Hospice workers' and family of hospice patients' perception of hospice care in Poland

Mickiewicz I.[1], Krajewska-Kułak E.[2], Kułak W.[3], Kędziora-Kornatowska K.[4], Muszyńska-Rosłan K.

[1] Public Palliative Care Unit, Suwałki, Poland
[2] Department of Integrated Medical Care, Medical University of Białystok, Poland
[3] Department of Pediatric Rehabilitation, Medical University of Białystok, Białystok, Poland
[4] Chair and Department of Geriatric, Collegium Medium UMK, Kraków, Poland
[5] Department of Pediatric Oncology, Medical University of Białystok, Białystok, Poland

ABSTRACT

Introduction: The history of palliative care dates back to the 1950s.
Purpose: To examine the perceptions of hospice workers and family members of hospice patients related to hospice care in Podlaskie province in Poland.
Materials and methods: The present study included 103 hospice workers and 104 family members of patients in hospice. The survey approach was used.
Results: 56.7% families and 95.1% hospice workers considered hospice comprehensive care for terminally ill patients. In all, 84.6% of the families and 91.3% of the staff thought positively about hospice. Lack of knowledge of family on dying patients (43.3% families and 61.2% hospice workers), low level of funding for hospices (50% families and 64.1% hospice workers) and a small number of hospices and palliative care clinics (47.1% families and 53.4% hospice workers) are the most common problems in palliative care. According to 78.8% of the families and 84.5% of the staff, a specialist of palliative medicine should work in hospice. 62.5% of the families and 75.7% of the hospice workers were convinced that a nurse with a specialization should also work in hospice. According to 92.9% of the families and 96.9% of the staff, the patient and their family receive support in hospice.
Conclusions: Most of the respondents were convinced that hospice is an appropriate place for terminally ill patients. Lack of knowledge of family on dying patients, low level of funding for hospices, a small number of hospices and palliative care clinics are the most common problems in palliative care.
Key words: hospice, hospice workers, families, perception

***Corresponding author:**
Department of Integrated Medical Care
Medical University of Białystok
7a M C Skłodowskiej str.
15-096 Białystok, Poland
Tel. +48 85 748 55 28
E-mail: elzbieta.krajewska@wp.pl (Elżbieta Krajewska-Kułak)

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INTRODUCTION

Palliative care is a specialized form of medicine which aims to enhance the quality of life of patients and their families who are faced with serious illness. It focuses on increasing comfort through the prevention and treatment of distressing symptoms. In addition to expert symptom management, palliative care focuses on clear communication, planning, and coordination of care. [1-4]

The terms "palliative care" and "hospice care" cannot be used interchangeably. Hospice is only one type of palliative care that can be provided in the last six months of life. Traditional palliative care can be offered any time in the course of an illness and ideally should begin at the time of diagnosis.

A World Health Organization statement describes palliative care as "*an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*." [5]

The term "palliative care" is increasingly used with regard to diseases other than cancer such as chronic, progressive pulmonary disorders, renal disease, chronic heart failure, HIV/AIDS, and progressive neurological conditions. In addition, the rapidly growing field of pediatric palliative care has clearly shown the need for services geared specifically for children with serious illness [6,7].

Hospice was first introduced in the 1970s (HFA, 2001). Family members are integral participants in the process. They provide day-to-day care, stepping into a caregiver role that is often entirely foreign. For this reason, the hospice team provides counseling services and support to family members as well as patients.

In Poland, palliative care is a specialized form of medical care or treatment financed from public resources. Observing the regulations, there should be one home hospice in every county and one stationary medical care unit (palliative care unit) or stationary hospice in every 2-3 counties. A palliative medicine centre should function along with stationary or home units or oncology hospitals within [7].

The National Health Fund (NHF) reimburses health service under stationary conditions (provided by palliative medical care departments or stationary hospices), ambulatory conditions (palliative medicine centres) and home ones (home hospices for children and adults). Hospital support teams and day-care units are not financed by the NHF. Additional sources of financing are as follows: local government donations and the support of non-governmental organizations (associations and foundations). The long outstanding problems are insufficient financing, shortage of hospital beds, lack of standards and staff shortages [8].

