Palliative care in the perception of families with patients oncology surgery

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ABSTRACT

Introduction: The family's participation in palliative care is usually very high, especially when the patient is in hospice home care.

Aim of the study: The study aimed to assess the perception of palliative care by families of oncological patients from Podlaskie Province, Poland.

Materials and methods: The study included 108 oncology surgery patients' families, 50.8% women and 49.2% men, aged 40 to 80 years. The study used the method of a diagnostic survey with the use of a proprietary questionnaire.

Results: 66.7% of people recognized the hospice as comprehensive care for the terminally ill patient; 74.9% of them had positive associations with the hospice; 82.4% of people believed that death was a natural phenomenon; 75.2% were against euthanasia; according to 89.8%, the information provided to the family in a hospice should be comprehensive; support in the hospice should be provided mainly by a permanent clergyman (76.4%) and people after the loss of a loved one (65.4%); the most desirable religious practices in the hospice were the mass (86.7%), rosary prayer (81.6%), confession (81.2%) and sacraments (81.2%); in the hospice showing a lot of kindness, smile and courtesy on the part of the hospice staff to patients (92.5%) and their families (88.5%); the patient should have unlimited access to a clergyman of his religion (98.8%), a psychologist (98.1%) and a physiotherapist (94.6%) in a hospice; according to 87.3% of patients' family members, the society does not pay much attention to palliative care; problems in hospice care result from the growing number of patients with chronic diseases (96.7%) and the lack of public knowledge about palliative care (92.7%); improvement of the quality of medical care in hospices would be achieved by an increase in the number of staff (87.4%) and an increase in the number of beds (82.4%).

Conclusions: In the opinion of most families of patients with cancer, hospice is comprehensive care for terminally ill patients and the right place for terminally ill patients, regardless of their diagnosis. The respondents considered a permanent clergyman and people after the loss of a loved one to be the most appropriate people to provide support to hospice patients. The respondents saw problems in patient care at the end of life, mainly in the increasing number of patients with chronic diseases and the lack of knowledge of society about palliative care, its increase in the number of medical personnel, and the increase in the number of beds. The respondents considered the hospice as a place for people suffering from an incurable disease, regardless of the diagnosis, in which the patient does not feel lonely, has support, can feel safe, and as a form of care for the patient, it would be recommended to other families

Keywords: families of oncological patients, hospice, opinions

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INTRODUCTION

The first information about places where patients were cared for comes from Asia Minor, from Sebasta, from 356. Also, in this part of the world, in Caesarea Cappadocia, Bishop Basil the Great founded the "City of Mercy", a center he called *xenochodium* (hospice), intended for the homeless, wanderers, and the sick [1].

Until the 18th century, the dominant view was that the hospital was to serve all the poor, which was related to the Christian idea of mercy, and a more appropriate term for hospitals at that time was the term orphanage. It was only later that hospitals also began to perform medical functions. It is generally believed that the history of palliative care dates back to the 1950s and 1960s, when the modern St. Krzysztof, was founded by Saunders in London [2].

In the 30 years since its opening, about 4,000 hospices have appeared worldwide, including in Poland.

The British weekly The Economist [3] has published the "Index of the quality of dying," comparing the quality and availability of palliative (terminally ill) care in 40 countries around the world. He points out that this form of care is not widespread, as less than 8% of the approximately 100 million people who can be provided with it each year have access to it [3]. For example, in Poland, thanks to a large number of home care units, Poland ranks 5th in Europe in terms of the development of palliative care [4].

The Latin word "*hospes*", after Sauders [5], means "*both the stranger and the host*", and "*hospitium - both the place where they meet (hospitable home, inn) and mutual relationship (friendship, hospitable adoption)*".

In 1842, Jeanne Gardier, following Wałdowska [6], opened the first home for the dying in Lyon ("Hospice and Calvary"), and the word "hospice" was used for the first time to describe a place intended for the dying. In 1879 the Daughters of Charity established a hospice in Dublin for young people dying of tuberculosis [6]. In 1905, the Hospice of St. Joseph in London, and at the end of the 19th century, Protestant hospices started operating (in 1885 - Friedensheim Rest House, in 1891 - Our Lord's Sanctuary, and in 1893 - St. Luke's House of the Dying Poor) [7].

