Osveščenost in pričakovanja obiskovalcev ambulant družinske medicine o paliativni oskrbi v Sloveniji

Awareness and expectations of visitors to family medicine practices about palliative care in Slovenia

Avtor / Author

Erika Zelko[1,2], Dorotea Gašpar[1], Estera Gjuras[1], Nevenka Krčevski Škvarč[1,3]

Ustanova / Institute

[1]Univerza v Mariboru, Medicinska fakulteta, Katedra za družinsko medicino, Maribor, Slovenija; [1]Zdravstveni dom Ljubljana, Slovenija; [3]Univerza V Mariboru, Medicinska fakulteta, Inštitut za paliativno medicino in oskrbo, Maribor, Slovenija;

[1]University of Maribor, Faculty of Medicine, Department of Family Medicine, Maribor, Slovenia, [2]Public Health Centre Ljubljana, Ljubljana, Slovenia, [3]University of Maribor, Faculty of Medicine, Institute for palliative medicine and care, Maribor, Slovenia;

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Izvleček

Namen: *Paliativna oskrba in paliativna medicina se v Sloveniji v zadnjih letih intenzivneje razvijata. Podatki o osveščenosti prebivalcev in njihovih pričakovanjih glede paliativne oskrbe (PO), so pomembne informacije za nadaljnji razvoj in raziskovanje na področju paliativne oskrbe.*

Metode: *Izvedena je bila presečna raziskava, v katero smo povabili 2000 posameznikov, starejših od 18 let. Informacije so bile zbrane z uporabo strukturiranega vprašalnika, sestavljenega iz 18 vprašanj. Za analizo smo uporabili opisno statistiko. Stopnja statistične značilnosti je bila določena s p≤0.05.*

Rezultati: *58,6% udeležencev raziskave je menilo, da so slabo osveščeni o PO. Večino informacij so dobili s preko medijev (radio, televizija, internet) in neposredno iz izkušenj v družini in prija-*

Abstract

Purpose: *In Slovenia, palliative medicine and care are developing more intensively in the last years. Appraisal of the existing evidence on, expectations in, and awareness about palliative care (PC) in Slovenia is essential to inform the emerging practice and future research.*

Methods: *A cross–sectional survey of 2000 individuals aged over 18 years old was performed. Information was collected using a structured questionnaire consisting of 18 items. Analysis of the questions is presented using descriptive statistics. The significance level was set at p ≤0.05 in all analyses.*

Results: *58.6% of participants report having little awareness of PC, with most information received via media (radio, TV, internet) and experience obtained directly or through family and friends. In*

Naslov za dopisovanje / Correspondence
doc. dr. Erika Zelko, dr. med.
Medvedova 10, 1000 Ljubljana,
Slovenia
Telefon +386 31510496
E–pošta: erika.zelko@um.si;
erikazelko@gmail.com

teljskem krogu. Bolje osveščene o PO so bile ženske, udeleženci z višjo izobrazbo in višjo starostjo. 69,6% udeležencev naše raziskave bi rado umrlo doma. Bolnik v domačem okolju potrebuje dober nadzor telesnih simptomov (93,8%), zdravstveno nego in oskrbo (65,9%) ter podporo s strani prostovoljnih negovalcev (41,4%). Izpostavili so tudi potrebo po telefonski konzultaciji svojcev in bolnikov v primeru zapletov (55,4%). Obrazec vnaprej izražene volje pozna 28,4% udeležencev raziskave.

Zaključek: *Predstavljeni podatki raziskave zagotavljajo empirično podlago, ki lahko predstavlja izhodišče razprave o smrti, umiranju in vnaprejšnjem načrtovanju oskrbe v družbi. Soočanje z vprašanji ob koncu življenja je nenazadnje neizogibno za vse nas. Vsi pacienti imajo pravico do človeškega dostojanstva in miru v zadnjem življenjskem obdobju.*

this sample, increasing age, being female and higher levels of education were related to higher reported levels of awareness of PC. 69.6% of our participants said they wish to die at home. According to our participants, patients at home need, their physical symptoms be well controlled (93.8%), followed by medical and health care (65.9%), and support from voluntary carers (41.4%) and they also highlighted the wish of relatives and patients to be consulted via telephone by a health care providers in case of problems (55.4%). 28.4% confirmed they know the advance healthcare directive form.