In some countries, there is a clear distinction between hospice and palliative care, whereas in other countries, the terms are used synonymously. If a distinction is made, it can be related to the institutional framework, describing a palliative care unit as a ward within a general hospital versus an inpatient hospice as free-standing service. However, the distinction can also relate to the indications for admission or the type of interventions offered. Using this framework, in Germany for example a palliative care unit as part of a hospital primarily aims at crisis intervention and medical stabilisation, whereas an inpatient hospice provides end-of-life care for patients who cannot be cared for at home [9].

This study sought to examine the perceptions of hospice workers and family members of hospice patients related to hospice care in Podlaskie province in Poland.

MATERIALS AND METHODS

The study was conducted in the period between January 2010 and December 2010. A questionnaire was used to elicit data. The present study included 103 hospice workers and 104 family members of patients in hospice (inpatient hospices**)**. The groups of hospice workers (nurses, doctors) were from seven hospices of the Podlaskie province. Almost all patients had cancer disease The group of family members of patients were from the mentioned hospices. The survey approach was used. A postal questionnaire was sent only to family members of patients in hospice. For hospice workers, the questionnaire was given by the authors of this study. A total of 150 questionnaires were sent, and 103 were returned, giving a response rate of 68.6% (hospice workers). In family members, a total of 150 questionnaires were handed out, and 104 were returned, giving a response rate of 69.3%. This questionnaire consisted of seven questions, inclu-ding demographic data (gender, age, education level, place of residence, hospice name, twenty questions regarding perception of palliative care and satisfaction with hospice care).

Descriptive statistics were used to examine each study variable individually. The differences among the groups were determined by the Chi–square test. The significance level was set at $p < 0.05$. Statistical analysis was performed by SPSS ver. 11.0 PL. The study was approved by the ethics committee of the Medical University of Bialystok (no R-I-002/62/2010). Informed consent was obtained from each of the respondents.

RESULTS

There were 103 hospice workers: 88% were women and 12% were men. Almost 54% had received a university education, and 35% had received an advanced degree.

Nearly 48% of all hospice workers were less than 40 years old, and 52% were 40 years old or older. Sixty-five percent had received a university education and 35% had received a higher education. Of the responding hospice workers, 23% had less than six years of work experience, 30.1% had between 6 and 10 years, and 46.6% had more than 15 years of work experience. Of the respondents, 78.6% lived in the city and 21.4% lived in the country.

There were 104 family members of patients in hospice: 67% women and 33% men. Almost 76% had received a university education and 24% had received higher education. Nearly 19% of family members of patients in hospice were less than 40 years old, 19% were between 40 and 50 years, and 30% were older than 50 years. According to 67.5% of the family members, waiting time for admission to hospice was less than 8 days, 16.1% said the waiting time was 8 to 14 days, and 16.3% reported a wait of more than 14 days.

Nearly all of the hospice workers (95.1%) were convinced that hospice provides comprehensive care for terminally ill patients. More than half (56.7%) of the family members were convinced that hospice provides comprehensive care for terminally ill patients. Significant differences between hospice workers and family members were found (Table 1).

More than half (55.3%) of hospice workers saw hospice as appropriate for terminally ill patients regardless of their diagnosis and 47.6% saw it as appropriate for patients with cancer. Similarly, in family members group, 52.9% of the respondents saw hospice as appropriate for patients with cancer and 55.8% saw it as appropriate for terminally ill patients regardless of diagnosis. Details are shown in Table 2.

The majority of hospice workers (68.9%) believed that hospice is appropriate for terminally patients because the family is not always able to provide these patients with adequate care. Nearly 40% of the respondents said that the number of people in need of palliative care is increasing. Only 1% saw the home as appropriate for terminally ill patients. Significant differences between the test groups were found (Table 2).

More than half (52.4%) of the hospice workers declared an absence of fear while they were thinking about hospice, and 36.9% of family members had an opposite opinion. Almost 36% of the family members of patients in hospice reported an absence of fear, 29.8% were somewhat fearful, 26% less fearful and 8.7% definitely not, while they were thinking about hospice. Significant differences (p = 0.001) between the groups were found.

The respondents reported that society has not paid much attention to palliative care; hospice workers at 62.1% vs. family members at 33.7% (p = 0.001) or definitely has not paid attention to it, 27.2% for hospice workers and 27.2% vs. family members - 26%, respectively.

