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*The authors were both involved in the analysis of the data and the writing of the paper.

An international study of healthcare professionals' understandings of palliative care

Abstract

Introduction: The development of palliative care across the World is varied and often limited. The purpose of this comparative study was to explore healthcare professionals' (doctors, nurses, and healthcare workers) understanding of palliative care in several different countries.

Patients and methods: Eight focus groups were held in eight different countries using open-ended semi-structured questions that allowed participants to report on their understanding and experience of palliative care, the referral to services and the difficulties in providing and accessing palliative care. Transcriptions were subjected to thematic analysis.

Results: Sixty people in total participated in focus groups held across eight countries. The main themes derived from the data included: definitions of palliative care; place of death and last care; and barriers to providing palliative care. Knowledge and understanding of palliative care vary across countries and between professionals and family carers. Cultural attitudes around death and dying in some countries appear to impact the introduction, availability, and use of palliative care services. The place of death of people with palliative care needs may also be influenced by resources and cultural norms.

Limitations: The participants were self-selected and may not be representative of the wider views within each country.

Conclusions: Increased educational interventions about palliative care for both professionals and the public would help improve palliative care provision, taking into account the social and cultural norms within communities.

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Key words: palliative care, cultural differences, place of death, education, professional knowledge

Introduction

The World Health Organisation (WHO) defines palliative care as: "An approach that improves the

quality of life of patients (adults and children) and their families facing problems associated with a life-threatening illness. It prevents and relieves suffering through the early identification, correct

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assessment and treatment of pain and other problems, whether physical, psychosocial and spiritual” [1]. More recently, the International Association for Hospice and Palliative Care have developed a consensus-based definition which extends the involvement of palliative care more widely: “Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near to the end of life. It aims to improve the quality of life of patients, and their families and caregivers” [2]. This definition also stresses that palliative care policies and provisions should be applied throughout all healthcare settings [2].

Nevertheless, despite these global definitions, there is concern that the role of palliative care may not be clearly understood by healthcare professionals. For example, a study of Dutch medical schools found that 48% of medical students answered questions about palliative care correctly and only 60% reported feeling confident enough to provide palliative care [3]. In Spain, a study validating The Palliative Care Knowledge Test reported that only 53.7% of questions on palliative care were answered correctly by healthcare professionals, who indicated that they needed further education on the topic [4]. Moreover, a systematic review of twenty studies from ten countries showed that many oncology nurses did not possess adequate knowledge of palliative care approaches, which varied according to their education, experience, and clinical setting [5].

Within the public, there is a similar lack of knowledge about palliative care, including what is involved and when it may be appropriate. A literature review of 13 studies from 9 countries found that up to 70% of people had not heard of palliative care, and less than half had any knowledge of what type of palliative care might be offered [6]. Common perceptions included palliative care being associated only with a terminal illness and end-of-life care and that palliative care was for cancer patients and those who were imminently dying. A national study, using data from the USA Health Information National Trends Survey, also indicated that only around a third (34%) of the surveyed public reported that they had some knowledge of palliative care and only 51% of these people were then able to answer three basic questions about palliative care correctly [7]. The purpose of this pilot study was to explore and understand what professionals across various countries understood about palliative care and in particular the involvement of people with non-malignant diseases.

Patients and methods

Study design

Before developing the study, a small group of clinicians and academic staff ($n = 3$) discussed the research topic and advised that an exploratory study design utilizing focus groups would be most appropriate to gain people’s expressed understandings of a defined area of interest — palliative care — in a non-threatening way [8].

