

## PallCHASE Webinar #9

### Clinical Education Series: Hidden Lives, Hidden Patients

PallCHASE’s most recent webinar was the first of a four-part clinical education series focussing on how to plan and implement palliative care programming in humanitarian settings.

Dr. Kathryn Richardson, a palliative care specialist with MSF Geneva and a PallCHASE executive, first spoke about the programmatic elements of implementing palliative care in humanitarian settings. Next, Dr. Richardson described how to identify who needs palliative care and the steps involved in implementation. The process was divided into three key phases: planning, implementing, and monitoring/data collection. Regarding the planning phase, Dr. Richardson outlined the importance of prioritizing where to start, mapping actors, and engaging community members. Next, in the implementation phase, Dr. Richardson discussed setting a minimum standard for practice, assessing and utilizing available resources, and various aspects of training. Finally, Dr. Richardson highlighted the importance of developing well-defined data collection and monitoring methods, such as the example outlined below, to measure the impact of the implemented services.

#### MONITORING - INDICATORS

% of deceased patients with documented preferred place for end of life care (facility or home/ camp)	Performance standard 80%
% of patients and/ or caregivers receiving palliative care referred to MHPPS	Performance standard 80%
% of patients receiving palliative care with documentation of pain score (0-10)	Performance standard 90%
Number of days morphine was not available in the past month	Performance standard = < 4 days
% of patients receiving palliative care with documentation of a discussion with patient and/ or family	Performance standard 90%
% of staff involved in providing palliative care who have received palliative care training	Performance standard 90%

Next, Dr. Megan Doherty, Pediatric Palliative Access Director of Two Worlds Cancer Collaboration and PallCHASE Executive, spoke about assessing palliative care needs and barriers in humanitarian settings. Using the example of the Rohingya refugee crisis in Cox’s Bazar, Bangladesh, Dr. Doherty outlines how a rapid situational analysis was utilized to describe the needs of children and adults living with serious or life-threatening illnesses. Dr. Doherty outlined the process of conducting a palliative care needs assessment in humanitarian settings. Next, she described the importance of listening to patients and caregivers, deciding who to interview, developing an interview guide (see below), and data collection. Following this, the needs assessment results were discussed, highlighting needs such as pain relief, access to health care, basic needs, and caregiver needs. Other needs assessment components included the assessment of local health facilities and pharmacy surveys. Lastly, Dr. Doherty discussed knowledge dissemination of the needs assessment. Accessing the right people to disseminate knowledge, releasing an advocacy report, and publishing an academic article were highlighted as examples from Dr. Doherty’s work.

## Developing the Interview Guide (in 2 weeks)

### Literature Review

- Sphere guidelines (standards for humanitarian settings)- included Palliative Care for the first time!
- Previous PC needs assessments in LMICs- Bangladesh (2016), Vietnam

### Draft Interview Guide

- Input from global group of content experts (PC, NCDs, humanitarian)

### Pilot Interview Guide

- Tested with 10 Rohingya interviewers
- Tested with 20 Rohingya patients and caregivers
- Modifications to improve clarity of questions and response options based on Rohingya culture and refugees' experiences

### 2 Final Interview Guides

- Patients and Caregivers

Dr. Mhoira Leng, a palliative care specialist and PallCHASE Executive, facilitated this webinar's panel discussion. The first discussion topic was centred around context considerations when implementing palliative care in humanitarian settings. Mateo Cerro, a nurse working with MSF in South America, discussed his experiences implementing palliative care for patients with chronic kidney disease and the contextual factors that required consideration. Dr. Savita Butola, Medical Commandant, India, highlighted a need for undergraduate education relating to palliative care and the stigma associated with palliative care. Next, Mark Mwesiga, Executive Director of the Palliative Care Association of Uganda, described the context specificity of linking existing services with palliative care by leveraging well-defined information to communicate with political leaders.

The next topic of discussion was palliative care education and the integration of training programs. Dr. Kathryn Richardson discussed the necessity of integrating multiple training styles, including e-learning and in-person observational learning, to ensure accessibility to healthcare providers. Mark Mwesiga addressed the importance of raising general awareness at the government and community levels. In line with this, Mateo Cerro reiterated that it is "very important that we start from the beginning," advocating for healthcare education to include palliative care training.

Lastly, the panellists discussed the burnout and grief often experienced by healthcare workers who provide palliative care. Dr. Butola shared her observations of the benefits of online counselling for healthcare workers, particularly in regions where there may not be access to trained specialists. Mark Mwesiga shared the following quote, which inspired the group: "We cannot give what we do not have".

In the Day 1 panel discussion, Dr. Zipporah Ali, Palliative Care Consultant, and Dr. Ednin Hamzah, APHN Singapore, discuss the differences in palliative care in humanitarian and fragile settings. On the topic of opioid availability, Dr. Zipporah Ali emphasized the importance of advocacy and awareness.

PallCHASE's next webinar will be on July 26th (3pm London) and July 27th (8am London), 2023.