Most of the hospice workers (68.9%) were convinced that patients receive professional care. They are dying with dignity (66%), find relief and peace (39.8%), do not suffer (28.2%), they are struggling with an incurable disease (19.4%), or they are dying (10.7%). Similarly, most of the family members (68.3%) reported that patients get professional care, find relief and peace (28.8%), do not suffer (22.1%), they are struggling with an incurable disease (18.3%), or they are dying (10.7%).

Only 24.5% of the respondents in hospice workers and 22.1% family caregivers were convinced that hospice patients live with dignity. More than half of the hospice workers (66%) and 45.2% family caregivers (p = 0.005) reported that patients are dying with dignity.

The majority of hospice workers (84.5%) reported that doctors with a specialization in palliative care and nurses with the same specialization (75.7%) should work in hospice. Similar answers were reported by the family members of patients in hospice.

Hospice workers perceived that spiritual support for patients should include a priest or other member of the clergy (78.6%), nurse (49.2%), and doctor (30.1%). Family members reported similarly. Only 5.8% of these respondents indicated that family, friends, psychologists, and volunteers should provide spiritual support.

Almost all respondents of both groups (96.9% vs. 92.8% respectively) reported that patients received spiritual support. Hospice workers preferred the following religious practices in hospice: the mass (74.8%) and the rosary (42.7%). They also reported reflections of scripture (25.2%), reading religious books (19.4%), or the Stations of the Cross (7.8%). Similar answers were reported by family members.

The next question sought to get opinions on what is the pain and suffering of people at the end of life. Hospice staff indicated that the pain and suffering is the physical experience (67%), mental (54.4%), spiritual (47.6%), and experience preventing normal functioning (46.7%). Less frequently used terms included the element of human existence (22.3%) or grace (3.9%). Similar answers were reported by family caregivers.

More than half (64.1%) of hospice staff indicated there was a low level of funding for hospices, 61.2% indicated a lack of knowledge of family members about dying patients, 53.4% indicated that society has poor knowledge about palliative care, 30.1% a small number of qualified staffs, 23.3% burnout syndrome, 12.6% lack of skills cares of dying patients, 11.7% the lack of skills in contact with the patient's family. Interestingly, similar answers were noted in the group of family members.

In another question, the respondents were asked for an opinion about how the information about his or her health should be communicated to the patient. Only 24.3% of hospice workers and 32.5% of family family caregivers were convinced that patients should be given full information about their disease. Only 2.9% of hospice workers and 24% of family family caregivers had opposite opinions (p = 0.01).

On the question about acceptance death, 63.3% of hospice workers and 29.% of family members accepted death. Almost 30% of hospice workers and 61.6% of family members had an opposite opinion on this matter.

More than half (53.4%) of hospice workers reported sadness and 47.6% felt humility at the moment, of death of their patients. They also reported helplessness (31.1%), relief to the suffering (35%), mystery (27.2%), meditation (25.2%), extinguishes life (23.3%), grief (16.5%), peace (13.6%), void (3.9%), and fear (1.9%). Only 23.3% of the respondents could not identify their feelings and 16.5% felt something strange. Similar answers were reported by family members.

According to 45.6% of hospice workers and 62.4% of family members waiting time of patients' admission to hospice was short (p=0.03). Almost 40% of hospice workers and 30% of family members had an opposite opinion on this matter.

Most of the respondents in hospice workers (85.7%) and 78.6% in family caregivers were indicated that the patients and families were informed about mode of treatment.

Only 12.1% of hospice workers and 18% of family caregivers had an opposite opinion on this matter.

Almost all respondents of both groups (93.8% vs. 95.7% respectively) were convinced reported that the organization of care in hospice is good. The vast majority of hospice workers (89.7%) reported that doctor willingly informed family about patients health and only 3.1% had an opposite opinion. Similar answers were reported by family members.

The respondents of both groups (87.7% vs. 85.7% respectively) reported the patient families obtained prognosis disclosure. Only few respondents had an opposite opinion.

Almost all respondents of both groups (98% vs. 96.6% respectively) reported that patients receive a lot of smiles, kindness and courtesy of the staff.

Nearly all respondents were perceived that hospice protects the patient's dignity and family takes part in the patient care. Data are not shown.

Nearly half of hospice workers (46.2%) and 62% of family members reported that family can stay in the hospice without restriction.

