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Children's palliative care perceptions and educational needs among healthcare professionals in humanitarian settings

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Abstract

Objectives. Explore humanitarian healthcare professionals' (HCPs) perceptions about implementing children's palliative care and to identify their educational needs and challenges, including learning topics, training methods, and barriers to education.

Methods. Humanitarian HCPs were interviewed about perspectives on children's palliative care and preferences and needs for training. Interviews were transcribed, coded, and arranged into overarching themes. Thematic analysis was performed using qualitative description.

Results. Ten healthcare workers, including doctors, nurses, psychologists, and health-project coordinators, were interviewed. Participants identified key patient and family-related barriers to palliative care in humanitarian settings, including misconceptions that palliative care was synonymous with end-of-life care or failure. Health system barriers included time constraints, insufficient provider knowledge, and a lack of standardized palliative care protocols. Important learning topics included learning strategies to address the stigma of serious illness and palliative care, culturally sensitive communication skills, and pain and symptom management. Preferred learning modalities included interactive lectures, role-play/simulation, and team-based case discussions. Participants preferred online training for theoretical knowledge and in-person learning to improve their ability to conduct serious illness conversations and learn other key palliative care skills.

Significance of results. Palliative care prevents and relieves serious illness-related suffering for children with life-threatening and life-limiting conditions; however, most children in humanitarian settings are not able to access essential palliative care, leading to preventable pain and suffering. Limited palliative care knowledge and skills among HCPs in these settings are significant barriers to improving access to palliative care. Humanitarian HCPs are highly motivated to learn and improve their skills in children's palliative care, but they require adequate health system resources and training. These findings can guide educators in developing palliative care education packages for humanitarian HCPs.

Introduction

Each year, more than 21 million children experience serious health-related suffering, as a result of chronic or life-limiting health conditions (Connor et al. 2017). To relieve this suffering, palliative care, which focuses on addressing pain and other physical symptoms as well as social, emotional, and spiritual suffering, is needed. The 2018 Lancet Commission on Palliative Care and Pain Relief identified palliative care as “an essential component of any response to humanitarian emergencies and crises,” yet for children in humanitarian settings, palliative care is rarely available, with provision neglected due to a focus on saving lives (Knaul et al. 2018; Krakauer et al. 2019). Several palliative care programs in humanitarian settings have been described; however, there are very few programs which specifically focus on the unique needs of children and their families (Doherty and Khan 2018; Pinheiro and Jaff 2018; Yantzi et al. 2023).

Training humanitarian health workers to provide palliative care has been identified as an important step to improve access to palliative care in these settings (Hannon et al. 2016; Sasaki et al. 2017). One previous study described a virtual learning program (Project ECHO), which

trained healthcare professionals (HCP) working in a humanitarian response in Bangladesh on general principles of palliative care, but was not specific to pediatrics (Doherty *et al.* 2022). The knowledge, attitudes, and beliefs of HCP play a vital role in determining the success of palliative care program implementation and delivery. Without training and support, HCP may be hesitant to initiate palliative care, as they struggle to identify which children will benefit and may fear that families will not accept palliative care (Davies *et al.* 2008).

Several scales have been developed to understand and quantify the palliative care knowledge, attitudes, barriers, and learning needs of HCP, but these have been primarily designed for high income countries, and none are tailored to the experiences of humanitarian settings (Lazenby *et al.* 2012; Loera *et al.* 2023; Ross M *et al.* 1996). There are no published studies describing pediatric palliative care knowledge, attitudes, or learning needs in humanitarian settings. Studying the specific learning needs and preferences of humanitarian HCP is important because prior training experiences and healthcare delivery and practices may vary substantially from those in other settings.

The aim of this study is to explore humanitarian HCP's attitudes and perceived barriers to implementing palliative care for children in humanitarian responses and to identify their educational needs and preferred methods of learning. This information will guide educators in developing educational activities which can support humanitarian HCP to deliver palliative care for children in these settings.

Methods

Qualitative description methodology was selected to produce a rich description of participants' experiences and attitudes toward palliative care and palliative care training while remaining close to the data (Bradshaw *et al.* 2017; Sandelowski 2000). The study consisted of qualitative interviews with humanitarian HCP, including front-line clinical staff as well as those with roles in healthcare management. Both locally recruited and internationally mobile HCP were included.

Sampling and recruitment

Potential participants were recruited from humanitarian health organizations and relevant palliative care organizations and networks by email. The study utilized the established collaborations and networks of study team members (MD, KR, RY) with humanitarian and palliative care organizations to share the study information with potential participants. Additional recruitment occurred via online media including digital announcements with relevant professional organizations, social media chat groups, and word of mouth. HCP were eligible for study participation if they had worked in a humanitarian setting for at least 2 months. Participants were recruited between January and December 2023.

