

“Their suffering also plagues us”: moral experiences of MSF staff providing end-of-life care in Cox’s Bazar, Bangladesh

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Introduction

855,000 Rohingya refugees live in overcrowded camps in Cox’s Bazar, Bangladesh where MSF operates Goyalmara Hospital, the only dedicated pediatric and neonatal hospital serving the camps. Palliative care services have been prioritized due to the medical complexity of patients. While palliative care is increasingly recognized as an important component of humanitarian interventions, little is known about the experience of and impact on staff delivering end-of-life care.

Methods

This focused ethnography was conducted between March–August 2021 at Goyalmara Hospital. Data collection involved participant-observation, individual interviews with national (17) and international staff (five), focus group discussions with national staff (five), and analysis of protocols and other documents. A coding scheme was developed using transcript narrative summaries to identify key concepts and constant comparison techniques between and within data sources. Data were coded using NVivo 11.

Ethics

This study was approved by the MSF Ethics Review Board (ERB) and by the ERB of Bangladesh University of Health Sciences.

Results

Moral experiences of staff were influenced by perceived duty of ensuring every effort was made on behalf of patients; ambiguity around the concepts of palliative and end-of-life care, and the perception of palliative care as withdrawal of treatment when “we have nothing to do”. Staff reported coping with frequent deaths by reassuring themselves that they had done their best, yet expressed frustration that MSF could not or would not refer patients for higher-level treatment that they believed was available, and over the lack of transparency of such policies. A perception that further referral for Bangladeshi children was possible in contrast to Rohingya led to a troubling acceptance by staff of discriminatory care pathways. The absence of home-based palliative care, communication barriers, and inconsistent access to morphine, contributed to a sense of powerlessness. Palliative care decision-making was led by expatriate doctors. Although nurses felt more engaged compared with previous roles, several doctors felt uncomfortable with decisions and unable to contradict expatriates. Revolving expatriates with different decision-making approaches undermined national staff confidence. Protocols were seen by all to promote consistency and were utilised by national staff to justify decisions when there was disagreement with expatriates. Non-medical staff were observed to play an important role in sharing difficult news with families but they reported feeling unprepared for this responsibility.

Conclusion

Ensuring clarity and transparency of referral policies and ceiling-of-care criteria is needed to support staff coping mechanisms and to ensure that palliative care is not perceived as a substitute for life-saving care. Non-medical staff require adequate training and support if they are involved with communicating end-of-life decisions to families.

Conflicts of interest

None declared.



Rachel Yantzi is a pediatric critical care nurse from Hamilton, Canada. She has completed two assignments with MSF in the Central African Republic in 2009, and most recently in Cox’s Bazar, Bangladesh from October 2020 to August 2021. While in Bangladesh, Rachel was Nursing Activities Manager for the neonatology department at Goyalmara Mother-Child Hospital. She was involved in several quality improvement initiatives in the neonatal and pediatric critical care departments, and led an ethnographic study focused on MSF staff experiences of end-of-life care. She holds a master’s degree in community health nursing and public health from the University of Illinois at Chicago, and a bachelor’s degree in nursing from Goshen College. She is currently pursuing doctoral studies in Health Research Methodology at McMaster University in Hamilton, Canada.