Conclusion: *The survey data presented here provides an empirical basis from which we can begin stimulating discussions about death, dying and support empowered decision–making, as confronting end of life issues is inevitable for us all. All patients have the right to dignity and peace through their last stages of life.*

INTRODUCTION

Palliative care uses a holistic approach for improving the quality of life of patients and their families who face problems associated with life–limiting illnesses. It helps prevent and relieve suffering (1). In 2019, the European Forum for Primary Care (EFPC) published a position paper about palliative care in primary care. Among other important conclusions, it highlighted that educating the public and organising public advocacy campaigns for palliative care are important factors for improving the provision of palliative care (2). Awareness of palliative care is important for overcoming the taboo associated with death and dying in the society. A previous study reported the lowest level of awareness in the United States, where 70.2% of the participants had not heard of palliative care (3). In Sweden, 43% of the participants reported having some awareness, while in Italy, 59.4% of the survey participants reported having heard of palliative care (4–5). Similar results are reported from a Canadian survey (6). The greatest awareness of palliative care was reported in Northern Ireland (7), where 83% of the participants had heard of palliative care.

Until 2003, palliative care was not developed in the Slovenian healthcare system (8). However, it has been developing more intensively in recent years (9–10). In the next 10 years, the population of Slovenia is predicted to be two million, with the highest percentage of increase occurring in individuals aged ≥65 years (11). In total, 20,485 people died in Slovenia in 2018; of these, 17.2% (3,527) died in nursing homes, 51.61% (10,573) died in medical institutions, 24.77% (5,076) died at home and 6.4% (1,309) died elsewhere. Thus, the present annual mortality rate of ~1.09% of the population is also expected to increase (12). The aging society will need some long-term end-of-life (EoL) care (13). Meeting patients' EoL preferences forms an important part of EoL care (14). However, for this purpose, it is important to know the needs and preferences of the overall population and of each individual. Surveys conducted over the last decade have suggested that the general population has a lack of knowledge of palliative care and a negative perception towards it (4,7,14,15). A review of the existing evidence on palliative care needs, palliative care preferences and awareness of palliative care in Slovenia is essential to guide emerging practice and future research. The present study aimed to assess the public awareness of and expectations about palliative care in Slovenia.

METHODS

Type of study and settings

In the present study, a cross-sectional survey was conducted to assess the public awareness of palliative care in Slovenia. The survey was conducted after receiving approval from the relevant research ethics committee on 10.7.2019 (No.: 10 UKC-MB-KME-67/19).

Participants

We aimed to obtain 2,000 responses (representing approximately 1% of the population) from individuals aged between 18 and 80 years in Slovenia.

Translation and pilot testing

For the first family medicine-based survey on palliative care awareness and expectations in Slovenia, we used a Swedish questionnaire (4). Before that, the questionnaire was translated, validated and adapted to our needs. We were in contact with the Swedish research team during the translation process, as we aimed for a valid survey that not only allowed for international comparison but also was culturally and linguistically relevant in Slovenia. The initial translation was performed by a native Swedish speaker who was fluent in Slovenian. Then, this translation was commented on and further adapted by a native Slovenian speaker who was fluent in Swedish. Translating an existing instrument into a second language requires more interpretation and adaptation than a naive translation (16). Therefore, after receiving initial comments from our national collaborators, we used a convenience sample and conducted a think-aloud session in order to revise the items that were unclear, in line with the approach used by Klarare et al. (16). Following this, we sent the online survey to 20 people; their responses were controlled to ascertain the functioning of the survey with reasonable variance.

Data collection

The randomized sample of participants was taken among coincidentally chosen patients from 40 family medicine practices. We included practices that cooperated with the medical faculty in the pedagogical process. The potential participants received the invitation via an e-letter, which contained a link to the online survey or to a paper version of the survey to be administered at the practice. All participants willing participate in the survey were included in the study until a predetermined number of responses per practice was obtained.

The first page of the survey contained information about the survey (a short description of the project aims and the voluntary nature of participation) and an option to continue or decline participation. The survey contained two sections and was estimated to take 10 min to complete. Section 1 consisted of 14 multiple-choice questions that aimed to gather specific information about the respondent's awareness of and expectations about palliative care. Section 2 contained four demographical questions.

Data analysis

The analysis of the responses is presented using descriptive statistics. Differences in the responses based on gender, age and education were assessed using chi-square tests. Differences in age distribution were assessed using the Mann-Whitney U-test. The significance level was set at ≤ 0.05 in all analyses.

