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Postgraduate palliative care education and curricular issues in Central Asia, Eastern and South-Eastern Europe: Results from a quantitative study

Abstract

Introduction. The WHO Europe Office, together with the European Association for Palliative Care, is supporting the development of an interdisciplinary core curriculum for health care professionals in the European Region, which is to be given to the countries as a recommendation.

Material and methods. Between April and September 2018, a research journey to Central Asia, Eastern and South-Eastern Europe took place. It covered two main tasks: collecting quantitative data using a survey and collecting qualitative data by conducting on-site interviews. This article contains the quantitative part. Experts in palliative care education in 23 countries were invited to fill out a questionnaire. The data received from 23 questions were statistically evaluated by IBM SPSS Statistics 25.

Results. 27 surveys received from 21 countries were evaluated. In one-third of the surveyed countries, there is still no postgraduate training in palliative care. The main barriers to the development of educational work are limited political interest, followed by limited educational structures, missing curricula, lack of trainers and the limited healthcare system. For 92.6% of all respondents, a WHO-recommended interdisciplinary postgraduate core curriculum would help promote palliative care in their country.

Conclusion. There is a high need for postgraduate education in general and the intended core curriculum in particular. The results of the survey, along with those from the interviews in a later second part of the publication, are essential for the development of a core curriculum.

Palliat Med Pract 2020; 14, 2: 81–88

Key words: palliative care; post-graduate education; curriculum; Central-Asia, Eastern- and South-eastern Europe

Introduction

Palliative care is impossible without education [1]. Therefore, education is of substantial importance to the development of palliative care [2, 3]. It is an indispensable dimension, as indicated in the recently formulated consensus-based definition by the Inter-

national Association for Hospice and Palliative Care [4]. As early as 2003, the Council of Europe stated the need for adequate training for all occupational groups involved in palliative care provision [5]. Content and components of the training were formulated in curricula, which should have become part of a “National Education Plan” [6].

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Palliative Medicine in Practice 2020; 14, 2, 81–88

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DOI: 10.5603/PMPI.2020.0008

The WHO Regional Office for Europe, together with the European Association for Palliative Care (EAPC), is supporting the development of an interdisciplinary core curriculum for health care professionals in the European region. Since 2016, the WHO Collaborating Center at the Institute for Nursing Science and Practice of Paracelsus Medical Private University (PMU) in Salzburg as a WHO CC has been committed to creating a core curriculum, which is to be given to the member states as a recommendation [7]. The focus on multidisciplinary is based on the importance of interprofessional learning in courses and practice placements [8–11] as well as on interprofessional cooperation in palliative care teams [12, 13].

There is a disparity of palliative care in the European area of WHO [14–19]. This gap in delivery and services is reflected in general developments in palliative care education as well as in specific developments in postgraduate education and training [20–24]. The recent Lancet Commission Report on Palliative Care and Pain Relief emphasised the importance of training and capacity building for the “system-wide integration of palliative care in low-income and middle-income countries” [25]. In order to improve the understanding of the country and region-specific needs, a field study was carried out in 23 countries.

Aim of the study

This study aims to describe current aspects of postgraduate palliative care education and curricular issues in the countries of Central Asia, Eastern Europe and South-Eastern Europe that are important for a core curriculum, as well as to evaluate to what extent the idea of creating a core curriculum is judged useful.

Material and methods

Between April and September 2018, a research journey to Central Asia, Eastern Europe and South-Eastern Europe took place. Taking into account the first two steps of the “Six-step approach to curriculum development for medical education,” drafted by Thomas and Kern [26], the field study covered two main tasks: collecting quantitative data by using a survey and collecting qualitative data by conducting on-site interviews, both in English. This article contains the quantitative part.