Sampling was purposeful, to ensure a diverse population, with targeted recruitment of participants with specific demographic characteristics to ensure maximum variation sampling, incorporating a wide range of perspectives (Given 2008; Maxwell 2012; Sandelowski 2000). The subgroups included in the sampling strategy are shown in Table 1. As data collection and analysis proceeded, the study team identified that HCP with palliative care training and experience were able to provide more detailed and nuanced views about palliative care learning needs, and as sampling progressed, specifically targeted these individuals.

Table 1. Demographic variables used to guide maximum variation sampling

Category	Groups represented in study sample
Region of humanitarian work	Asia, Africa, South America, North and Central America, Europe
Region of health professional training	Asia, Africa, South America, North and Central America, Europe
Focus of clinical work	Pediatric, adult
Years of professional experience	<5 years, 5–10 years, >10 years
Participation in Project ECHO on palliative care	Yes, no
Type of staff	Locally employed, international/mobile
Professional role	Nurse, physician, other health professional, project coordinator
Main role	Clinical role, management role, combined

Sample size

Ten interviews were conducted and included in the study, which balanced feasibility and the need to address the research questions. Data saturation was not considered an appropriate endpoint since this concept is contested and participants' experiences could theoretically have infinite variations (Sandelowski 2000). However, during iterative data analysis, repetition of themes emerged in later interviews.

Data collection

Demographic data were collected at the beginning of each interview. Semi-structured interviews were conducted using an interview guide, including open-ended and probing questions, to promote topic exploration (Supplement 1) (Ritchie and Lewis 2003).

The interview guide was developed based on a literature review by the research team, with expertise in children palliative care and care in humanitarian emergencies. The guide was piloted with 1 humanitarian HCP, with subsequent modifications to improve clarity and ensure that questions and probes reflected experiences in humanitarian settings.

All interviews were conducted online via video-conferencing (Zoom) to promote accessibility and reduce cost and other burdens. Interviews lasted 30–45 minutes, were recorded and automatically transcribed by Zoom and then reviewed manually for accuracy. Interviewers also took notes and kept reflective journals, which were included as data sources. Interviews were conducted by 2 study team members (SR, MD), with the pilot and first 3 interviews conducted jointly to ensure standardization of the interview process and approach. Both are pediatric palliative care physicians who have more than 5 years' experience in teaching and delivering palliative care for children in humanitarian settings. SR trained in India and has practiced palliative care in South Asia and the Middle East. MD is a Canadian-trained physician, who has practiced palliative care in South Asia and Canada. The interviewers were able to bring their understanding of palliative care in humanitarian settings and education of HCP to support the development of the

research questions and data analysis (Aburn et al. 2021; Fleming 2018).

Data analysis

Data was analyzed using thematic analysis following the approach described by Braun and Clark using NVivo-12 (QSR International Inc., Cambridge, MA) (2021). The preliminary coding scheme was prepared by the team and refined as analysis proceeded. Transcripts were coded by 1 author (ZB) and verified independently by 2 coauthors (MD, SR) to ensure coding consistency and accuracy. Codes were subsequently amalgamated into subthemes and overarching themes. Findings were reviewed with additional research team members (KR, RY), to establish consensus.

The researchers incorporated reflection of their personal and professional experiences while conducting data collection and analysis, noting that several research team members have been leaders and faculty for online and in-person teaching on palliative care for HCP in humanitarian settings.

Ethical considerations

All participants provided written consent to participate and for audio recording. The study was approved by the Children's Hospital of Eastern Ontario Research Ethics Board (CHEO 22/90X).

Results

Participant demographics

Ten HCP participated in interviews. Six participants were international staff, while four were locally recruited. Professional roles included nurse (4), physician (4), clinical psychologist (1), and project coordinator (1). The duration of professional experience ranged between 2.5 and 33 years. Most participants ($n = 8$, 80%) had previous palliative care training experience, which was expected given the purposeful participant recruitment strategy. Table 2 summarizes additional characteristics of the interview participants.

Interview findings

Two key themes and five subthemes emerged from the qualitative data analysis, which are summarized in Table 3.

