

PUBLIC KNOWLEDGE OF PALLIATIVE CARE AND THE FUNCTIONING OF HOSPICES IN POLAND

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A. Study design/planning • B. Data collection/entry • C. Data analysis/statistics • D. Data interpretation • E. Preparation of manuscript • F. Literature analysis/search • G. Funds collection

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ABSTRACT

Introduction: In line with the guidelines of the World Health Organization (WHO), palliative care focuses on improving the quality of life (QoL) of patients struggling with chronic disease that is not amenable to causal treatment. Guaranteed services in that field are provided in accordance with the Announcement of the Minister of Health of 28 March 2018.

Aim of the study: To determine the level of public knowledge of the basic aspects of palliative and hospice care in Poland.

Material and methods: The study, carried out in 2020, involved 249 people. The material was collected using an online questionnaire. The research tool was the author's questionnaire. Statistical calculations were made using STATISTICA 10 PL software.

Results: The level of knowledge about hospice care was slightly above average ($M = 20.4$, $SD = 2.5$). Most of the respondents were aware of the idea of the hospice (71.89%). The awareness of the presence of perinatal hospices in our country already had the highest quality of the group (42.97%). Fees for hospice care were expected by 28.51% of the respondents. There was a weak, positive, statistically significant correlation between the level of knowledge and the age of the respondents ($R_s = 0.166$, $p = 0.0087$). The variables most strongly associated with the level of knowledge were education ($p = 0.0005$) and medical profession ($p < 0.0001$).

Conclusions: The general level of public knowledge was slightly above average. Some areas require modification. The knowledge exhibited by the medical community was much higher than in the rest of the group. The nascent perinatal hospice movement in Poland requires intensified public education campaigns.

Key words: hospice, palliative care, public knowledge.

INTRODUCTION

The word 'palliative' comes from the Latin word *palliates* and means 'covered with a mantle'; the term 'hospice' from the Latin *hospes* means 'hospitality' [1]. Being under the care of inpatient or home hospices also means being under palliative care. This form of medical care applies to people of all ages, including the perinatal stage, where special care is focused on the parents of an unborn child with numerous serious defects [1]. In line with the guidelines of the World Health Organization (WHO), palliative care focuses on improving the quality of life of patients struggling with a chronic and progressive disease that is not amenable to causal treatment, and the form and extent of care should be individually tailored to the pa-

tient's needs [2]. Therapeutic activity promoted in the idea of hospice care focuses on the prevention of suffering resulting from somatic ailments, as well as on the multifaceted support of the psychological, social, and spiritual spheres of sick people. This is the holistic dimension of this care [3-5]. Guaranteed services in the field of palliative and hospice care in Poland are provided in accordance with the Announcement of the Minister of Health of 28 March 2018 [6]. According to this, palliative care can be provided in inpatient, home, and outpatient settings. Importantly, access to palliative care clinics and hospices is not limited only to people with neoplastic diseases [6]. Although inpatient hospice care is provided to patients in the terminal stage of their disease, it does not mean that their lives will end in the next few days.

In Poland, palliative care services are financed under contracts with the National Health Fund (NFZ) [7, 8], whereas foundations and associations whose

activities include palliative care are financed mainly by tax deductions for public benefit organizations, public collections, and contributions from companies and natural persons [9, 10].

Table 1. The age of the participants – descriptive statistics

Variable	M	SD	Me	Q1	Q3	Min.-max.
Age	30.5	12.5	25	23	36	18-73

M – mean, SD – standard deviation, Me – median, Q1 – first quartile, Q3 – third quartile, min. – minimum, max. – maximum

Table 2. Sociodemographic data

Variables	n	%
Sex		
Male	43	17.27
Female	206	82.73
Place of residence		
Village	55	22.09
A city other than a voivodeship city	50	20.08
Voivodship city	144	57.83
Education		
Primary, vocational, secondary	99	39.76
Higher	150	60.24
Declared faith in God		
Yes	182	73.09
No	67	26.91
Medical profession		
Yes	80	32.13
No	169	67.87
Work in hospice care		
Yes	8	3.21
No	241	96.79
Volunteering in a hospice		
Yes	8	3.21
No	241	96.79
Presence at the death of a person in hospice		
Yes	38	15.26
No	211	84.74
Presence at the death of a person (any)		
Yes	113	45.38
No	136	54.62
Participation in hospice campaigns		
Yes	129	51.81
No	120	48.19
I am currently under hospice care		
Yes	2	0.80
No	247	99.20
A loved one is under hospice care		
Yes	49	19.68
No	200	80.32

n – total number, % – percentage of respondents

AIM OF THE STUDY

The aim of this study was to determine the level of public knowledge of the basic aspects of palliative and hospice care in Poland. We expected a medium level of knowledge, with the lowest percentage of correct answers to questions about perinatal hospices and the financing of this form of care.