RESULTS

We distributed 2,000 surveys in total. A total of 1,168 people responded to the surveys. Of these, 153 responses were incomplete and were therefore excluded from further analysis. Thus, 1,015 respondents aged between 18 and 80 years were included in the analyses. The response rate was 65% and the mean age of the respondents was 44.6 (± 12.8) years. The 153 excluded responses were from the online survey; the respondents finished only the first page of the survey. Analysis of 49 (32%) non–respondents revealed that younger people were less likely to complete the survey than older people. Moreover, there was a significant difference in the non–response rate between men and women.

Awareness of palliative care

Only 34 (4%) men were willing to participate in the survey. The paper version of the survey was more frequently used by the elderly generation. Table 1 provides the most important findings regarding awareness of palliative care. In total, 43.1% of the respondents obtained information about palliative care via the TV, radio or newspaper. The internet and social media (35.6%) were the second most important sources of information, followed by friends and relatives (21.0%). The respondents' knowledge of the aim of palliative care was assessed by asking them to choose a relevant response from a list of six items (Table 2).

Needs of patients and relatives

Based on the needs of patients and relatives, we noted some differences in the responses (Table 3). A slightly higher number of men recognised hospice housing as important support centres for providing palliative care to their relatives. Women expected more bereavement support than men. When asked to choose a preferred site for receiving palliative care, most respondents, regardless of their age and gender, chose their own home as the preferred site. Respondents with lower reported levels of education more commonly chose the hospital as their preferred site for receiving palliative care

Table 1. *Demographic background of respondents, in relation to self-assessed awareness of palliative care.*

	Awareness about palliative care			**p***
	Never heard	**I heard something**	**I know something or I know a lot**	
Gender				**p<0.001**
Woman	112 (16.8)	385 (57.9)	168 (25.3)	
Man	95 (27.3)	209 (60.1)	44 (12.6)	
Age				**p<0.001**
18-29	78 (32.9)	108 (45.6)	51 (21.5)	
30-49	73 (19.9)	219 (59.8)	74 (20.2)	
50-59	23 (10.4)	142 (64.3)	56 (25.3)	
60 or more	33 (17.5)	125 (66.1)	31 (16.4)	
Education				**p<0.001**
Primary school and less	17 (34.7)	31 (63.3)	1 (2.0)	
Secondary school	97 (23.8)	230 (56.4)	81 (19.9)	
University	83 (17.6)	287 (60.8)	102 (21.6)	
Postgraduate qualification (PhD, MSc)	10 (11.9)	46 (54.8)	28 (33.3)	

* *chi-square test*

(28.6%), while those with postgraduate education more commonly choose hospice housing (31%) (p<0.001). Both these findings were statistically significant.

In total, 65% of the respondents mentioned that cancer patients should receive palliative care, 48.6% mentioned stroke patients, 48% mentioned dementia patients, 46.6% mentioned multiple sclerosis patients, 45.2% mentioned amyotrophic lateral sclerosis (ALS) patients and 45% mentioned heart failure patients. Only 26.6% of the respondents mentioned patients with (human immunodeficiency virus) HIV infection.

Preferences regarding palliative care and place of EoL care

The respondents' views on what optimal palliative care should include are represented in Table 4.

Younger people (p<0.001) and women (p<0.001) expected more information about financial issues. Moreover, younger age (p<0.001), female gender (p=0.002) and higher reported levels of education (p<0.001) were found to be significantly correlated with a higher expectation of help related to mental health issues. In addition, women more commonly asked for care at night (p=0.002) and younger people more commonly expected hospital care (p=0.002). Respondents with higher reported levels of education expected the provision of more frequent care throughout the day (p=0.003), the availability of someone on the phone to answer their and their relatives' questions in the case of any issue (p=0.003) and the provision of hospice care (p<0.001).

