

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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Context: Goyalmara Mother-Child Hospital



Unchiprang Makeshift Settlement (UMS, Camp 22) PC: Rachel Yantzi





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Study Aims

1. To document and describe the lived experience of providing palliative and end of life care in Goyalmara Hospital in order to inform program implementation in this and other MSF contexts.

2. To understand the ethical implications on staff of integrating palliative and end of life care into holistic care.





Methodology

- Focused ethnography informed by moral experiences theoretical framework
- Inductive analytic approach using narrative summaries and qualitative coding in Nvivo 11
- Ethics approval: MSF and Bangladesh University of Health Sciences Ethics Review Boards







Results: MSF staff's vision of the staff-caregiver relationship

Effort & Action

 They know and we know that we did our best 'Maya' (Tenderness & Affection)

 They see that we love their baby

Sympathy & Empathy

 We imagine our family in their situation, and they know we feel their pain

Humanity

 We have a shared human experience and treat them as we would treat our family

Trust

 They believe that we are acting in their child's best interest Communicating clearly and honestly

They believe and understand what we are saying

They appreciate us

 They express gratitude for the care we provide



 We remain with them and comfort them





Results: Breakdown in the staff-caregiver relationship

Being seen as a 'mechanical person':

 Maintaining our ability to show empathy 'We are saying one thing, they understand something else':

Struggling to build understanding

Relationship Breakdown

'They blame us':

Feeling blamed by caregivers for the death of a child

'They make the wrong decision and take him away':

Struggling to understand parents' decisions





Conclusions

- Positive relationships with caregivers may alleviate an important source of moral distress for MSF staff involved in paediatric palliative care
- Access to trained medical & cultural translators (24/7) is crucial to facilitating positive relationships with caregivers
- Training and supports are needed:
 - Safe and open spaces for communication
 - Strategies to balance empathy & self-care
 - Communication skills
 - Family-centered care
 - Grief resilience
 - Impacts of trauma and healthcare exclusion





References

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