According to Doboszyńska [8], "*palliative care is active, comprehensive care for patients whose disease is not amenable to effective causal treatment. It includes the management of pain and other symptoms and the management of mental, social, and spiritual problems.*"

The study aimed to assess the perception of palliative care by families of patients with cancer from Podlaskie Province, Poland.

MATERIALS AND METHODS

The research was carried out in 2020 after obtaining the approval of the Bioethics Committee no. APK.002.175.2020 of the Medical University of Bialystok. A total of 130 questionnaires were distributed. Ultimately, the study covered 108 oncology surgery patients' families, including 50.8% of women and 49.2% of men aged 40 to 80 years.

The study used the method of a diagnostic survey with the use of a proprietary questionnaire. The obtained results were subjected to a descriptive statistical analysis in which their percentage distribution was determined for the qualitative features.

RESULTS

In the opinion of 64.8% of respondents, pain and suffering at the end of life is primarily physical experience. This experience prevents normal functioning (56.2%), a spiritual experience (32.9%), a mental experience (32.8%), an element of human subsistence (27.8%), punishment for sins (1.2%) or evil (0.8%).

The respondents declared that during contact with the dying, they most often (48.2%) felt fear. It was not felt by 26.1% of people, and 25.7% had a problem with an unambiguous declaration. 59.4% of family members declared not to avoid contact with the dying. It was avoided by 28.9% of respondents, and 11.7% were not declared on this issue.

The majority of respondents (72.1%) believed it was necessary to fight for the patient's life in the event of the inevitability of death. 82.4% of respondents believed that death is a natural phenomenon that should be considered and fought against as long as possible, but one must come to terms if it is inevitably approaching.

Most people (75.2%) were against euthanasia, but 14.4% of respondents favored unequivocal euthanasia, and 5.1% disagreed on this issue. Euthanasia under certain conditions would be accepted by 5.3% of the respondents. The respondents considered the accepted methods of euthanasia to turn off life-support equipment (25.8%), abandonment of resuscitation (25.6%), and administration of the drug in a lethal dose (12.8%). In comparison, 35.8% did not consider any of these methods as applicable. Most of the representatives of the surveyed families (53.1%) were against the legal acceptance of euthanasia. However, many people (30.2%) had no opinion on the above issue. 16.7% of the surveyed families were in favor of accepting euthanasia.

It was shown that 74.9% of patients' family members had positive associations with the hospice, negative only 9.1%, and 16% of the respondents could not clearly define their position on this matter. Furthermore, 56.7% of respondents did not feel anxiety when thinking about the hospice, 19.3% did not feel it, and the remaining 24% had a problem with an unambiguous declaration.

The respondents believed that hospice is comprehensive care for the terminally ill (66.7%). It is the right place for terminally ill people because the family is not always able to provide appropriate care (61.8%), that it is the only appropriate a place for terminally ill people (50.4%); the hospice is an institution providing inpatient palliative care (33.3%) and that it is a place where the patient has a chance to fight for life and live with dignity (31.9%). In addition, the respondents claimed that patients in hospices receive professional care (79.1%), they can die with dignity (86%), and find relief and peace (56.1%).

According to 65.6% of respondents, the hospice is a place for people suffering from an incurable disease, regardless of diagnosis, a place for people who have cancer only - 59.2% of respondents, only for patients just before death - 53.2%, and 6.7% had no opinion on this point.

The waiting time for admission to the hospice should be less than 8 days - 47.5% of family members, from 8 to 14 days - 31.2%, over 14 days - 26.2%.

In the respondents' opinion, the information provided by the hospice to the family should be comprehensive (89.8%), and 10.2% of people had a problem with an unambiguous answer. According to 97.5% of people, a doctor and 96.8%, a nurse should be willing to provide information to the patient's family. The most significant number of people (76.4%) believed that the family should obtain full information about the patient's prognosis. 12.5% had the opposite belief, and 11.1% had a problem with the answer.