Participants

The doctors and other health professionals were approached at medical conferences, as this allowed more time and fewer logistical restraints for the participants. This took place before the COVID-19 pandemic and, therefore, before the increased use of online video conferencing. The locations included Europe — Croatia, Germany, Norway and Portugal, Africa — Nigeria and South Africa, Asia — Sri Lanka and Australasia — New Zealand. This reflected a range of countries, both in the development and availability of palliative care as ranked by the Economist Intelligence Unit and cross-country comparisons [9, 10]. An information sheet outlining the nature, risks and benefits of the study, was given to those delegates who expressed an interest when approached by the researcher. They were delegates known to the researcher or groups that were already meeting and agreed to participate in the study. This afforded accessible samples of healthcare professionals who were conference attendees and interested in the topic. It also meant that venues were available for each focus group, with an area set aside at each conference centre to ensure privacy. The conference milieu meant that participants were relaxed, and it was hoped that being away from their workplace meant that they were more likely to be open to discussing the topic of palliative care.

Sample

A total of 48 healthcare professionals agreed to take part in the focus groups including 26 (54%) females and 22 (46%) males (Table 1). Ages ranged from 21 to 65. Each group involved participants from a specific country, either from the country hosting the conference or a group of researchers from one country attending the meeting. They included consultants/specialists in neurology, general practitioners/family doctors, anaesthetists involved in pain management, trainee doctors, particularly in neurology, specialist nurses, physiotherapists, social workers, and volunteers from patient support organizations. Their experience in these roles varied from 2 to 40 years.

Table 1. Countries involved in the study and details of participants

Country	Economist ranking 2015 ¹	2021 Expert assessment score ²	2021 Expert assessment ranking ²	2021 Expert assessment grading ³	Palliative care development ⁴	Morphine usage DOME	Country specific sample	Type of health professional	Females/males
Europe									
Croatia	Not ranked	Not ranked	Not ranked	Not ranked	3a	4481	5	3 General Practitioners 1 Anaesthetist 1 Volunteer	4/1
Germany	7	86.9	15	B	4b	30038	5	5 General Practitioners	2/3
Norway	13	87.9	11	B	4b	20919	3	3 Neurologists	0/3
Portugal	24	Not ranked	Not ranked	Not ranked	4b	4350	4	1 General practitioner 1 Intensive therapy unit doctor 1 Nurse 1 Social worker	3/1
Africa									
Nigeria	77	73.6	40	C	3a	0.82	8	4 doctors 4 nurses	6/2
South Africa	34	51.1	73	F	4a	187	10	10 Neurology trainee doctors	6/4
Asia/Australasia									
New Zealand	3	87.7	12	B	4b	16949	5	1 Physiotherapist 1 Nurse 2 Volunteers 1 Respiratory care doctor	3/2
Sri Lanka	65	86.1	16	B	3a	152	8	7 neurologists 1 senior trainee neurologist	2/6
Total							48	37 doctors 5 nurses 4 volunteers 1 Social Worker 1 Physiotherapist	26/22

¹Economist Intelligence Unit Ranking of Palliative Care [9]; ²Cross-country comparison of expert assessments of the quality of death and dying [10]; ³Cross-country assessment and grading A (highest) to F (lowest); ⁴Palliative care development [13] (Category 1 No known palliative care activity — 47 countries, Category 2 Capacity building — 13 countries, Category 3a Isolated palliative care provision — 65 countries, Category 3b Generalised palliative care provision — 22 countries, Category 4a Preliminary stages of integration — 21 countries, Category 4b Advanced state of integration — 30 countries [10]); DOME — distributed opioid morphine equivalent — as morphine in mg/patient in need of palliative care, average 2010–2013 [32]

Methods

Focus groups were held as these allowed a loose format to help participants feel relaxed [11]. The first author facilitated each of the eight focus groups, setting aside around 7 minutes at the start of each discussion for introductions, ethical considerations (see below) and ground rules (including listening and turn-taking). A set of eight open-ended questions was used:

1. What is your role in the care of people at the end of life?
2. How long have you been involved in the care of people who are at the end of life?
3. What does palliative care mean to you?
4. What do you think of the referral process for palliative care?
5. What are the difficulties of providing palliative care?
6. At what stage of the illness would a person be admitted to a hospital/hospice?
7. Have you any experience in working with specialist palliative care/hospice services in the care of someone with an intellectual disability?
8. Is there anything you feel is important to say on this subject?