Almost all recommended treatment in hospice to other patients and their families.
On the other hand, one-third of hospice workers and 40.3% of family members suggested that patients should staying in at home. And one-third of the respondents did not have an opinion on this matter.

DISCUSSION

This survey found that palliative and hospice were positively perceived by the most of respondents. Although one limitation of this study is that survey was not validated.

The indications to palliative care have been under debate for many years [2]. Defining the criteria for admission to palliative care is a problem not only in Poland, similar discussions were in other countries. In her opinion the primary criterion for admission should be the intensity of symptoms of an incurable disease. Patients with cancer diseases are entitled to care offered by the palliative care units from the moment the pain appears. The place of treatment of patients with non-cancer diseases should be determined by a specialist of palliative medicine together with a specialist dealing with a given disease. Palliative care should be provided not only to cancer patients, but also to patients dying due to chronic diseases. In the palliative care team, a nurse plays a major role, she is the one who spends most time with the patients, provides care, talks and supports both the patient and his family [9-11].

Leppert et al. [4] evaluated difficulties in informing bad news concerning the disease and prognosis in students and physicians. Only 1/3 of the surveyed both students and doctors were able to give appropriate definition of euthanasia, and 82% of students and 90% of physicians would not perform euthanasia. Bad news concerning cancer diagnosis and prognosis is a major difficulty for both students and physicians. The authors concluded that there is the lack of knowledge of bioethics and most of the respondents were against euthanasia.

Pietruk [6] evaluated the opinions on hospice among 50 hospice workers and 50 students of the Medical University of Warsaw. In the opinion of 80% of the medical personnel and 68% of the students, hospices are needed in Poland.

According to 94% of the medical personnel the society pays too little attention to palliative care. These findings are in agreement with our results.

A CBOS (public opinion research center) report from October 2009 on a national sample (N=1096) of Poles [3] showed that the majority of voters (61%) believe that in the case of terminally ill patients whose pain cannot be relieved, the law should allow doctors to administer drugs that cause painless premature death if such is the wish of the patient and his/her or her family. The contrary opinion was held by nearly one-third of respondents (31%). Similar results were reported by Wilczek-Różyczka et al. [12]. Our findings are comparable these studies.

Kowalewska et al. [10], assessed students and nurses knowledge on palliative care and euthanasia. Differences in the definition of palliative care between nurses and students were noted. The word hospice was defined as care for the dying patient and euthanasia as death on demand" or murder." Most respondents did not want work in a hospice.

The CBOS report [2009] showed that most of the respondents' express positive perception of the palliative care. Almost all, 94% respondents supported the home hospices [8].

According to Pyszkowska [11] a good quality of life the patient is achieved by multidimensional procedures of specialist palliative care units by managing the pain and other symptoms (symptomatic treatment), spiritual and social suffering, and helping the family during the illness and after the patient's death in the time of bereavement.

An active presence of the Church in ministering to the terminally ill results from a belief that faith can brighten the mystery of suffering and death with the light of truth was studied by Masłowski et al. [13] .

Our study confirms prior researches [14,15] on positive perception of hospice care

Flakus [14] sought to answer the question whether, and to what extent, the hospice as an institution is fulfilling its aims and tasks regarding social support to the patient and his/her family. The opinions of respondents about hospice were positive. Physicians demonstrated very positive attitudes toward hospice [15,16]. They had correct knowledge about some aspects of hospice, but were uncertain about correct answers on the majority of items. They had erroneous knowledge on few items.

Religious activities, attitudes, and spiritual experiences are prevalent in older hospitalized patients and are associated with greater social support, better psychological health, and to some extent, better physical health. Awareness of these relationships may improve health care [17,18]. Wroński [19] emphasizes that one of the basic patients' right is the right to pastoral service during hospital stay . Managers of medical outposts have legal obligation to provide patients with a possibility to participate in religious ceremonies and contact with their chaplain in the hospital. Our findings are comparable with the abovementioned studies.

Pain is a complex, multidimensional perception with affective as well as sensory features. The palliative care specialist can address suffering proactively as well as reactively by treating potentially chronic pain and symptoms aggressively and promoting the psychosocial well-being of the patient at every opportunity [20].