MATERIAL AND METHODS

The study was carried out from July to November 2020. Due to the COVID-19 pandemic, the material was collected using an online questionnaire. The research tool was the author's questionnaire, a part of which concerned the functioning of hospices in Poland. The participants were asked about selected aspects of the organization of hospice care in Poland, which may shape general attitudes towards hospices and affect the possible readiness to use this form of assistance. The questionnaire consisted of the 'yes', 'no', and 'I don't know' statements. Statistical calculations were made using STATISTICA 10 PL software. The level of statistical significance was set as $p < 0.05$. Qualitative variables (nominal and ordinal) were described by the number (n) and frequency (%). Measurable variables were described by means of the arithmetic mean (M), standard deviation (SD), median (Me), lower (Q1) and upper (Q2) quartiles, as well as the minimum and maximum values (min and max). Spearman's rank correlation coefficient significance test was used to verify the correlation between measurable variables. The comparison of knowledge between people who differed in selected sociodemographic variables was performed using Student's *t*-test. The level of the respondents' knowledge was assessed based on 12 questions, by giving 2 points for each correct answer, and 1 point for each incorrect answer. This resulted in a point range between 12 (complete lack of knowledge) and 24 (complete and correct knowledge).

This study did not require approval of the local Bioethics Committee (decision no. KB-0012/45/07/2020/Z).

RESULTS

There were 249 participants in the study. The mean age of the respondents was 30.5 (SD = 12.5). Details of the age distribution are shown in Table 1.

A vast majority of the study group were women (82.73%), residents of voivodship cities (57.83%), people with higher education (60.24%), and those declar-

ing faith in God (73.09%) – no questions were asked about a specific religion.

An important element that may shape the level of public knowledge of hospice and palliative care is the experience of death and dying. 45.38% of the respondents happened to be present at the death of a person, while the group that experienced accompanying a dying person in a hospice was much smaller (15.26%). The sociodemographic data of the study group are shown in Table 2.

Most of the respondents were aware of the idea of the hospice movement (71.89%), not identifying the name 'hospice' solely with the building. The respondents did not exclude people under the age of

65 years from the group of hospice patients (93.57%). However, only 42.97% of the surveyed were aware of the existence of perinatal hospices. The lowest level of knowledge was shown by the respondents in the field of payments for hospice care. Fees for hospice care were expected by 28.51% of the subjects, while 42.57% were unsure as to the principles of its financing (Table 3).

In the next stage of statistical analysis, the responses were categorized into 2 groups: the first included correct answers, and the second group included incorrect and 'I don't know answers'. Table 4 shows the results by decreasing percentage of correct answers, thus highlighting those areas of knowledge

Table 3. The knowledge of the functioning of hospices – descriptive statistics

Statements	Yes		No		I don't know	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
A hospice is just the name of the building where sick people are staying	54	21.69	179	71.89	16	6.42
Hospice care is a type of care that can only be provided in a dedicated building	73	29.32	157	63.05	19	7.63
Only sick elderly people (65+) may receive hospice care	5	2.01	233	93.57	11	4.42
Only patients over the age of 18, with no upper age limit, may receive hospice care	17	6.83	208	83.53	24	9.64
Hospice care can also be provided to children from birth to 18 years of age	192	77.11	23	9.24	34	13.65
Hospice care can also be provided to parents of an unborn, very ill child (so called a perinatal stage)	107	42.97	31	12.45	111	44.58
Hospices are created by priests and nuns so they can only be used by Catholics or other Christian denominations (Protestants, members of the Orthodox church)	12	4.82	220	88.35	17	6.83
Hospice care costs a lot, so not everyone can afford it	44	17.67	138	55.42	67	26.91
Only people in the last days of their lives are provided with hospice care	50	20.08	185	74.30	14	5.62
Hospice care is free	72	28.92	71	28.51	106	42.57
A hospice is a place where only people with cancer stay	26	10.44	208	83.53	15	6.02
Hospice care is a type of care that can also be provided in the home setting	198	79.52	19	7.63	32	12.85

n – total number, % – percentage of respondents

Table 4. The knowledge of the functioning of hospices – descriptive statistics

Statements	Correct answer		Incorrect + 'I don't know' answers	
	<i>n</i>	%	<i>n</i>	%
Only sick elderly people (65+) may receive hospice care	233	93.57	16	6.43
Hospices are created by priests and nuns so they can only be used by Catholics or other Christian denominations	220	88.35	29	11.65
Only patients over the age of 18, with no upper age limit, may receive hospice care	208	83.53	41	16.47
A hospice is a place where only people with cancer stay	208	83.53	41	16.47
Hospice care is a type of care that can also be provided in the home setting	198	79.52	51	20.48
Hospice care can also be provided to children from birth to 18 years of age	192	77.11	57	22.89
Only people in the last days of their lives are provided with hospice care	185	74.30	64	25.70
A hospice is just the name of the building where sick people are staying	179	71.89	70	28.11
Hospice care is a type of care that can only be provided in a dedicated building	157	63.05	92	36.95
Hospice care costs a lot, so not everyone can afford it	138	55.42	111	44.58
Hospice care can also be provided to parents of an unborn, very ill child	107	42.97	142	57.03
Hospice care is free	72	28.92	177	71.08

n – total number, % – percentage of respondents

that represent a gap in the respondents' knowledge of hospice care. As shown in Table 5, the social group represented in our research was generally characterized by a slightly above average level of knowledge of hospice care in Poland ($M = 20.4$, $SD = 2.5$).

