

Level of knowledge about palliative care of patients in rehabilitation services

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Abstract

Objectives. One of the objectives of the study was to quantify the participants' knowledge of palliative care by asking them to answer a set of questions that were specific to the field, but clear and easy to understand. Another objective of the study was to observe the participants' level of knowledge according to their background and gender.

Material and methods. The research activity at the basis of the study consisted in administering questionnaires to a sample of 100 patients from the rehabilitation services, i.e., the Physical Medicine and Recovery Department of the Victoria City Hospital, Brasov County. The participants were given a questionnaire consisting of 26 questions related to palliative care. Thus, the structure of the 26-question questionnaire consisted of three open-ended questions (questions 1,2,26), twelve closed dichotomous questions (questions 3,8-14 and 16-19), two closed trihotomous questions (questions 4,6) and eight multiple choice questions (questions 7,15,20-25).

Results. Out of the 100 respondents, the majority of survey participants stated that they were partially familiar with palliative services, knowing some information about the topic. Of the remainder, 15% said they were very familiar with the topic, and 7% had not heard of palliative care at all.

Conclusions. Given the results obtained from the administration of the questionnaires to the described sample, the level of knowledge about palliative care is moderate, with gaps that need to be strengthened by information both, through the media and through medical staff, which would lead to the dismantling of myths and misconceptions.

Keywords: palliative care, rehabilitation, cancer diseases, quality of life

Rezumat

Obiective. Unul dintre obiectivele studiului l-a reprezentat cuantificarea cunoștințelor participanților la studiu vizavi de paliatie prin solicitarea de a răspunde la un set de întrebări specifice domeniului, dar totuși clare și ușor de înțeles. Un alt obiectiv al studiului a fost reprezentat de observarea gradului de informare a participanților în funcție de mediul de proveniență și genul acestora.

Material și metode. Activitatea de cercetare aflată la baza realizării studiului a constat în administrarea de chestionare unui eșantion de 100 de pacienți din serviciile de recuperare, respectiv, Compartimentul de Medicină fizică și Recuperare din cadrul Spitalului Orășenesc Victoria, județul Brașov. Participanților li s-a oferit un chestionar alcătuit din 26 de întrebări legate de sfera îngrijirilor paliative. Astfel structura chestionarului format din cele 26 de întrebări a constat în trei întrebări deschise (întrebările 1,2,26), douăsprezece întrebări închise dihotomice (întrebările 3,8-14 și 16-19), două întrebări închise trihotomice (întrebările 4,6) și opt întrebări cu răspuns multiplu (întrebările 7,15,20-25).

Rezultate. Din cei 100 de respondenți, majoritatea participanților la studiu au afirmat că sunt parțial familiarizați cu serviciile paliative, cunoscând câteva informații despre acest subiect. Din restul rămași, 15% au afirmat că sunt foarte familiarizați cu acest subiect, iar 7% nu au auzit deloc despre acest tip de îngrijiri.

Concluzii. Având în vedere rezultatele obținute în urma administrării chestionarelor eșantionului descris, nivelul de cunoștințe cu privire la îngrijirile paliative este unul mediu, cu lacune care necesită consolidare prin informare atât prin mijloace mass-media, cât și prin intermediul personalului medical, fapt ce ar duce la desființarea miturilor și concepțiilor greșite.

Cuvinte cheie: paliatie, recuperare, boli oncologice, calitatea vieții

Introduction

The last decade has led to important developments in human rights standards for dealing with palliative care. The identification of access to palliative care and the treatment of pain as human rights issues first emerged among lawyers and doctors as early as the 1990s. Clinical Practice Guidelines for Quality Palliative Care were first launched in 2004, expanding the focus of palliative care to include not only dying patients, but also patients diagnosed with life-limiting illnesses. [1, 2]

Palliative care is an essential component of the health services available to people in need of such care. The alleviation of human suffering, whether it is psychological, physical, social or spiritual, is a global ethical responsibility. The primary objective of palliative care services is to relieve suffering and improve the quality of life of patients with progressive chronic diseases and for their family members. [3]

The World Health Organization indicates that "palliative care is applicable from the onset of illness, in conjunction with other therapies that are intended to prolong life, such as

chemotherapy or radiotherapy, and includes those investigations needed to better understand and manage complications." Early integration of palliative care is of great importance to enable medical teams to provide early relief of physical and psycho-social suffering, to establish a relationship with patients and families, and to discuss discharge planning issues that could result in the prevention of deaths in both, hospitals and intensive care units.