More than 60% of the participants from all age groups thought that the topic of death and dying is not discussed enough within the society. In particular, women (p<0.001) and respondents with higher reported levels of education (p<0.001) wanted to speak

Table 2. *Aim of palliative care according to gender, age and education of the study participants.*

	Aims of palliative care						**p***
	Accelerates dying and death	**Postpone death**	**It allows the patient to continue an active life**	**Soothes the patient**	**Improve the quality of life**	**I do not know**	
Gender							**p<0.001**
Woman	6 (0.6)	16 (2.4)	39 (5.9)	133 (20.0)	388 (58.3)	83 (12.5)	
Man	3 (0.9)	10 (2.9)	31 (8.9)	85(24.4)	165 (47.4)	54 (15.5)	
Age							**p<0.001**
18-29	4 (1.7)	6 (2.5)	14 (5.9)	45 (19.0)	123(51.9)	45 (19.0)	
30-49	1 (0.3)	9 (2.5)	27 (7.4)	45 (19.0)	210 (57.4)	45 (12.3)	
50-59	0 (0.0)	8 (3.6)	15 (6.8)	45 (19.0)	129 (58.4)	20 (9.0)	
60 or more	4 (2.1)	3 (1.6)	14 (7.4)	50 (26.5)	91 (48.1)	27 (14.3)	
Education							**p<0.001**
Primary school and less	2 (4.1)	4 (8.2)	5 (10.2)	14 (28.6)	10 (20.4)	14 (28.6)	
Secondary school	7 (1.7)	14 (3.4)	34 (8.3)	86 (21.1)	194 (47.5)	73 (17.9)	
University	0 (0.0)	7 (1.5)	3 (3.6)	86 (21.1)	292 (61.9)	46 (9.7)	
Postgraduate qualification (PhD, MSc)	0 (0.0)	1 (1.2)	3 (3.6)	19 (22.6)	57 (67.9)	4 (4.8)	

more about dying (p<0.001). Moreover, 71% of the respondents thought that information about palliative care should be readily available in the society.

Table 5 presents data about the preferred place of care in the last days of life.

Women (32.3%) (p<0.001) and respondents with higher reported levels of education (p=0.005) had significantly greater awareness of advance care directives.

DISCUSSION

This is the first family medicine–based survey of family practice visitors aged between 18 and 80 years in Slovenia. We found that 58.6% of the respondents had little awareness of palliative care, with most information being received via media (the radio, TV and/or internet) and experience being obtained directly or through family

Table 3. *What do you think the most important needs of the patients and relatives according to palliative care are?*

Needs of the patients (ranking 1-3 of importance)	n=1013 (%)	Needs of the relatives (ranking 1-3 of importance)	N=1013 (%)
Relieve physical suffering	950 (93.8)	Home care	762 (75.3)
Medical and nursing home care	667 (65.9)	Psychologist support	621 (61.3)
Support of the informal caregivers	419 (41.4)	Accessibility of volunteer carers	483 (47.6)
Spiritual care	401 (39.6)	Hospice housing centres	430 (42.5)
Specialist medical care	335 (35.0)	24-hours specialist medical care	394 (38.9)
Psychologist support	227 (22.4)	Support for relatives during bereavement	324 (32.0)

Table 4. *What should be offered to patients and their families included in palliative care?*

Needs of the patients (ranking 1-3 of importance)	N=1013 (%)
Relief of physical symptoms at home	779 (76.9)
Patient care at home during the day	561 (55.4)
Someone to help to relieves mental distress (e.g., helplessness, anxiety, fear, depression ...)	476 (47.0)
Someone who could be reached over phone for advice to patients and relatives	432 (42.6)
Care for caregivers	
Medical care at Hospice	363 (35.8)
Patient care at home during the night	355 (35.0)
Medical care at hospital	
In-home support (cleaning, shopping, driving…)	305 (30.1)
Someone who relieves spiritual distress (e.g. spirituality, spiritual help, religiosity)	255 (25.2)
Information and counselling about financial assistance	254 (25.1)
Alternative therapy like aromatherapy, reflexology…	253 (25.0)

and friends. In the present sample, increasing age, female gender and higher reported levels of education were related to an increased awareness of palliative care. In the case of relatives, the greatest cause of stress was the organisation of home care (75.3%). Moreover, 28.4% of the respondents confirmed that they knew of advance care directives.

Awareness of palliative care

Similar surveys have been conducted in different countries (3–7,17). Slovenian respondents reported receiving information about palliative care mainly through the media and internet. Communication and planning could help prevent some distress associated with death and bereavement (18). We were interested not only in palliative care awareness but also in the participants' views on the factors associated with palliative care. In total, 54.6% of the respondents associated palliative care with the concept of improvement in a patient's quality of life; some international studies also support this (7,17,19–20).