The survey comprised thematic blocs: a. Demographics and structures in providing palliative care, b. Palliative care education and perceived barriers. The questions included multiple-choice, yes-no questions with free-text fields, open-ended free-text fields, and verbal rating scale ranging from 0 = very low, 1 = low, 2 = moderate, 3 = high, to 4 = very high. The data received from 23 questions were statistically evaluated

by IBM SPSS Statistics 25. Due to the low total number of respondents, there was no comprehensive thematic analysis for the free-text answers. Instead, they were mostly noted as quotes. The data of the qualitative exploration will be published separately.

Results

Twenty-nine potential participants activated the online survey. Two of them did not enter any data and four additional hand-written questionnaires were handed in personally to the study team without consent for research so that these six could not be included in the analysis. Finally, 27 surveys were considered. The 27 questionnaires were received from the following 21 countries: Kyrgyzstan, Tajikistan, Kazakhstan, Uzbekistan, Azerbaijan, Georgia, Armenia, Latvia, Lithuania, Belarus, Ukraine, Republic of Moldova, Romania, Albania, Greece, Turkey, Cyprus, Bosnia and Herzegovina, Poland, Hungary, Czech Republic.

Demographics and structures in providing palliative care

The professional background of the experts was named as medicine (66.7%, $n = 18$), psychology (18.5%, $n = 5$), and nursing (11.1%, $n = 3$). 7.4% ($n = 2$) added researcher, and 3.7% ($n = 1$) did not reply. Their place of work (multiple answers were allowed) was described as university (40.7%, $n = 11$), hospital (33.3%, $n = 9$), hospice (25.9%, $n = 7$), mobile care team (11.1%, $n = 3$), and other ($n = 6$, 22.2%), such as non-governmental organizations, public health and reform centers or regional palliative care center. 18.5% ($n = 5$) did not respond. 59.3% ($n = 16$) of respondents had more than 10 years working experience in palliative care setting, 25.9% ($n = 7$) had from 5 to 10 years, and 7.4% ($n = 2$) had less than 5 years. 7.4% ($n = 2$) chose the option “other”.

Six questions were focused on the educational profile of the key persons. Summarised, referring to the population of $n = 27$ cases, it can be said: regarding formal education training (multiple answers were possible), 44.4% ($n = 12$) had the qualification train the trainer, 37.0% ($n = 10$) had a basic course provided by a university or another educational institution. 88.9% ($n = 24$) are involved in teaching palliative care. 37.0% ($n = 10$) have more than 10 years teaching experience in palliative care, 33.3% ($n = 9$) have 5 to 10 years. For 63.0% ($n = 17$) of the respondents, the university is the place of teaching (multiple answers were allowed), followed by the hospice (37.0%, $n = 10$). 85.2% ($n = 23$) typically teach together with other experts. The experts were asked to name three of the main fields of expertise (free-text fields). Most entries in the first two fields were pain therapy and

psychology, in the third was organisational aspects (each 14.8%, n = 4).

Structures in providing palliative care

The EAPC White Paper on palliative care standards and norms [27] describes a three-step ladder of different levels in providing palliative care. 48.1% (n = 13) of the experts indicated that general palliative care exists in their country, specialized palliative care was started by 44.4% (n = 12), and a palliative care approach by 18.5% (n = 5). 4% (n = 2) described others: “at the time of answer we do not have a palliative care system”, and “some scattered elements” existed, which are not “synchronized and formally organized”.

Different kinds of services for people with life-limiting illnesses (multiple responses were accepted) were specified by the experts as home palliative care teams (70.4%, n = 19), inpatient palliative care units (59.3%, n = 16), inpatient hospices (51.9%, n = 14), palliative care beds in community hospitals (37.0%, n = 10), hospital palliative care support teams (25.9%, n = 7), palliative care beds in nursing homes (22.2%, n = 6), palliative care nurse (7.4%, n = 2), and “others” (33.3%, n = 9), e.g. out-patient clinics, day care centres or help line for patients.

Palliative Care Education and Perceived Barriers

Core Competencies

Using the 10 core competencies of the EAPC [11, 28] as an educational requirement was highly approved by the experts (Table 1).

The highest percentage obtained core competence two with 66.7% (n = 18) for “very high importance”. In the addition of the percentages for “very high” and “high”, each of the core competencies rates over 80.0%.