In hospice, the patient's physical, mental and spiritual condition depends on his or her attitude, according to 68.6% of the respondents. The fact that he should always know it was convinced by 28.5%, and the remaining 2.9% had a problem with an unambiguous answer.

The patient should receive as much information as he or she wishes convinced by 64.5% of the respondents. 12.7% of the surveyed families favored the patient's full knowledge of the disease and the fact that the patient should not be told anything because the patient suffers anyway. Hence, it is better to protect him from negative news - 20.8%.

Most respondents (65.2%) were convinced that the patient and family should be informed about their rights, and 34.8% of the respondents said that they did not need to have such information.

According to the respondents, the following people should work in the hospice: every doctor (98.2%), nurse (97.5%), a nurse with a specialization or course in palliative medicine (87.6%), physiotherapist (85.3%), psychologist (83.4%), a physician specializing in palliative medicine (64.8%), an oncologist (54.3%) and a nun (45.3%).

A large group of respondents (68.3%) stated that as a family, it should take part in the care/treatment of the patient. Although 12.5% of respondents disagreed with this opinion, the patient's health condition was dependent - 18.8%, and 0.4% did not comment on this issue.

Most respondents (54.7%) believed that a patient in a hospice does not feel lonely. However, 35.1% of the respondents said otherwise, and 10.2% said it is difficult to state unequivocally.

Support in the hospice should be provided by a permanent clergyman (76.4%), a nurse (52.3%), people after the loss of a loved one (65.4%), a doctor (45.7%), a nun (11.7%), lay people clerics (7.9%), ministers of the Eucharist (5.7%) and lay members of the religious movement (5.4%). In addition, it should be provided to the patient (98.7%), family (95.9%), and staff (87.4%).

Currently, the respondents considered the most desirable religious practices in the hospice the mass (86.7%), rosary prayer (81.6%), confession (81.2%), sacraments (81.2%), reflection on the texts of the Holy Scriptures (35.7%), reading religious books (9.6%), the Way of the Cross (10.2%) and individual prayers (9.6%) and conversations with a priest (3.9%). However, 8.7% of respondents had a problem with giving an unambiguous answer.

In the opinion of 92.5% of respondents - patients and 88.5% - families, the hospice should show a lot of kindness, smile, and courtesy on the part of the hospice staff. However, the other respondents had no opinion on the above issue.

According to the surveyed family members, the conditions in the hospice should be very good (93.5%) or at least good (6.5%). The largest group, 99.3%, said that the hospice should take care of the cleanliness of the rooms. Only 0.7% of the respondents did not express their opinion.

Also, the majority (99.7%) were convinced that the hospice should ensure the patients' safety. A similar group (98.9%) was convinced of the need to ensure patients' intimacy and dignity (98.3%), and only 1.1% and 1.7%, respectively, did not declare themselves unequivocally.

According to 98.8% of respondents, patients should have unlimited access to a clergyman, a psychologist (98.1%), and a physiotherapist (94.6%).

The hospice would recommend 78.4% of the respondents to other families as a form of care for the sick; they would not - 20.4% of them, and 1.2% did not expressly express their opinion on this issue.

According to 87.3% of patient's family members, society does not pay much attention to palliative care, a different opinion was expressed by 9.6%, and 3.1% did not have an opinion on this matter.

The respondents saw problems in an increasing number of patients with chronic diseases (96.7%); a lack of knowledge of society about palliative care (92.7%), and a lack of knowledge of their relatives about how to deal with the dying patient (89.9%). Also, respondents reported a lack of skills in caring for a dying patient (88.7%), the burnout syndrome of members of the therapeutic team (86.7%), a small number of centers in inpatient and palliative care clinics (79.9%). In addition, the respondents emphasized a small number of suitably qualified staff (74.5%), too low financial expenditure on hospices (68.9%), and the absence of psychological skills of the staff (65.4%).