The level of knowledge and sociodemographic variables

In the study group, there was a weak, positive, and statistically significant correlation between the level of knowledge and the age of the subjects ($R_s = 0.166$, $p = 0.0087$). The variables that showed the highest association with level of knowledge were education ($p = 0.0005$) and medical profession ($p < 0.0001$). The other variables were not related to the level of knowledge presented by the respondents ($p > 0.05$) (Table 6).

DISCUSSION

The therapeutic possibilities of modern medicine significantly extend the life expectancy of modern man, but even they run out someday. This applies to patients of all ages. From the foetal period to late old age, a person's somatic condition may become so fragile that it is impossible to restore its proper functioning enabling long-term survival. This opens a wide area for palliative medicine, including hospice care. Although the number of inpatient and home

hospices in Poland is constantly increasing, they are still not able to fully cover the needs of patients who have completed causal treatment. Nevertheless, every patient can and should make efforts to be included in the preferred form of palliative care. However, public awareness of the realities of palliative care plays a key role in taking this step. This issue became the subject of research for this study. As it shows, the knowledge of selected aspects of hospice care (on which the researchers' attention was focused) has reached a high level. Even though the idea of the hospice is strongly rooted in human religiosity, for the majority of the respondents, the patient's stay in a hospice was not equated with the necessity of belonging to a particular religious group. However, 16.47% of the respondents had a misconception about the disease that qualifies a patient for a hospice – they thought it was only a cancerous process. Therefore, it is necessary to emphasize the necessity of providing correct information by the medical staff taking care of terminally ill people, enabling them and their caregivers to apply for hospice care. A slightly smaller percentage of incorrect answers related to this aspect was found in the CBOS survey "Poles about hospices and palliative care" (10.44%) [11].

According to Polish legislation, the stay of patients under hospice care, in all its forms, is free. Economic issues and the related barriers in access to medical care are unfortunately, as it turned out in our research, insufficiently well or even poorly recognized by the respondents. More than a quarter of the surveyed group (28.51%) believed that this form of care should be paid for from the household budget. The percentage of those who had no knowledge of the subject is also worrying (42.57%). It is worth noting, however, that according to more than half of the respondents (55.42%) these costs should not be so high as to make it impossible to make these pay-

Table 5. The knowledge of the functioning of hospices – descriptive statistics

Variable	M	SD	Me	Q1	Q3	Min.-max.
Level of knowledge	20.4	2.5	21	19	22	12-24

M – mean, SD – standard deviation, Me – median, Q1 – first quartile, Q3 – third quartile, min. – minimum, max. – maximum

Table 6. The relationship between selected sociodemographic variables and the level of knowledge concerning hospice care

Variables	n	M	SD	Me	Z	p
Education						
Below tertiary level	99	19.8	2.5	20.0	-3.49	0.0005*
Tertiary level	150	20.8	2.3	21.0		
Declared faith in God						
Yes	182	20.3	2.4	21.0	-2.11	0.0352*
No	67	20.9	2.6	21.0		
Medical profession						
Yes	80	21.3	2.3	22.0	4.38	< 0.0001*
No	169	20.0	2.4	20.0		
Presence at the death of a person						
Yes	113	20.8	2.4	21.0	2.22	0.0262*
No	136	20.1	2.5	21.0		

n – total number, M – mean, SD – standard deviation, Me – median, Z – statistic test, p – p-value

ments. Nonetheless, all the beliefs described are erroneous and may significantly contribute to complete resignation from applying for hospice care, assuming that they have not been corrected on an ongoing basis by third parties, such as health care professionals. Consistent with our research, the Public Opinion Research Center (CBOS) results also demonstrated a lack of knowledge among Poles about financing hospice care for patients. Every third respondent (33%) believed that hospice costs were covered by patients and their families [11]. As we predicted, the general level of knowledge was significantly influenced by medical education ($p < 0.0001$). The median for the knowledge score among healthcare professionals was 22.00. This result is satisfactory and is a good prognosis for the educational opportunities offered by our environment. The same relationship was demonstrated by dos Anjos Dixe *et al.* in a Portuguese study [12].

Although hospices are primarily associated with elderly patients, the need for this type of care also applies to children. A high percentage of the study group had this knowledge (77.11%), but the functioning of perinatal hospices was known to less than half of the respondents (42.57%). This may be due to the fact that at present there are very few of them in our country (only 17) [13, 14]. The author's research was accompanied by a billboard campaign informing people about the existence of these hospices in Poland. It can therefore be assumed that the rate of correct answers at the moment should be higher, although further research in this field would be worthwhile.

CONCLUSIONS

The general level of public knowledge was slightly above average. However, some areas require modification through the provision of correct educational content.

The knowledge exhibited by the medical community was much higher than in the rest of the group. Therefore, nurses and physicians who work with people in terminal stages of life should be encouraged to promote the idea of hospice care.

The nascent perinatal hospice movement in Poland requires intensified public education campaigns.

Disclosure

The authors declare no conflict of interest.

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