Each group took between 20 to 40 minutes with an average of 28 minutes. Six hours of data were captured. Each focus group was recorded and transcribed, with any identifying information removed at the time of transcription.

Ethics

An Information Sheet was given to all potential participants and time was set aside for people to read it, and ask questions. The focus group facilitator then ran through the information sheet verbally to make sure that everyone had understood the nature of the research, and what was involved. All participants were made aware of the voluntary nature of participation and that they could withdraw from the focus group at any point without giving a reason. They were also informed that they could withdraw their data up until the point at which anonymous transcription had occurred. Each person was then given a consent form which they were asked to sign before the group discussion. A favourable ethical opinion was obtained from the Tizard Centre Research Ethics Advisory Committee at the University of Kent (REF: 241018).

Analysis

Both authors independently analysed the data according to Braun and Clarke's five-step thematic process [12]. This involved: familiarization with the data by reading and re-reading the transcripts; gene-

rating initial codes for each transcript — then across all the transcripts and identifying relevant quotes to exemplify the codes; reviewing themes by checking if and how these worked with coded extracts. Potential themes were discussed between both authors until an agreement was reached. Three main themes (presented below) were delineated from the data.

Results

Focus Groups were held at conferences in eight countries with a varied availability of palliative care services (Table 1). Each group comprised, on average seven participants (range 3–14) and they were predominantly doctors or nurses. Their experience ranged from newly qualified doctors, in the initial stages of training, to retired consultants with 40 years of experience. The three main themes significant to participants were delineated from the data:

Theme 1: Understanding of the role of palliative care

This theme centred around how palliative care was understood and included a subtheme of how other disease groups were included within services. Participants in the groups from across Europe (Germany, Norway, Croatia) in general stated that they understood "palliative care" to mean "end of life care" and that similarly their patients and families and the general public usually associated it with dying. This was qualified by the following participants stating:

- "People who are dying are not acutely ill" (Neurologist, Norway)
- "Palliative treatment is lowering symptoms without the aim of prolonging life" (Germany)
- "Palliative care is for an illness that is incurable" (Croatia)
- "End-of-life care is a substantial chunk of what we do — but not all we do" (New Zealand)

Nevertheless, these participants also understood that the role of palliative care could be wider, incorporating the management of symptoms and maintaining the quality of life. The timing of involvement was regarded as complex with many participants appreciating that the early involvement of palliative care would be ideal although in reality services were reported as being often restricted to care towards the end of life.

In Sri Lanka, however, participants reported that patients and families expected more active treatment and that this restricted discussion of the options of palliative care. Participants stated that this generally related to the cultural perspectives of health that incorporated a denial of approaching death:

- "...there is a perception that »everything should be done«. When the patient is declining in health I talk with the family and their perceptions are that we can do something, and if we refuse there is someone else who will do this, and we will lose the patient. Some patients use alternative treatments and if we do not do as they wish they may go elsewhere" (Consultant Neurologist, Sri Lanka).
- "There is a different culture, and people seem to accept the person is dying more in the West than in Sri Lanka. They want us to do things" (Consultant, Sri Lanka).

Similarly, participants from Nigeria reported that people attended hospital expecting to be cured, often having tried alternative treatment first. If no treatment was offered, they would return home since they often had limited funds to pay hospital fees. This reduced the opportunities to discuss palliative care: "People come to hospital late, as they may have seen traditional healers, and expect to be treated and do not want to talk about palliative care" (Doctor, Nigeria).

Subtheme: The disease groups involved in palliative care

Participants from a range of countries talked about restrictions in palliative care involvement due to the perceptions that it was primarily for and/or focused on cancer patients leading to restrictions on services for non-cancer patients, such as those with neurological disease or intellectual and developmental disabilities (IDD):

- "Most hospices are cancer orientated and do not take neurological patients" (Norway);
- "I think in motor neurone disease (MND) it's well established but in other diseases, I don't think we're geared up to it" (South Africa).