According to the respondents, the improvement of the quality of medical care in hospices would result from increasing the number of medical personnel (87.4%), increasing the number of beds (82.4%), increasing financial outlays for hospices (56.9%), improving the qualifications of medical personnel (55.3%), better supply of medical equipment (45.6%), support for patients and family (39.2%), communication with the patient, family, and care for the patient terminal (31.9%), and more conversations with the patient and his family (30.9%).

DISCUSSION

According to WHO assumptions, palliative care after Czerwik-Kulpa [9] is active and comprehensive care provided to all patients whose disease no longer responds to recovery treatment. Its goal is to achieve the best possible quality of life for patients and their families, and to cover patients in the end-stage of all diseases for which there is no causal treatment, i.e., patients in the end stage of neoplastic diseases, and those suffering from neurological diseases, patients with heart failure, patients with AIDS and patients with non-cancerous respiratory diseases [8]. Ciałkowska-Rysz [10] believes that the hospice is too often described in the social consciousness as the place of the patient's death and rarely is seen as a place of support, symptom control and dignified life, until natural death, i.e. a place of professional medical care. Palliative care is often confused with care for the chronically ill, long-term care or geriatrics. According to the author, the definition is understood differently, not only in each country, but also in different environments. The world lacks functional definitions and clearly defined frameworks for the palliative care structure [10]. The 2009 CBOS report [11] conducted on a representative random sample of 1096 adult Polish residents showed that the knowledge about the assumptions and functioning of hospice care among Poles is quite diverse. 24% of respondents were not aware of this issue at all, 36% showed only the basic scope of information, and less than 30% had average knowledge in this matter. Only every tenth respondent (10%) was well aware of the activities of hospices. More than half of the respondents (52%) have not encountered hospice services because there was no such center in their town or its vicinity, and none of their relatives was and is not covered by hospice care. Moreover, neither they themselves nor anyone from their family or friends did not work and did not work in the hospice as a volunteer [11]. The respondents from the present study most often believed that hospice is comprehensive care for the terminally ill because the family is not always able to provide proper care . They claimed that the patients were professionally cared for there (79.1%), that they could die with dignity (86%) and that they found relief and peace (56.1%). In their opinion, this hospice is a place for people suffering from an incurable disease, regardless of the diagnosis (65.6%).

In the study by Łukaszuk et al. [12], the first thought about hospice, according to 48% of the respondents, was negative. Only 47% of the respondents thought about it positively, and only 3% of all respondents strongly believed that "a hospice is also life", only 25% answered "rather yes", while "definitely no" was answered by 11% of the respondents, "rather not" 49% [12]. Currently, the majority of (74.9%) surveyed representatives of the families of cancer patients had positive associations with the hospice and, when thinking about the hospice, they did not feel (56.7%) fear.

Death is still the most sensitive and delicate topic in life, but it is always a highly traumatic experience for everyone. Copp [13] suggests that nowadays, death is not accepted as a natural part of human life, and the staff caring for the sick are thus constantly strengthened in their fear of dying and death. Currently, the majority of respondents (64.8%) equated pain and suffering at the end of life with an experience primarily physical and at the same time believed (82.4%) believed that death is a natural phenomenon and that it is essential to fight for the patient's life in the event of the inevitability of death. (72.1%).