Cultural-religious aspects

The experts were asked whether there were any cultural-religious aspects to consider when applying the competencies. 59.3% (n = 16) of them agreed, 40.7% (n = 11) disagreed. In the case of affirmative answers, they were asked to describe these aspects. 51.9% (n = 14) gave some detailed explanations, 7.4% (n = 2) did not provide information. In the following, three comments from Central Asia are quoted: (a) „Parents-child relationships are very strong in my country. Currently, having very few ideas about palliative and hospice care people are sceptical about the implementation of palliative care in the structure of medicine.” There is a „very curative approach to medicine. Even incurable cases are treated in hospitals, which make it hard both for the patient and his surrounding and hospital staff. Also, opiophobia was implemented to doctors and people throughout the whole Soviet Union government. Therefore, patients and doctors are very scared of appointing narcotic analgetics.” (b) „Some religious leaders say that the pain was sent to them by God as a punishment for sins in their life or as a trial, and they must endure and through pain come to purification and transition to another life.” From the same expert: „some religious leaders say that while taking morphine, a patient may die due to cancer complications and be clouded and will not be able to answer questions correctly at God’s court.” (c) The country „is home to about 130 nationalities and ethnic groups. Although they live in harmony, special attention should be paid to cultural peculiarities. The majority of the population is bilingual ..., but many people, especially in rural areas, do not understand Russian.”

The descriptions from other countries highlighted religious aspects as well, especially Muslim

Table 1. Participants’ ratings of the importance of core competencies in palliative care in % (n = 27)

Importance of core competencies in palliative care	Very high	High	Moderate	Low	Very low	Missing values
1 Apply the core constituents of palliative care in the setting patients and families are based	37.0	48.1	7.4	3.7	3.7	0
2 Meet patients’ physical needs	66.7	22.2	3.7	7.4	0	0
3 Meet patients’ psychological needs	55.6	29.6	0	3.7	7.4	3.7
4 Meet patients’ social needs	44.4	40.7	11.1	0	3.7	0
5 Meet patients’ spiritual needs	48.1	37.0	3.7	7.4	3.7	0
6 Respond to the needs of family carers	37.0	48.1	3.7	3.7	7.4	0
7 Respond to the challenges of clinical and ethical decision-making	37.0	44.4	11.1	3.7	3.7	0
8 Practice comprehensive care co-ordination and interdisciplinary teamwork across all settings	51.9	33.3	3.7	3.7	7.4	0
9 Develop interpersonal and communication skills	55.6	33.3	0	7.4	3.7	0
10 Practice self-awareness and professional development	55.6	33.3	0	7.4	3.7	0