The participants often were involved with non-malignant patients, particularly progressive neurological disease, and wanted to provide palliative care themselves and to have access to specialist services, for complex issues: "As neurologists, we undertake palliative care" (Norway).

In some areas there was little coordination of palliative care services and poor links between services involved in patient care:

- "In Croatia the oncologist does not have the time and people fall through the holes in the system — no formal referral process and no real coordinated palliative care treatment pathway" (Croatia);
- "It's a very bureaucratic process... you make the referral of the patient when he's diagnosed, trying to see if he can get a place (in a hospice) when he needs it, or when you do it, it probably will be too late because the patient is already dead" (Portugal).

Medical care for people with IDD was considered to be especially limited and patients with IDD were rarely seen by palliative care services. This was partly a result of the provision of social care provision for people with IDD. In Europe community care (care at home or in residential settings) seemed to mean that individuals were less often hospitalized when ill and had limited contact with healthcare professionals. This could result in additional issues when carers/family members died:

- "We saw one patient who when her mother died her sister took over her care" (Nurse, Croatia);
- "Their parents take care of them, they stay at home, and they appear again in a crisis" (Nurse, Portugal).

Theme 2: Place of death and care

Although many participants talked of patients wanting to die at home, this was not always possible, due to a lack of support services at home. This varied across countries with a greater chance of home death in Europe. In some parts of Norway it was reported that palliative care teams were able to provide support at home, although there were no hospices: "People may come to hospital only chosen if there are complications or the family were unable to be »up to it«" (Doctor, Norway).

Participants from Sri Lanka and Croatia stated that families were, in general, less prepared for the dying phase and families resulting in an insistence on hospital admission so that "everything is done" for them:

- "If we do not treat the patients, they (families) may go elsewhere" (Consultant, Sri Lanka);
- "They come to the hospital to have more treatment, which is what they expect, and they hope it will prolong life" (Croatia).

There were also practical issues in caring for someone at home, with fewer services and hospital specialist teams unable to make home visits:

- "They might go home if there is no money and they cannot afford treatment in hospital, but they may come back again if there are symptoms" (Nigeria).
- "If the patient wants to die at home, he must have a strong family. We can only support them on the phone" (Germany).

Theme 3: Barriers to providing palliative care

Barriers to providing palliative care included pressures on health care professionals' time, lack of knowledge and experience of palliative care, resources, and cultural beliefs of the country as outlined below in the following subthemes accompanied by key quotes.

Subtheme: Time

Participants in all of the countries represented talked about heavy caseloads resulting in restricted time they could provide to assess and support patients and families, thereby reducing their ability to provide “good” palliative care: “We do not have enough time to communicate with our patients” (Doctor, Sri Lanka)

Subtheme: Knowledge and experience of palliative care

All participants talked about their lack of training and experience stating that this was associated with the absence of official recognition of palliative care as a speciality:

- “We need a qualification for doctors so we can develop” (Sri Lanka);
- “There is a lack of knowledge (around drugs) in primary care” (Neurologist in Norway);
- “We only had a few sessions on palliative care as an undergrad” (Neurology trainee, South Africa).

Subtheme: Availability of resources

Participants from Sri Lanka, Croatia and Nigeria in particular reported limited resources and little access to palliative care with few specialist palliative care teams to refer patients to. Similarly, in Portugal and Norway, palliative care services were reported to be limited out of the main cities:

- “It’s not uniform across Portugal, in one area there is only one hospice of 12 beds for the whole area” (Nurse, Portugal);
- “There are services in the cities but not in the countryside” (Doctor, Portugal);
- “Home hospice is important as people want to stay at home, we would like to have this option, but it is not available now” (Doctor, Sri Lanka).