In the present study, almost half of the respondents reported that pain and suffering in the end of life are physical perceptions. The assessment of quality of life of oncological patients, was presented in many reports [21]

In an Irish study [22] from 1993. The vast majority of patients receiving chemotherapy for cancer knew their diagnosis. However, the patients in this study displayed a poor knowledge of the potential side-effects of their chemotherapy and of the names of the drugs they were receiving as part of their chemotherapy.

A Spanish study from 1994 [23] revealed that more than half of the patients had not been informed of their diagnosis and 42%f did not want to receive more information.

Fakhoury et al. [24] assessed associations between informal caregivers' satisfaction with services delivered to their dying cancer patients. More than half (52%) of informal caregivers were satisfied with community nurses. In a British survey from 1992 [25], despite general satisfaction with medical treatment, 65% of carers cited inadequate control of symptoms. The experience and opinions of carers of the patients dying of cancer in Pontefract Health District were obtained by semistructured interview approximately six months after bereavement. Similar findings was reported by Addington-Hall et al. [26]. A half of carers were dissatisfied with hospital care of dying cancer patients.

In another study, Lecouterieri et al. [27] an information provision was deemed un-satisfactory by a large proportion of respondents, and that dissatisfaction with care received from hospital. In the present survey, the majority of the respondents (85.7%) were satisfied with hospice care. Spirituality lies at the frontier of palliative care. It is now recognized as a salient end-of-life need offering to reduce overall suffering and remarkable existential possibilities to patients [15,17,28]

Recently, there has been considerable interest shown in research studies that identify the needs of dying patients and their families, as well as the needs of health care professionals who care for the dying [10,21,28]. Death, as the final stage of one's life, causes many emotional states since, it is related to the process of dying. Nurses experience various types of emotions in their professional work when accompanying a dying patient. [10,12].

The CBOS report from 2001 on a national sample (N=968) of Poles [6] showed that most of the respondents (60%) did not afraid of death. Our results are consistent with the abovementioned report. Almost 39% of family members of patients in hospice and 84.9% of hospice workers did not afraid of contact with the dying. patients, low level of funding for hospices, a small hospice. Lack of knowledge of family on dying patients, low level of funding for hospices, a small number of hospices and palliative care clinics are the most common problems in palliative care

CONCLUSIONS

Most of the respondents were convinced that hospice is an appropriate place for terminally ill patients. Patients' families assessed the quality of health care better than the medical staff. Lack of knowledge of family on dying patients, low level of funding for hospices, a small number of hospices and palliative care clinics are the most common problems in palliative care.

Table 1. Respondents' opinions about hospice definition.

Respondents	**Answers**					
	a	**b**	**c**	**d**	**e**	**f**
	N (%)	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**
Hospice workers	**98 (95.1)**	24 (23.3)	6 (5.8)	17 (16.5)	0 (0)	0 (0)
Family members	**59 (56.7)**	49 (47.1)	11 (10.6)	13 (12.5)	4 (3.8)	2 (1.9)
	P values (p<) or (ns) not significant					
	0.001	0.001	ns	ns	ns	ns
Legend	a. comprehensive care for terminally ill patients; b. palliative care institution ; c. home for terminally ill patients ; d. to accompany the patient; e. there is no knowing; f. others					

Table 2. Respondents' opinions about hospice legitimacy.

Respondents	**Variant of answers***								
	a	**b**	**c**	**d**	**e**	**f**	**g**	**h**	**i**
	N (%)	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N(%)**	**N (%)**	**N (%)**	**N(%)**
Hospice workers	37 (35.9	18(17.5	**71 (68.9)**	12 (11.7)	41 (39.8)	0 (0)	1 (1)	0 (0)	0(0)
Family members	42 (40,4	20(19,2)	**53 (51)**	14 (13,5)	27 (26)	0 (0)	0 (0)	0 (0)	2 (1.9)
	P values (p<) or (ns) not significant								
	ns	ns	0.01	ns	0.05	ns	ns		ns
Legend	a. Yes, this is an appropriate place for terminally ill patients.; b. Yes, this unloading to the hospital departments. ; c. Yes, family is not always to provide appropriate care.; d. Yes, because this is the appropriate place for people who do not have anywhere to go.; e. Yes, because an increasing number of people in need of palliative care.; f. No, such centers are not needed.; g. No; h. I did not have an opinion on this matter.; i. Others								
* respondents could indicate multiple answers									

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