These services consist of assessing the severity of the patient's symptoms and determining the methodology for dealing with them, providing decision support, assisting in matching patient and caregiver expectations with the optimal treatment regimen for each individual, and providing interdisciplinary care models across institutions. Palliative care services integrate the expertise of a team of specialists from different fields to meet the complex needs of seriously ill patients and their families. Members of a palliative care team usually include medical, nursing and social care professionals, with additional support from the chaplain and professionals from nutrition, rehabilitation, pharmacy as appropriate. Studies over time show that palliative care is beneficial when introduced at the time of diagnosis of a serious, life-threatening illness, applied at the same time as the initiation of all other appropriate medical therapies. The fact that palliative care has led to improved quality of life is consistent with the results of other studies of both, non-hospice palliative care and hospice [4,5].

In view of the above, this paper aims to measure the level of knowledge about palliative care services of a sample of patients in rehabilitation services. Taking into account that physiokinetic therapy is a method of choice in combating certain symptoms and increasing the quality of life of patients in palliative care services, and the importance of interdisciplinary collaboration, it is intended to analyze the level of awareness of this type of care of patients receiving treatment in the sphere of medical rehabilitation, the purpose of the work being to measure the level of knowledge about palliative care that patients in rehabilitation services have.

The objectives proposed in this paper are to assess the knowledge of patients in rehabilitation services about palliative care, the needs of patients who use these services, their suffering and difficulties. It will also seek to identify the sources of information of the study participants about the field of palliative care, the extent of their interaction with people receiving such services, their views about referral to palliative care services and potential misconceptions and myths about palliative care.

Material and methods

The current study is a quantitative observational study and the research activity at the basis of its realization consisted in administering questionnaires to a sample of 100 patients from the rehabilitation services, namely, the Physical Medicine and Recovery Department of Victoria City Hospital, Brasov County. Participants in the study were given a questionnaire consisting of 26 questions related to palliative care. Thus, the structure of the 26-question questionnaire consisted of three open-ended questions (questions 1,2,26), twelve closed-ended dichotomous questions (questions 3,8-14 and 16-19), two closed-ended trihotomous questions (questions 4,6) and eight multiple choice questions (questions 7,15,20-25).

The first 5 questions required the completion of first and last name initials, age, gender, level of education and background. Questions 6 and 7 sought to identify the level of information

about palliative care and sources of information. Thus, for the question "How familiar are you with the concept of palliative care?", the response options given were "not at all", "partially" or "very familiar", and for question 7, a multiple choice question, "If you have heard about this type of service, what is the source of information?", the response options given were "Internet/social networks, newspapers/magazines, medical staff, close friends/family members, own experience, others". This was followed by a series of dichotomous questions with true/false response options, shown in the table below.

Table 1 - Series of dichotomous questions in the questionnaire

Question 8	Palliative care means end-of-life care.
Question 9	Palliative care is provided when nothing else can be done for the patient.
Question 10	Palliative care can be provided to any patient who needs it, regardless of age.
Question 11	Patients in need of palliative care are terminally ill, dying patients.
Question 12	Palliative care can only be provided in a hospital setting.
Question 13	Palliative care services are only for patients with various forms of cancer.
Question 14	Palliative care quickly leads to the patient's death.
Question 16	Before the start of palliative treatment all other types of treatment will be discontinued and abandoned.
Question 17	The aim of palliative care is to combat the patient's physical, psychological, social and spiritual suffering.
Question 18	Good communication based on transparency and trust between carers and patients is needed in palliative care.
Question 19	One of the goals of palliative treatment is to improve the patient's ability to participate in normal daily activities.

Another question, a multiple-choice question phrased as follows: "What do you think are the factors that hinder the general public's awareness of palliative care services?" had the following response options: "fear of discussing illness or death", "lack of information about the availability of these services", "questioning the effectiveness of this type of care", "lack of trust/interest in these health services".

Another multiple-choice question in the questionnaire, "The goals of palliative care include", had the following response options: "Pain relief", "Fighting symptoms such as depression, anxiety", "Convincing the patient that there is nothing more that can be done for them", "Spiritual/religious support", "Limited communication of information about the progress of the disease to the patient and their family", "Ensuring the patient's dignity", "Improving quality of life".

The following multiple-choice question, "Palliative care can be provided", had the following answers: "in hospital", "in a unit

specialised exclusively in palliative care", "at home", "in a doctor's surgery of any speciality".

A multiple-choice question asked about the composition of the multidisciplinary team, so it was worded as follows: "The multidisciplinary team responsible for providing palliative care consists of" and had the following variants: "Doctor", "Nurse", "Psychologist", "Priest/spiritual counsellor", "Physiotherapist", "Nutritionist".

For the multiple-choice question, "Palliative care consists of", the available answers were: "Appropriate medication to relieve symptoms", "Personalised physiotherapy programme", "Support for the patient's family to adapt to the patient's situation and needs", "Nutritional support", "Spiritual counselling", "Curative treatment".