Subtheme: Cultural beliefs

The influence of culture was viewed by many participants as affecting the discussion and practice of palliative care. Participants from Sri Lanka and Africa reported that conflicts within families concerning which relative would be best placed to care for the individual were not unusual, with a reluctance to discuss difficult issues with the patient themselves. This scenario was also described by participants from New Zealand who aligned the issue with particular communities where collective decisions were normative:

- “Relatives do not want us to disclose bad news. It stops us from communicating” (Doctor, Sri Lanka);
- “You may have to decide with 20 or 30 people (family members) rather than an individual” (Doctor, New Zealand).

Participants in South Africa and Nigeria also discussed the common practice of patients seeking medical advice from traditional healers, before or simultaneously with receiving hospital treatment. Whilst, on the one hand, participants respected spiritual and cultural belief structures and did not wish to discount them, on the other hand, they recounted how the role of traditional healers was complex — often leading patients to believe that they could be cured, and that hospital medicine was ineffective, which could lead to late presentation of symptomology at the hospital:

- “Patients are often seen with late-stage cancer, as they have been seeing a traditional healer for many months before they come to the hospital” (Nurse, Nigeria);
- “If you speak about an end-of-life patient you are considered a witch” (Neurology trainee, South Africa).

A kind of circular argument arose when a late presentation at the hospital invariably meant that the patient was less well: “The traditional healer blames everyone else (health care professionals) when the person becomes less well” (Neurology trainee, South Africa).

Participants in Sri Lanka specifically talked about the expectations of patients and families to be admitted to the hospital and receive treatment, even if this was unlikely to benefit the patient. This was often related to patients and families being reluctant to talk about dying and death. This made any discussion about the change in emphasis of care to comfort and palliative care complex:

- “The relatives do not want us to disclose bad news and there is a perception that »everything should be done«” (Doctor, Sri Lanka);
- “We cannot talk about dying or death at all” (Doctor, Sri Lanka).

There were examples of some cultural groups refusing pain medication and the difficulties this caused for the caring team. In Nigeria medication was also not available or unaffordable for patients in pain and any case, was not necessarily regarded as helpful: “Some patients will not take any painkillers” (Nurse, Nigeria).

Discussion

This study enabled healthcare professionals to voice their experiences and concerns about palliative care in a relaxed forum. It also provided a lens through which to view the differences and similarities of experiences across countries. A major theme common to all groups was that palliative care is associated with cancer care and end-of-life. This was thought to negatively affect the involvement of professionals and patients and

the acceptance of palliative care earlier in the disease process or for non-malignant diseases. However, there was an understanding of the role of palliative care in the management of symptoms and the maintenance of the quality of life, as defined in the World Health Organization (WHO) definition [1]. Similar issues have been discussed in other studies with a call for the term palliative care to be changed to terminology more akin to “supportive care” in the care of people with cancer to describe a palliative care approach earlier in the disease progression [14]. This aims to enable earlier involvement of services to support patients [15] and seems to have reassured oncologists to refer patients on to supportive care services without having to use the term palliative care [16]. However, a systematic review of the cognitive barriers and facilitators emphasized both the need for improved communication and emotional management skills for professionals, as well as the encouragement of a cultural shift in the beliefs and attitudes to palliative care [17]. Whilst a name change might help, altering the attitudes of both professionals and the public to a more positive framework would also be useful [14].

There is an increasing move to extend palliative care to all patient groups, adopting a public health approach, with greater community understanding and involvement in care [18]. Both the White Paper for Global Care Advocacy and the International Association for Hospice and Palliative Care (IAHPC) have advocated for a more inclusive approach and a widening of all diagnoses [2, 19]. The newer definition from the IAHPC focuses on palliative care being for “all ages with serious health-related suffering due to severe illness and especially of those near to the end of life” [2]. The comments of participants in this study indicate that this change in the attitude of both professionals and the public will necessitate education for all [20].