Perceptions of children's palliative care

Key components of palliative care for children. Participants defined palliative care as holistic care for patients with life-threatening illnesses that focuses on quality of life, relieving suffering, and symptom management, noting "palliative care is an approach in which we take holistic care of the needs of the patient: physical, spiritual, social, emotional. Palliative care should be initiated at the first contact of a patient with a health suffering condition or terminal illness." (P4)

Participants described a wide variety of illnesses where children would benefit from palliative care, including cancer, advanced organ disease/failure, neurological conditions, genetic disorders, neonatal conditions (e.g. prematurity, congenital malformations), and traumatic injuries. Participants identified the different illness trajectories which children may have, noting that some children would require palliative care for a short duration while others for months or years. As a [physician working in x country] described, "we have neurological patients- cerebral palsy with severe malnutrition- but those would be not immediate acute palliative

Table 2. Interview participant demographics ($n = 10$)

Category	<i>n</i>	%
Gender		
Female	7	70
Male	3	30
Country of residence		
Bangladesh	1	10
Brazil	1	10
Germany	1	10
India	1	10
Kenya	2	20
South Sudan	1	10
Spain	2	20
Sri Lanka	1	10
Country of most recent humanitarian work		
Angola	1	10
Bangladesh	1	10
India	1	10
Kenya	1	10
Sierra Leone	1	10
South Sudan	2	20
Sri Lanka	1	10
Sudan	1	10
Yemen	1	10
Type of staff		
International staff	6	60
Locally recruited	4	40
Professional role		
Nurse	4	40
Physician	4	40
Psychologist	1	10
Project coordinator	1	10
Main role		
Frontline clinical	7	70
Both clinical and manager/supervisor	3	30
Primary focus of clinical work		
Both adults and children	5	50
Children	3	30
Adults	2	20
Years of professional experience		
<5 years	2	20
5–10 years	4	40
>10 years	4	40
Previous palliative care training		
Project ECHO	7	70
Other palliative care training	1	10
No	2	20

Table 3. Study themes and subthemes

Perceptions of children's palliative care
Key components of palliative care for Children (who, when, how)
Barriers to providing palliative care for children
Training in palliative care
Learning preferences of participants
Previous training experiences
Motivation to participate in training

care patients, but more mid- to long-term patients...I would like to explain that palliative care is not just end of life care. It can be a huge grey zone and you can do curative treatment while you are starting palliative care, they are not opposite.” (P9)

Perceived barriers to providing palliative care for children.

Participants described patient-related and health system barriers to palliative care implementation. Among patients and family members, there were challenges in addressing collusion and the misconception that palliative care is synonymous with end-of-life care or represents a failure. “So palliative care does have a low acceptance. It is not that people do not want to understand. They understand it conceptually, but I think in terms of principle, they believe that palliative care is for someone who is in the dying stage, when in fact, it starts as soon as the diagnosis happens.” (P7)

Health system barriers included insufficient bed space in health facilities, a limited number of HCP, and limited access to essential palliative care medications and medical supplies, particularly opioids. Participants also noted that despite patients wanting to provide home-based palliative care, this was often not possible. “We could not provide them with oxygen, morphine, or other things that would decrease the pain or suffering...So our community management of palliative care patients was almost zero and that was very sad.” (P9)

The instability of emergencies also prevented planning, as 1 participant noted, “[in my setting] every project is an emergency project. There is no existing project. Everything is an emergency.” (P5)

Palliative care knowledge and attitudes among HCPs also limited implementation. As 1 HCP described, “palliative care does have a very low acceptance because [healthcare workers] see it as a sign of failure. And there's a high attention on the curative aspect” (P7). Despite being personally motivated, participants noted that other staff members may not be interested in participating in training programs. “I've learned from my experience that many people think this, and many people think that, and that let's talk about these myths. I would put a lot of effort into explaining [that palliative care is] not something we do when there is nothing else to do. We should erase this phrase from our vocabulary, and how it is also as important as the rest of curative treatment.” (P9)

Participants noted that standardized palliative care guidelines would support HCP, as would additional training to overcome discomfort when disclosing bad news, reviewing goals of care, and discussing end-of-life with patients and family members.

“Earlier, I used to think that it's only in [my] context. But when I joined this program, I understood, it's kind of everywhere that communication is not really part of the education of the physician. Specifically, talking about the end-of-life care or the topic of dying, because dying is like the most certain thing of human experience, but this is the least discussed topic, I think, in the medical field all across the world. But I think if I give a very contextual space

to it, I think more capacity building of all the incoming doctors and nurses would really be helpful to let them understand that medicine is just one part of the treatment per se. But communication, you know, building up a rapport with them, it's an important part of it, as well. And I think that is the thing that palliative care really teaches. It's the communication aspect of it.” (P7)

Palliative care training

Learning preferences: Topics, training structure, and barriers.