Another multiple-choice question sought to identify conditions requiring palliative care. Asked "For which of the conditions listed below can palliative care be provided?", the options available were: "Cancer disease", "Hypertension", "Multiple sclerosis", "Heart failure", "Dementia".

The last multiple-choice question in the questionnaire, "What do you think are the main patient needs in palliative care services?" had the following response options: "Relief of physical symptoms such as pain, nausea, vomiting", "Feeling of reconciliation with the Divine", "Financial support", "Presence of loved ones with the patient".

The last question in the questionnaire is an open-ended question that aims to observe the respondent's perception of palliative care and was worded as follows, "What are 3 words that come to mind when you think of palliative care?"

The questionnaire was assembled in such a way as to investigate the level of information and opinions of the participants regarding the goals of palliative care, the relationship of the medical staff with the patient and their family, the needs of patients with palliative care needs and symptom control.

Results

Participants in the study ranged in age from 28 to 83, with an average age of 54.96. Most respondents to the questionnaire, 29%, were in the 50-59 age category and the fewest in the 20-29 age category.

Given that the institution where the research was conducted serves both rural and urban patients, the higher percentage is represented by the urban category, i.e. 57% and only 43% by the rural category.

When asked "How familiar are you with the concept of palliative care?" the response rate ranged from "not at all" to "partly" to "very familiar". the majority of survey participants said they were partially familiar, knowing some information about the topic. Of the remainder, 15% said they were very familiar with the topic and 7% had not heard anything about this type of care.

A correlation was made between the participants' background and their level of awareness of palliative care to see if awareness is influenced in any particular way by the background factor. So as can be seen in the graph below, only 1% of urban respondents said they had not heard at all about palliative care as opposed to 6% of rural respondents, while 48% of urban participants said they were partially familiar with the topic, only 30% of rural respondents said the same.

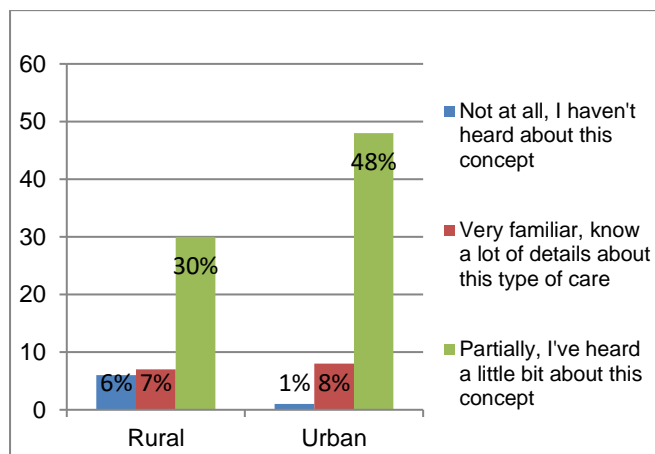


Figure 1 - Correlation between background and knowledge about palliative care

Another correlation was made between the level of awareness of the topic under discussion and the gender category, thus according to the graph illustrated below it can be seen that both female and male participants were predisposed to state that they were partially familiar with palliative care. Also, both gender categories had the lowest rate of stating that they had not heard about this topic at all, namely 6% for the female category and 1% for the male category.

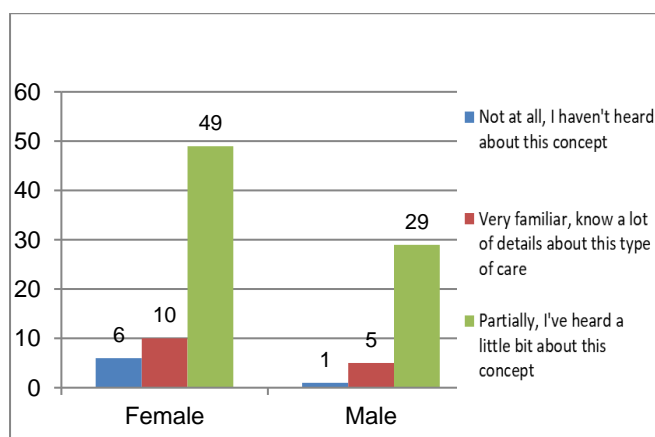


Figure 2 - Level of familiarity with the concept of palliative care by gender

Looking further to identify the most common sources of information it was observed that the main source of information about palliative care services for the sample members was "close friends/family members" at 44%, followed by "medical staff" at 35% and "internet/social media" at 27%. There were participants who also mentioned other sources of information such as medical studies or television, but the rate of these responses was only 5%.

For the statements in items 8 and 9, "Palliative care means end-of-life care" and "Palliative care is provided when nothing else can be done for the patient" where participants were asked to answer "true/false", the majority of respondents considered the first statement to be false while the second was considered by the majority to be true.