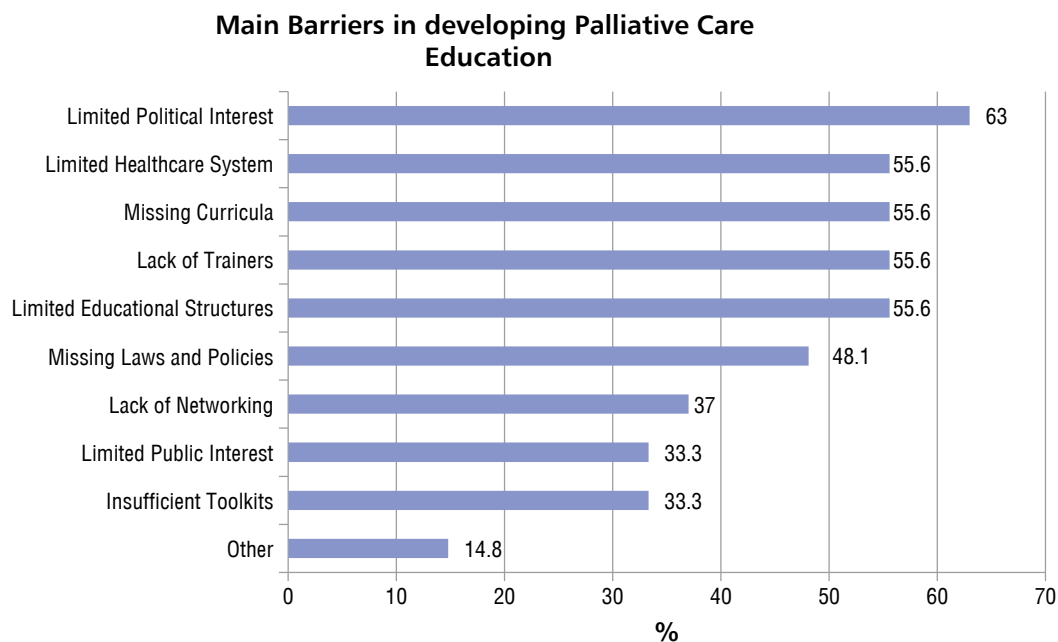


Figure 1. Participants’ ratings of the presence of certain main barriers in developing palliative care education in their countries% (n = 27, multiple answers possible)

and Christian cultures and beliefs. Also, strong family ties and family-centred communication were pointed out. In this context, “a lot of taboos around speaking about death and dying” were mentioned. Considerations on ethical questions were also given “due to the lack of some regulations”, e.g. regarding “medical proxy or advance care planning”. Furthermore, specialists in palliative care had a “potential role ... in ethical discussions/consultations with other specialists about futile/overzealous treatment and acceptance that caring for the dying is thus valuable for the doctors”.

Main barriers in developing palliative care education

The finding of limited political interest is noteworthy. 63.0% (n = 17) cited this deficiency as the biggest barrier. The overall results are presented in Figure 1.

Postgraduate Palliative Care Education

Postgraduate education, hours and certification

Of the experts, 63.0% (n = 17) confirmed the existence of palliative postgraduate education in their country. 33.3% (n = 9) refuted, and 3.7% (n = 1) did not reply. In the case of existence, the experts were requested to give information about the hours which the teaching comprised for different professional groups, and if this education was certified. The results for medicine, nursing and interdisciplinary education are listed in Table 2.

On psychology, the following information was provided: 3.7% (n = 1) of the experts answered 0-10 hours, 14.8% (n = 4) said 31–40, and 3.7% stated 161-170; missing values were 77.8% (n = 21). On social work, 3.7% (n = 1) said 11–20 hours, 14.8% (n = 4) answered 31-40, and missing values were 81.5% (n = 22). On pastoral work, 3.7% (n = 1) indicated 0-10, 7.4% (n = 2) replied 11–20 hours, 3.7% (n = 1) to 21-30; missing values were 85.2% (n = 23). On academic staff and leaders, 7.4% (n = 2) answered 0-10 hours, 3.7% (n = 1) said 191–200, and missing values were 88.9% (n = 24). On allied healthcare professionals, the values 0–10 and 11–20 hours each received 3.7%, and missing values were 92.6% (n = 25).

In response to the question of whether or not the training courses were certified, 48.1% (n = 13) agreed for medicine and nursing, for psychology and social work 14.8% each (n = 4), for pastoral work 11.1% (n = 3), for academic staff 7.4% (n = 2), and for interdisciplinary courses 11.1% (n = 3). 3.7% (n = 1) did not have certification for medicine and nursing, 7.4% (n = 2) each for psychology and allied healthcare professionals, for social work, pastoral work, academic and interdisciplinary staff 3.7% (n = 1) each. The percentages refer to the total number of 27 cases.

