achieve excellence in the professional practice and on the part of the professionals to guarantee quality requires a deep reflection on values, knowledge, attitudes and norms that should be directed towards the objectification of the internal good.⁽¹³⁾

In the same way, the nursing professional plays a fundamental role in improving the quality of life of the patient with an advanced or terminal illness; the motto that encompasses the philosophy of palliative care includes "cure sometimes, improve often, care always." In this sense, providing palliative care is to give the most basic concept of care, the same care that meets the needs of the patient, regardless of where he or she is being cared for. One definition of palliative care is that "palliative care neither hastens nor delays death in which life/death is a normal process, aiming at the best quality of life, until the end."⁽⁸⁾

The WHO⁽¹⁹⁾ states that patients and their families understand the nature of the disease and the prognosis is a crucial aspect of palliative care near the end of life. In addition, palliative care specialists help patients and their families determine appropriate medical care and align the patient's goals of care with those of the health care team. Finally, establishing the need for a medical proxy, advance directives, and resuscitative status is an integral part of palliative care at the end of life. Patients approaching the end of life may experience extreme symptoms that include physical, spiritual, and psychosocial suffering.

Important factors for seriously ill patients include adequate control of pain and other symptoms, avoiding prolongation of the dying process, achieving a sense of self-control, finding meaning in life, and easing the burdens of caring for family and loved ones while strengthening and completing those same relationships. As death approaches, the symptom burden increases while the patient's and family's tolerance for physical and emotional stress decreases. At this time, primary palliative care interventions should take precedence, and the focus on restorative care should diminish.⁽²²⁾

Palliative care promotes and improves the quality of life of patients and their families facing problems associated with life-threatening illnesses through the prevention and relief of suffering by early identification and accurate assessment and treatment of pain and other physical illnesses, psychosocial and spiritual problems, is an interdisciplinary approach that involves the patient, family, and community in action; indeed, the practical and philosophical notion of an interdisciplinary team is crucial to providing quality palliative care.⁽²³⁾

Thus, the composition of palliative care teams varies according to patient needs and available resources; the

presence of a nurse is constant and constitutes the first link between team, patient, and family, implementing the health plan established in each context of care: Nurses, therefore, play a fundamental role in palliative care, acting in the best interest of patients and their families and providing care on an ongoing basis.

While dying is a normal part of life, death is often treated as an illness; as a consequence, many people die in hospitals, alone and in pain; that is why palliative care focuses primarily on anticipating, preventing, diagnosing, and treating the symptoms experienced by patients with a serious or life-threatening illness and helping patients and their families make medically important decisions. The ultimate goal of palliative care is to improve the quality of life for both patient and family, regardless of diagnosis. However, palliative care, unlike hospice care, is not dependent on prognosis. As the end-of-life approach intensifies, the role of palliative care intensifies and focuses on aggressive symptom management and psychosocial support.⁽²⁴⁾

Compassionate palliative care requires professional preparation of specialists in this field to explore issues of integrity preservation that will foster growth in dignity and transcendence; open, reflective questions are key to optimizing this communication and assessing patient and caregiver willingness to engage.⁽⁸⁾

CONCLUSIONS

Physicians, psychologists, nurses, and social workers can enhance the patient's peace and psychosocial spiritual comfort. The role of palliative care at the end of life is to alleviate the suffering of patients and their families by comprehensively assessing and treating the physical, psychosocial, and spiritual symptoms that patients experience. As death approaches, a patient's symptom burden may worsen and require more aggressive palliation; once death has occurred, the role of healthcare providers is primarily focused on supporting the patient's family and bereavement.

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