Thus, 54% of respondents believe that palliative care does not mean end-of-life care, which is entirely correct, as palliative care is available to those who need it as soon as they are diagnosed with a chronic progressive illness.

In the case of the second statement, 54% of the participants believe it is true that palliative care is provided when nothing else can be done for the patient, while only 46% consider this to be false, the latter being the correct one.

In the questions "Palliative care can be given to any patient who needs it, regardless of age" and "Patients who need palliative care are terminally ill, dying" with the response options "true/false", a significant percentage of the sample considered the first statement to be true, while opinions were divided on the second statement.

Thus, in the case of the first statement, 94% of the participants in the study considered it true that palliative care is available to any patient who needs it, age not being an eligibility criterion, which is correct because palliative care can be provided to any patient diagnosed with an incurable disease, regardless of age.

In the case of the second statement, 52% of survey participants decided that the statement that patients with palliative needs are dying patients is false, a correct response based on the previous arguments that any patient diagnosed with a progressive, life-threatening chronic condition can benefit from palliative care.

In the case of the questions "Palliative care can only be provided in a hospital setting" and "Palliative care services are only available to patients with different forms of cancer" with the response options "true/false", both were considered false by a large proportion of participants, namely 73% for the first statement and 63% for the second.

Therefore, the predisposition of the group of respondents towards the correct options, i.e. the truth that palliative care cannot be provided exclusively in a hospital setting and that palliative care is not only for cancer patients, indicates the presence of basic information about these services.

The question "Does palliative care lead quickly to patient's death" with the answer options "true/false" was considered false by almost all participants in the study, 96%, which shows that most of them are confident that palliative care brings real benefit to the patient diagnosed with a chronic progressive disease.

However, it should be noted that the claim that palliative care leads rapidly to the death of the patient is false, as palliative care aims to improve the patient's quality of life.

In the case of the question, "In palliative care services there is a need for good communication based on transparency and trust between health care staff and patient" and, "One of the goals of palliative care is to improve the patient's ability to participate in normal daily activities", most of the respondents considered the two statements to be true so that in the case of the first one 97% of them thought it was true and in the case of the second one 93% of them thought it was true.

It is necessary to specify the veracity and accuracy of the statement that in palliative care services transparent communication based on trust is necessary to build a close relationship between health care professionals and patient, which will benefit the difficult situation.

One of the multiple-choice questions aimed to observe which goals are important and relevant from the study participants' point of view for a patient in palliative care services. After collecting the responses, it was observed that among the most popular answers were "Pain relief", which was present in 86%

of the responses, "Improving quality of life", which was present in 74% of the responses and "Fighting symptoms such as depression, anxiety", which was present in 64% of the responses. Then "Ensuring the dignity of the patient" was present to the extent of 48%, followed by spiritual or religious support to the extent of 27%, then there were a small number of responses which included the variants of limited communication of information to the patient and relatives and the patient's belief that nothing can be done, meaning in percentages 15% and 3%.

Therefore, it is necessary to specify that normally the goals of palliative care include pain relief, ensuring the patient's dignity, combating psycho-emotional symptoms, transparent and trust-based communication, spiritual support and thus increasing the quality of life.

In another multiple-choice question, respondents were asked to choose from the options presented those they considered to be the patient's needs in palliative care services. The most chosen options were relief of physical symptoms (49%), followed by the presence of loved ones with the patient (30%), then a sense of reconciliation with the Divine (13%) and financial support (8%).

In the case of this question, the correct answers may vary from one patient to another depending on traits, lifestyle, living environment.

Discussions

The collection of the answers to the questions and the observation of their variation reveal an moderate level of information, but also a slight uncertainty in terms of having information on palliative care. It was also possible to observe a slight inclination towards associating this type of care with suffering, sadness and death, especially after analysing the last question of the questionnaire, where words such as courage, hope, but also resignation and suffering predominate. The predominant sources of information were close friends, family members or medical staff, responses from which indicate the possible experience of a chronic progressive illness of one or more people around the respondent to the questionnaire. Also, in the questions that focused on the needs of the palliative patient or the goals of palliative care, there was a tendency towards responses that involved coping with physical and psychological symptoms, pain relief and then choosing responses such as nutritional support, family presence or spiritual support.

Final conclusions

Palliative care is still unknown to certain segments of the population because of misconceptions about it, its association with serious illnesses such as cancer and even death, and a lack of interest in or confidence in such services. In conclusion, taking into account all the above and the results obtained from the administration of the questionnaires to the described sample, the level of knowledge about palliative care is moderate, with gaps that need to be strengthened by information both, through the media and medical staff, which would lead to the dismantling of myths and misconceptions.

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