

COMMUNICATION, EMPATHY, AND TRUST: LIVED EXPERIENCES OF CAREGIVER-STAFF RELATIONSHIPS WHILE PROVIDING PALLIATIVE AND END-OF-LIFE CARE TO CHILDREN IN COX'S BAZAR, BANGLADESH

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Abstract language: English

Topic: Family centred care

Background and aims: MSF Goyalmara Hospital in Cox's Bazar, Bangladesh, offers the highest level of paediatric and neonatal care serving the Rohingya refugee camps. Efforts are underway to integrate palliative care due to high mortality and medical complexity of patients, yet little is known about the experience of staff delivering palliative and end-of-life care.

Methods: This focused ethnography was conducted between March and August 2021 at Goyalmara Hospital. Data collection involved participant-observation, individual interviews with locally-hired (17) and international staff (5), focus group discussions with locally-hired staff (5), and analysis of protocols and other documents. A coding scheme was developed, and data coded using NVivo 11.

Results: Staff perceived gaining the trust of caregivers (parents, grandparents) to be an essential step to providing palliative care and a source of professional fulfillment. Misunderstanding and mistrust were morally distressing to staff, and they experienced intense guilt when they believed that misunderstandings contributed to children's deaths. Efforts to ensure caregiver understanding were complicated by language and cultural differences between staff and caregivers. Staff felt an obligation to suppress their emotional responses to death and dying, even though they acknowledged that this risked caregivers perceiving them as uncaring. Tensions emerged as some staff passed moral judgement on caregivers who they felt were making the 'wrong decision', or who brought a child to hospital too late to save their life. Likewise, staff perceived that caregivers did not always believe the staff were acting in their child's best interests. Other staff were able to empathise with the impacts of grief and systematic exclusion on caregivers' reactions and decision-making.

Conclusions: Positive therapeutic relationships with caregivers may alleviate an important source of moral distress among staff. Access to translation services, communication and grief resilience training, and appreciating psychological impacts of systematic healthcare exclusion on communities may mitigate this distress.

This study is: Approved by an Ethics Review Board (ERB). Please specify:

Details: This study was approved by the MSF Ethics Review Board (ID 20109) and by the Ethical Review Committee of Bangladesh University of Health Sciences (BUHS/ERC/EA/21/31).

1. I confirm that the abstract and that all information is correct: Yes

2. I confirm that the abstract constitutes consent to publication: Yes

3. I confirm that I submit this abstract on behalf of all authors.: Yes

4. Selected for either oral or poster presentation.: Yes

Conflict of interest to declare?: No