The study highlighted the influence of culture in relation to when dying and death are confronted by people with serious and progressive disease. Culture may be described as “a dynamic framework that evolves through historical, political and social forces... and each subgroup creates a dynamic system of beliefs, values, lifestyles and opportunities” [21]. For the participants, culture including spiritual beliefs, impacted preferences for continuing active treatment until death, even if professionals considered that this could lead to inappropriate and futile treatment and increased distress of the patients and their loved ones. Cultural issues, whilst complex and difficult to navigate, clearly need to be explored and discussed during training.

Within many western countries open communication and discussion of options as regards palliative care has become the norm, intending to maintain pa-

tient autonomy [22]. However, varied communication patterns exist in different countries and often without including the patient [21, 23]. The participants explained how this presents a challenge and a need to develop culturally competent health care that is meaningful to patients and families [24].

The issue of non-uptake of medication due to mistrust of its efficacy and how this links to cultural norms and values was a subtheme of the present study and bears out other research [20]. The role of traditional healers was a particular issue for healthcare professionals in South Africa and Nigeria. It has been suggested that traditional healers have a key role in psychological and spiritual support and decolonized collaboration may be important, even if challenging, since healers may enable a greater understanding of deeply held beliefs [25]. Such collaboration may prevent delays in the uptake of medical services, which often occur when traditional healers are involved.

The preferred place of death of patients varied, with both the hospital and home regarded in equal measure as the best place to die according to participants from different countries. This disparity of views has been observed in other research — a study mapping place of death of cancer patients in 14 countries using death certificate data, showing that home deaths varied from 12% in South Korea to 57% in Mexico and hospital deaths varied from 26% in New Zealand to 87% in South Korea [26]. Cultural aspects may have a considerable effect on the place of death, as has been discussed above.

Several barriers to the development of palliative care were discussed by the groups, in particular insufficient time, the lack of training, and insufficient resources. Many participants talked about how lack of time prevented them from having the in-depth conversations that they felt were necessary to discuss deeper issues around dying and death. This may also link to a lack of training; extremely limited educational activities at all levels — undergraduate, postgraduate and continuing education for experienced practitioners. These barriers have been shown before: resource availability, lack of awareness of resources, referrer and patient and family reluctance and eligibility criteria and reimbursement for programs [27]. Time and resource poverty have been raised as issues affecting the quality of palliative care in other studies [28] with a European qualitative study suggesting that a lack of education, regulation, certification of services, poor continuity of care, variable legal arrangements for palliative care and the lack of provision for non-cancer patients limited care provision [18].

Proponents of a community approach to palliative care have challenged palliative care services to consider

the meanings, social aspects and understanding of the experiences of communities of death, dying and loss, rather than just considering the clinical needs of patients [29]. There is a move to reach out to communities, where care and support are already provided by the community and the existing health services. They propose involving the community in a partnership approach, with social and cultural engagement, to transform services, and respond to the community [29]. This approach may enable all, health care professionals and the public, to fully understand and develop the benefits of palliative care.

A review of low- and middle-income countries found similar barriers to those reported in this study but in addition found non-availability of medication and widespread knowledge deficits for professionals, the public and politicians [30]. Although the World Health Assembly in 2014 approved the “Strengthening of palliative care as a component of comprehensive care throughout the life course”, a study of key experts suggested that barriers remained, including funding issues, cultural aspects of understanding, taboos, and inhibitions in discussing death and a lack of proposals for implementation [31]. These issues were all reflected in the present study focus groups.

Limitations

The choice of study locations was opportunistic, as they were undertaken at conferences and thus the participants were self-selecting and limited to those who could afford the time and money to attend conferences. Therefore, the present study sample cannot be regarded as representative of each country.

Conclusions

This study has shown that there is an understanding of the role of palliative care in different countries, but this is often limited to care at the end of life and to patients with cancer. The development of services appears to be affected by cultural issues — in the openness of communication about dying and death and the place of death. There is a need for education at all levels — politicians, health and social care professionals and the general public. Further research is needed to look at these issues, and the most effective ways of developing educational approaches, which address cultural needs.

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Declaration of conflict of interests

The authors declare that there is no conflict of interest.

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