Participants identified key training topics including: the philosophy of palliative care, overcoming palliative care stigma, communication skills, pain and symptom management, providing emotional support, and self-care.

Preferred learning modalities included virtual learning as well as hands-on training. Online training modalities were preferable for theoretical knowledge as this allowed learners to access knowledge at their convenience. Following online training, in-person training with palliative care experts would be helpful.

Suggested strategies to increase online engagement included incorporating more “breakout rooms” (virtual small group discussions) when using internet-based videoconferencing. Participants felt that case presentations were helpful for anchoring learning in practice experiences, “I would say that, having more case vignettes, would really be helpful, so that they could actually see how different contexts could happen in a palliative care setup. And what are the challenges that could pop up.” (P7)

Participants felt that including interdisciplinary teams in training would enhance holistic care. Barriers to participating in palliative care training included time, language, internet and computer access, and direct and indirect costs of training.

Previous training experiences. Participants described their previous training experiences, which included online training (specifically Project ECHO). Several respondents reported previous participation in Project ECHO training courses, which included regular weekly online sessions covering core palliative care topics. Project ECHO has been described elsewhere (Doherty et al. 2022, 2021).

Other training experiences included formal training through asynchronous online palliative care courses, attending conferences, reading research articles and guidelines, and training during health professional school (e.g. medical or nursing college). Less formal experiences included providing palliative care for their own family members, group chat discussions on social media, and receiving guidance from palliative care experts.

Motivation. Participants were highly motivated to participate in training, describing a personal interest in palliative care and a desire to improve the care they provide to patients. They appreciated receiving a course certificate and advice from a trusted mentor as motivators. “I wanted to learn more and hear more from others. The sharing that we used to go into [virtual small group discussion rooms] and we share. I wanted to learn more about what others are doing better. And how can I do also.” (P4)

Feeling connected to an online learning community and hearing how other HCP practiced palliative care around the world sustained their interest in online courses. “It was participative. It was short, like one hour, and it was really crisp and clear. I think that is the reason that I really liked it. It gave us some practical tools and knowledge that we can use, and that we could use in our day-to-day workspace. That is what made me continue.” (P7)

Discussion

This study describes the perceptions and learning needs of a diverse group of humanitarian HCP regarding children's palliative care. The study identifies key topics for pediatric palliative care training including communication skills, which allow providers to compassionately share prognostic information with families and discuss goals of care. A key finding from the study is the preference for virtual training on theoretical topics, and hands-on training for palliative care skills, particularly communication.

The study describes important barriers to pediatric palliative care acceptance which can be addressed through education, including the belief that palliative care represents failure and that palliative care is synonymous with end-of-life care. Health system barriers to training and implementing palliative care include inadequate physical space within health facilities, a limited number of trained staff, and the availability of opioids and other medicines essential for children's palliative care.

The 2020 Global Atlas of Palliative Care highlighted that over 97% of children in need of palliative care live in low- and middle-income countries (Connor et al. 2020). Despite this, access to pediatric palliative care in these settings remains extremely limited; a systematic review of global pediatric palliative care provision identified no services in 66% of countries (Knapp et al. 2011). A recent study identified a lack of HCP training on pediatric palliative care as a significant barrier to improving palliative care availability in humanitarian settings (Sasaki et al. 2017). This is the first study to specifically examine the educational needs of humanitarian HCP providing pediatric palliative care. The study identified key topics for training including identifying which children would benefit from palliative care, the philosophy of palliative care, addressing palliative care stigma, pain and symptom management, providing emotional support, and self-care. These topics are similar to palliative care learning competencies, which have been described by a wide range of professional bodies and organizations for HCP outside of humanitarian settings (Jeba et al. 2018; Paal et al. 2019). Communication skills are particularly important learning needs, especially when caring for children and interacting with their families. These findings are similar to palliative care educational needs assessments for interdisciplinary HCPs globally (Damani et al. 2018; Kaur et al. 2021; Selman et al. 2017). A key finding from this study is that learning needs of HCP in humanitarian settings are similar to those in other settings.

The significance of cultural perspectives in pediatric palliative care is an important consideration when designing palliative care training, as end-of-life care is inherently influenced by cultural norms and beliefs (Givler et al. 2024). Addressing communication barriers, the dynamics of shared decision-making and informed consent, the influential presence of family members, and the varying roles of patients and family members across different cultural contexts are key training considerations to ensure that humanitarian HCP can support palliative care with cultural competence. Training for HCP can help them to navigate the complexities arising from the tension between universal principles of medical care during a humanitarian crisis, of relieving suffering, while also addressing the culturally specific practices in end-of-life care. Future studies are needed to explore that relationship between palliative care principles and how these are translated into local healthcare practices (Samuels and Lemos Dekker 2023).