Needs associated with palliative care

There has been an ongoing debate in Slovenia about the adoption of an act regulating long–term care and home care, which also reflected in the responses of our respondents. For relatives, the greatest cause of stress was the organisation of home care (75.3%). In addition to the aforementioned needs, which correspond to the expectations addressed in palliative care, our respondents highlighted the wish of relatives and patients to be consulted via phone calls by a healthcare provider in the case of any issue (55.4%). Researchers from other countries have arrived at similar conclusions (3–7,21–26). Furthermore, 30.1% of our respondents expressed a great need for assistance in resolving social concerns, e.g. in regulating their situation at home, their finances (25.1%) and their future. The respondents responded that palliative care should primarily be provided to cancer patients (65%) and patients suffering from other chronic diseases (less than 50%). Similar results have also been reported in previous studies (27–29,30–31).

Table 5. *Preferred place of last days of life and dying*

	End-of-life care and dying				p*
	Home	**Hospital**	**Nursing home**	**I don't know**	
Gender					**P=0.001**
Woman	475 (71.4)	37 (5.6)	23 (3.5)	130 (19.5)	
Man	230 (66.1)	39 (11.2)	12 (3.4)	67 (19.3)	
Age					**p<0.001**
18-29	195 (82.3)	4 (1.7)	4 (1.7)	34 (14.3)	
30-49	261 (71.3)	16 (4.4)	6 (1.6)	83 (22.7)	
50-59	140 (63.3)	23 (10.4)	9 (4.1)	49 (22.2)	
60 or more	109 (57.7)	33 (17.5)	16 (8.5)	31 (16.4)	
Education					**p<0.005**
Primary school and less	29 (59.2)	10 (20.4)	1 (2.0)	9 (18.4)	
Secondary school	305 (74.8)	28 (6.9)	11 (2.7)	64 (15.7)	
University	315 (66.7)	35 (7.4)	19 (4.0)	103 (21.8)	
Postgraduate qualification (PhD, MSc)	56 (66.7)	3 (3.6)	3 (3.6)	21 (25)	

Preferences regarding palliative care

The knowledge of peoples preferred place of death is an important indicator of where pressures in the healthcare system may arise in future years (32).

In total, 69.6% of our participants responded that they wished to die at home; this corresponds to the findings of most international studies (3–5,7,17,20–21,33–34). The gap between wishes and reality is evident in some other studies (20,33–35). Martinez found that the cause of death had a stronger association with the place of death than with sociodemographic variables (36). Moreover, Gomes found that patients dying at home were calmer and their relatives' mourning process was less intensive (35). Only 15% of deaths occurred at home in Japan in 2015, and more men wished to die at home (37). In our study population, significantly higher numbers of men ($p=0.001$), participants with low reported levels of education ($p<0.005$) and participants older than 60 years ($p<0.001$) wished to die in a hospital. Further research is necessary to determine the factors that have a major impact on this decision.

The Slovenian Patients' Rights Act 2008 includes the right to respect advance care directives (38). Only 28.4% of the participants confirmed that they know of advance care directives; women ($p<0.001$) and participants with higher reported levels of education ($p=0.005$) were more aware of it. In 2018, Vilper at al. conducted a study in Switzerland to investigate the awareness and use of advance care directives; they found that 78.7% of adults aged 55 years and older had heard of it prior to the survey, while 24% reported having completed one (39). In the present survey, we were unable to confirm the hypothesis that older people are more aware of advance care directives.

Strengths and limitations

We would like to highlight that our survey was the first in Slovenia to involve 1,013 respondents. In addition to the online survey, paper versions of the survey were prepared, which were preferred by the elderly.

The limitations of our study include the choice of methodology. We chose family medicine practices to recruit participants in the summer, when it was more difficult to include participants from some places than others; this also reflected in the lower number of male participants. We also identified the need to add open–ended questions to our survey, which would give respondents the chance to answer in their own words, as was done in similar surveys conducted in other countries (4,6–7). The survey may be biased because it was administered via the internet, where the participants could find answers and help during the answering process.

CONCLUSION

The results of our survey showed that we have to improve the awareness and education on palliative care to widely implement palliative care in Slovenian population. Although the present findings cannot be generalised to the entire Slovenian population, we are confident that our results will assist in planning activities in the community. We hope that our findings form a solid basis for future discussions about death, palliative care and mourning.

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CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

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