In this context, the issue of euthanasia appears, which is still a topic that absorbs both society and people working in the medical profession, a sensitive, controversial topic, about which there is no general agreement. In the literature [14] there are many terms related to euthanasia, such as: voluntary or involuntary euthanasia, cryptanasia, active or passive euthanasia, terminal sedation, distanasis, persistent therapy, orthothanasia, assisted suicide, suicide by a doctor, right to death in dignity. The CBOS analysis [11] from 2009 showed that Poles have divided opinions on the conduct of a doctor who helps terminally ill people, at their request, in deliberately shortening their lives: 42% agreed, and 40% disapproved. Slightly more people were against the fulfillment by doctors of the will of the suffering, terminally ill, who demanded that they be given agents that caused death (44%) than believed that doctors should do so (40%). The prevailing opinion was that doctors should not be punished for facilitating their death at their request and under the influence of compassion (37%). Punishing in some circumstances and not in others was postulated by 24% of respondents, and almost the same number (25%) favored absolute punishment. If the fulfillment of the request of a terminally ill and suffering person is defined as euthanasia, more respondents considered such behavior unjustifiable (43%) than such behavior that could be excused (30%) [11]. In the current study, 75.2% of people were against euthanasia, but at the same time, 14.4% of respondents were in favor of unequivocal euthanasia, and 5.1% did not have an opinion on this issue. Euthanasia under certain conditions (death of the brain stem, very old age, incurable disease, cases when medicine has used its possibilities and has no chance of improvement) would be accepted by 5.3% of the respondents. The most frequently accepted methods of euthanasia by the respondents were turning off life-support equipment (25.8%) and abandoning resuscitation (25.6%). Most of the representatives of the surveyed families (53.1%) were against the legal acceptance of euthanasia.

The respondents from the Bartusek study [15] considered the small number of residential care centers and palliative clinics to be the biggest problem in palliative care. In the opinion of nurses, a significant problem was also the increasing number of patients with chronic diseases (19.3%) and the lack of public knowledge about palliative care (19.7%). The nurses' opinion in the first issue was shared by only 4.0% of doctors, and in the second - by 24.6%, ie more than the nurses [15]. Leppert et al. [16] compared students and doctors' and doctors' difficulties in communicating unfavorable news about the disease and prognosis. The percentage of respondents ready to provide complete information was 28% among students and 24% among doctors. The willingness to obtain complete information in this regard was expressed by 84% of students and 80% of physicians [16]. Mess et al. [17] assessed the need to inform a terminally ill patient. Most of the patients (85%) in this study stated that a person should always know that he or she had an incurable disease. Slightly less (70%) recognized the necessity to know about the impending death, believing that they needed it to be able to make an attempt to heal, manage their lives in time, and prepare for the inevitable [17]. Most of the surveyed (89.8%) family members of patients were convinced that the information provided to the family should be comprehensive (89.8%), and the family should obtain a full range of information about the patient's prognosis (76.4%). Most respondents (65.2%) were convinced that the patient and family should be informed about their rights, 97.5% believed that the doctor and 96.8% that the nurse should be willing to provide information to the patient's family. The knowledge of the patient that he is in a hospice made the patient's physical, mental and spiritual condition dependent on his or her attitude as much as 68.6% of the respondents. In addition, 64.5% of the respondents were convinced that the patient should receive as much information as they would like. In Ireland, for example, following Coughlan [18], the vast majority of patients receiving chemotherapy for cancer knew the diagnosis, while in Spain only 32% of patients received information about their current health status. The studies by Centeno-Cortes and Nunez-Olarte [19] showed that 42% of patients in palliative departments and only 27% of patients in oncology departments had full knowledge about their diagnosis.

The aforementioned research by CBOS in 2009 [11] showed that Poles almost universally speak of palliative care with appreciation. The activity of home hospices was supported by 94% of respondents (67% strongly), and 96% of inpatient hospices (including 71% definitely). However, despite the widespread social support for hospice activity, most respondents (57%) believed that inpatient hospice is a place where dying people should go only in exceptional circumstances, e.g. when the family is unable to provide them with specialist care. In other cases, the dying should stay at home [11]. Currently, the surveyed representatives of hospice families would recommend 78.4% of the respondents to other families as a form of patient care. The majority of them (54.7%) stated that a patient in a hospice does not feel lonely, that the conditions in the hospice, according to the surveyed family members, should be very good (93.5%), they should take care of the patients' safety and ensure intimacy (98.9%) and dignity (98.3%).