In many countries, palliative care for adults and children is not yet included in HCP training (e.g. nursing and medical undergraduate and postgraduate training). Ensuring that palliative care

is included in these curricula will ensure that all HCP receive basic training in palliative care and will improve knowledge and skills for HCP in humanitarian settings. Including palliative care in predeparture training for international mobile staff of humanitarian health actors, will prepare these HCP to relieve serious health-related suffering in the field. Dedicated teaching on children's palliative care would be beneficial to review unique aspects of pediatrics, including family-centered care delivery and children's differing involvement in the decision-making process (Chelazzi et al. 2023). Future studies should focus on developing the core competencies for children's palliative care knowledge, attitudes, and skills for humanitarian HCP, so that these can be integrated into future training programs both at a national level and within humanitarian health organizations.

Previous studies have identified barriers to palliative care integration in humanitarian settings, particularly the "lifesaving ethos of humanitarian organizations" and this study's findings support this (Hunt et al. 2020). Study participants identified that a lack of acceptance of palliative care was related to "high attention on the curative aspect [of treatment]" (P7), which was coupled with a belief among HCP that palliative care was a sign of failure. Interestingly, participants believed that overcoming this barrier was possible, suggesting discussions to emphasize that palliative care is not only for situations when there is "nothing else to do" and is "as important as the rest of curative treatment" (P9) would be effective. Future studies should look to determine effective educational interventions and other actions to address negative attitudes toward palliative care.

Training format: Online vs in-person

Online or virtual training has been proposed as an innovative method to increase access to specialist teaching, mentorship, and support for HCP in rural and remote areas (Arora et al. 2017). Virtual learning can be a particularly important tool to increase access to palliative care training in settings where there are very few palliative care experts, and to facilitate rapid training following natural disasters and during conflict where providing in-person palliative care training is challenging (Arora et al. 2017; Doherty et al. 2021). One previous study described a virtual learning and mentorship program, following the Project ECHO model, in the Rohingya Refugee Crisis in Bangladesh, with 10 weekly online learning sessions (Doherty et al. 2022). This program identified improvements in palliative care knowledge, skills, and attitudes among participants, but was not designed specifically for pediatrics or to assess patient- or community health-level outcomes. In the present study, a combination of virtual and in-person training was important for learning, with participants identifying their preference for virtual training for theoretical content, and hands-on training for practical skills. These findings are similar to those reported in the study in Bangladesh, where almost half of the participants noted that more clinical exposure or hands-on training was needed to lead to practice change, and similar findings have been reported in several other ECHO programs in South Asia (Doherty et al. 2022; Lynch-Godrei et al. 2024).

Ensuring the relevance of training to participants' local health-care context has been noted to be a particularly important consideration in virtual training, since faculty may not be working in the same health system or with the same level of resources and thus their treatment recommendations may not be available or feasible (Frehywot et al. 2013; Yennurajalingam et al. 2019). Our study

identified that clinical case vignettes would help learners “see how different contexts could happen in a palliative care setup” (P7) and the challenges which could occur. Further studies should explore learning program designs which optimize learning and practice change for participants, while balancing the resources required for such training.

Study strengths and weaknesses

This study provides a detailed description of the perceptions and educational needs of humanitarian HCP practicing pediatric palliative care, incorporating the perspectives of a wide range of countries and experiences. Thus, the study findings are expected to be relevant and applicable to educators designing palliative care training in a wide range of locations where humanitarian crises occur, globally. The limited number of study participants could be seen as a limitation of this study, and further interviews may lead to a wider variety of views and insights.

Conclusion

This study describes important aspects of the learning needs of humanitarian HCP caring for children with life-limiting health conditions, identifying the importance of specific learning topics related to palliative care, including the philosophy of palliative care, empathic communication, pain and symptom management, and addressing myths and barriers to palliative care. Preferred learning modalities varied for different types of learning, with virtual learning being preferred for theoretical or knowledge-based topics, while hands-on training through role play, clinical vignettes, and clinical experiences was preferred for developing palliative care skills. Addressing barriers to pediatric palliative care including misconceptions among patients and families as well as resource constraints within health systems are important considerations for training.

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Competing interests. All authors have no conflicts to declare.

Ethical approval. This research was conducted in accordance with the World Medical Association Declaration of Helsinki. Ethical approval for the study was received from the research ethics board of the Children’s Hospital of Eastern Ontario (Approval Number: 22/90X; Date: July 26, 2022).

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