Existing curricula, recommendations and international training programs

Of the participants, 66.7% (n = 18) confirmed that existing curricula are based on the recommendations of national or international associations. 29.6% (n = 8)

Table 2. Information on hours of teaching in postgraduate palliative care education by participants (n = 27)

Hours of Teaching	Medicine (n = 14)	Nursing (and Midwifery) (n = 15)	Interdisciplinary (n = 4)
0–10	2 (7.4%)	0	0
11–20	0	2 (7.4%)	1 (3.7%)
21–30	0	1 (3.7%)	0
31–40	2 (7.4%)	1 (3.7%)	0
51–60	0	1 (3.7%)	0
71–80	2 (7.4%)	4 (14.8%)	0
101–110	0	1 (3.7%)	0
111–120	1 (3.7%)	0	1 (3.7%)
161–170	1 (3.7 %)	0	0
181–190	0	1 (3.7%)	2 (7.4%)
191–200	6 (22.2%)	4 (14.8%)	0
Missing	13 (48.1%)	12 (44.4%)	23 (85.2%)

of the experts said that they are not based on these recommendations, while 3.7% (n = 1) did not answer. In the case of confirmation, the respondents could state the name of these associations.

59.3% (n = 16) of the experts pointed out that in their countries the existing training programmes are based on international programmes, such as ELNEC (End-of-Life Nursing Education Consortium) or EPEC (Education for Physicians on End-of-life Care). Other experts mentioned EONS, EPEC-O and clinical WHO guidelines. 29.6% (n = 8) did not reference such programs, and 11.1% (n = 3) did not provide information.

Postgraduate Curricula and Included Core Competencies

The key persons were asked which of the 10 core competencies are/should be included in the postgraduate curricula for doctors, nurses and interdisciplinary staff (yes-no answers). Their assessment shows differences in the significance of these competencies for occupation-specific and interdisciplinary curricula. For example, 70.4% (n = 19) affirmed that core competency five (meet patients’ spiritual needs) is/should be included in interdisciplinary curricula, just 55.6% (n = 15) indicated the same for curricula for physicians. Core competency seven (respond to the challenges of clinical and ethical decision-making) was also assessed differently. 85.2% (n = 23) affirmed that this competency is/should be included in curricula for physicians, 55.6% (n = 15) affirmed the same for interdisciplinary curricula. The overall results are indicated in Table 3.

Interdisciplinary Postgraduate Core Curriculum

We asked: “Do you think that an interdisciplinary core curriculum recommended by WHO would help to

promote palliative care education in your region/country”. 92.6% (n = 25) responded with yes, 3.7% (n = 1) with no, 3.7% (n 1) did not provide information. In the case of the no vote, we requested a brief comment. The expert wrote that it “may become challenging. There is no tradition of interdisciplinary postgraduate education for medical and other professionals.”

Discussion

Across the WHO European region, the provision of palliative care training for healthcare professionals is inconsistent. The lack of trained healthcare professionals is the main barrier to increasing access to palliative care. Thus, the WHO recommends that all healthcare professionals should get basic training on palliative care. The newly released EAPC Atlas of Palliative Care (2019) confirms an imbalance in the development of palliative care in this region, which is in many ways a gap between West and East. In terms of the legal frameworks to regulate palliative care provision: most countries in the European area of WHO have established legal frameworks for the provision of palliative care, however, specific laws were according to EAPC Atlas study reported only in eight countries. Sustainable Development Goals urge membership countries to substantially increase health financing and the recruitment, development, training and retention of the health workforce.

This study looks at palliative care developments focusing on the postgraduate palliative care education and curricular issues in Central-Asia, Eastern and South-Eastern Europe; in regions, where the struggle to introduce palliative care services is a matter of paramount importance.

The study demonstrates that 1/3 of visited countries have no post-graduate training for the different professional groups, and 60% of participants feel that the political interest to endorse palliative care is lacking.

In the countries surveyed, there exists an uneven development of postgraduate education in palliative care. The development of a core curriculum is a central component that can reduce this imbalance. In the process, it is important to develop a core curriculum that includes basic and intermediate level education, since countries still without postgraduate training will get recommendations for basic training that connects to an intermediate level. Furthermore, countries with existing basic training will receive recommendations for a higher level (intermediate); and all those countries without interdisciplinary training will get an impulse to set up such courses.