Palliative / hospice care, according to Pyszkowska [20], should be provided by a multidisciplinary team consisting of a doctor, nurse, social worker, psychologist, rehabilitator, occupational therapist, chaplain and volunteers, qualified non-medical caregivers, with the participation of trained family members and caregivers. The core of the team consists of qualified doctors and nurses, and they are led by a specialist in palliative medicine or a physician experienced in palliative care and appropriately trained in this field [20]. Respondents from Masłowski's study [21], who are members of the hospice team, expressed a strong opinion on the extension of the entity undertaking spiritual assistance in the hospice with nuns (37.3%), people after a relatives start (28.5%), seminary seminarians (25.8%).), permanent clergy (18.7%), lay ministers of the Eucharist (11.9%) and lay members of religious movements (11.9%). At the same time, they considered spiritual care as complementary in the holistic support system [21]. In the opinion of the present respondents, the following should work in the hospice: every doctor (98.2%), nurse (97.5%), a nurse with a specialization or course in palliative medicine (87.6%), physiotherapist (85.3%), psychologist (83.4%), a physician specializing in palliative medicine (64.8%), an oncologist (54.3%) and a nun (45.3%).

Palliative and hospice care use interdisciplinary knowledge and the principles of a holistic approach to patients to meet their physical, psychological, social, and spiritual needs. In the study by Bejda et al. [22] the presence of chaplains in hospices did not arouse any objections - as many as 87.3% of respondents (690 people) were in favor. A different opinion was expressed by 2.3% (18 people), and 10.4% (82 people) had a problem with an unambiguous declaration [22]. Almost all the respondents were convinced that a patient should have unlimited access to a clergyman, psychologist, and physiotherapist.

Masłowski [21] reported that patients dying from cancer usually mentioned the holy mass (53.4% of indications) and the prayer of the rosary (62.3%) among the religious practices that supported their suffering the most, and then sequence - the Way of the Cross (20.7%), considering the texts of the Holy Scriptures (18.4%), reading religious books (17.8%) or litany prayers (10.3%). Currently surveyed for the most desirable religious practices in a hospice, they recognized the mass (86.7%), the prayer of the rosary (81.6%), confession (81.2%), and the sacraments (81.2%).

The most common causes of dissatisfaction (low level of satisfaction) of patients with care include too rare contact with medical workers involved in the care, poor control of symptoms, including pain, poor communication, insufficient care equipment, and lack of emotional support from the family [23,24,25]. In the opinion of 87.3% of the currently surveyed family members of oncological patients, society does not pay much attention to palliative care. In their opinion, improving the quality of medical care in hospices would primarily result from increased medical personnel (87.4%) and beds (82.4%). On the other hand, they knew problems with patient care at the end of life, mainly in the increasing number of patients with chronic diseases (96.7%), lack of knowledge of the society about palliative care (92.7%), lack of knowledge of relatives about how to deal with the patient, lack of family psychological skills (89.4%), lack of skills in caring for a dying patient (88.7%). and members of the therapeutic team in occupational burnout syndrome (86.7%). In addition, a large group of respondents (68.3%) stated that, as a family, it should take part in the care/treatment of the patient.

According to Lecouterieri et al. [26], family participation in palliative care is usually very high, especially when the patient is under hospice home care. Therefore, knowing the preferences of family caregivers and the degree of satisfaction of their needs may not only improve care and increase its quality but also indirectly contribute to the better well-being of the patient himself. Family members' satisfaction may occur during care or after the patient's death [26].

CONCLUSIONS

1. In the opinion of most families of oncological patients, hospice is comprehensive care for terminally ill patients and the right place for terminally ill patients, regardless of their diagnosis.
2. The respondents considered permanent clergypersons and people after losing a loved one to be the most appropriate people to support hospice patients.
3. The respondents in palliative care were seen in the growing number of patients with chronic diseases and the lack of knowledge the society about palliative care, and its increase in the number of medical personnel and the increase in the number of beds
4. The respondents considered hospice as a place for people suffering from an incurable disease, regardless of the diagnosis, in which the patient does not feel lonely, has support, can feel safe, and would be recommended to other families as a form of care for the sick.

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The authors have declared no conflict of interest.

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