The results of the survey underline the concept of using the 10 EAPC core competencies as an excellent basis for this core curriculum. It has been highly approved by the experts in the present study and beyond [7] as an educational requirement. These were not formulated in the "EAPC White Paper on palliative care education" for specialist work but for basic and intermediate level [28]. They are based on the principles of interdisciplinary cooperation [11].

Each occupational group has its specific knowledge and its specific skills, which is reflected in the different assessment of the core competencies regarding their relevance for occupation-specific and interdisciplinary curricula. Spirituality and ethics were mentioned in the results. Furthermore, the core competencies four (meet patients' social needs) and six (respond to the needs of family carers) were assessed as more important for nursing compared with medicine. Core competency two (meet patient's physical needs) is/should be more integrated into curricula for medicine and nursing than in an interdisciplinary curriculum. All in all, the results in Table 3 are a clear indication that an interdisciplinary core curriculum should not include all core competencies to the same extent and the same depth. Therefore, the development of this curriculum intends to formulate occupation-specific parts to cover the specific needs of medicine, nursing, psychology, social work and pastoral work.

WHO Europe encompasses a wide area with rich cultural diversity. In the areas analysed strong family ties, faith and communication are highly important topics. The core curriculum should be mindful of the diversity of individual imprints and considers cultural competence [29] as part of spiritual competence. Palliative care serves dignity, and it does so with cultural sensitivity. At the same time, the responses make it clear that barriers can result from cultural-religious

convictions, in particular the condemnation of opiates (opiophobia). Figure 1 illustrates how numerous these barriers are for developing palliative care education, and above all the main problem is limited political interest. The recommendations of the core curriculum must consider these obstacles [30] to be relevant. Policymaking needs to be given a high priority.

Limitations of the study

Getting information from experts is acknowledged to be an independent primary source in health care studies, even though this method can imply problems [18]. In the present study, which provided data from 21 countries, the results mostly relate to information from just one key person per country. This is due to the context of the targeted countries of the survey. Added to this, there is a problem with language. English cannot be assumed. Both made it difficult to recruit multiple informants per country. As an important supplement and corrective to the quantitative part, however, a qualitative survey was carried out through conducting interviews. These results will be published separately.

The search for national experts led to a high percentage of respondents being doctors. Not all participants in a multi-disciplinary team are represented in the participants of the study, particularly missing is social work and pastoral work; and the ratio of doctors to nurses is 18 to 3.

With regard to the contents of the study, two limitations should be mentioned:

- Certification: A high percentage of the courses were indicated as certified. Since the term "certified" has not been defined previously, some uncertainty remains. Certifications, for example, may be associated with an exam, but this cannot be generalized.
- Three-step ladder of different levels in providing palliative care: There was only one variable in the questionnaire, which forced the participants to choose only one of the 3 structures. Some of them used the free text field for entering one or two of the other possible levels. In order to incorporate this content, two further variables were subsequently created by the authors. Then, the information in the free text fields was quantified according to the 3 levels and evaluated.

Conclusion

There is a high need for postgraduate education in general and the intended core curriculum in particular. The reasons that emerge from the results of the survey are the following:

- There is no post-graduate training in one-third of the countries.
- More than 90% of the experts judge an interdisciplinary core curriculum as helpful for promoting palliative care education in their region/country.
- In countries with existing training programs, there is a broad distribution regarding the number of hours of teaching. This allows conclusions on the possible and often limited range of topics and their intensity. Striking is the small amount of information regarding the curricula for psychologists, social workers, for pastoral workers and allied healthcare professionals, all necessary members of an interdisciplinary team.
- Only four (14.8%) respondents confirm the existence of training in an interdisciplinary way in their countries.

The results of the survey, along with those from the interviews in the second part of a publication, are essential for the development of a core curriculum. It becomes clear that the successful implementation of this curriculum has to overcome the main identified barriers to educational work, as well as cultural-religious aspects, have to be considered.

Acknowledgements

The authors thank all 27 experts who made essential contributions to the study by providing important data on their behalf or behalf of national associations.

Conflict of interests

Authors declare no conflict of interest.

Funding

This work was funded by the Paracelsus Medical Private University.

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