Exemption from ERB, Medical Director gave permission

MSF Paediatric Days 2022
Poster N°26

"LITTLE BY LITTLE WE ARE GETTING THERE": EXPERIENCES OF INTEGRATING NEONATAL AND PEDIATRIC PALLIATIVE CARE IN A REFUGEE CRISIS

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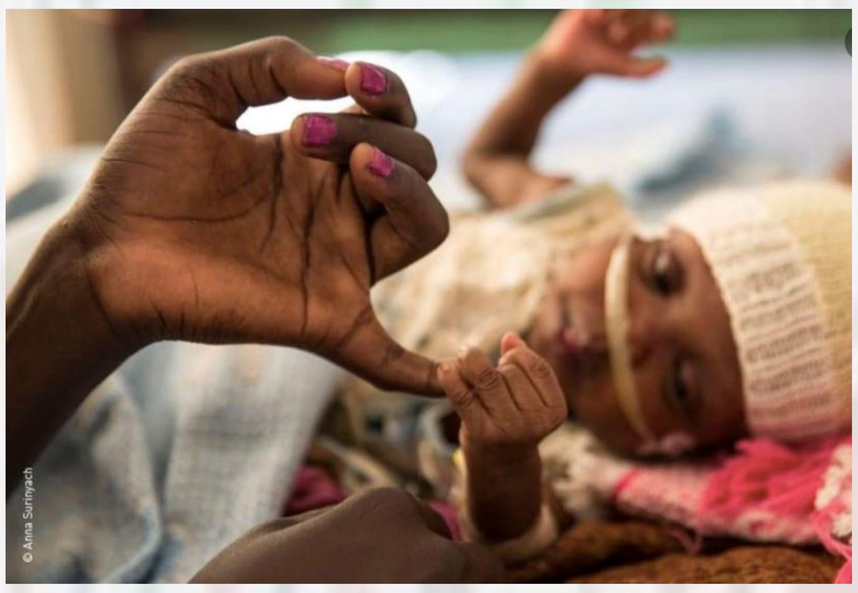
BACKGROUND AND AIMS

Decades of violence and persecution → **855,000 Rohingya refugees** in overcrowded camps in Cox's-Bazar District, Bangladesh

MSF Goyalmara Mother-Child Hospital → only paediatric/neonatal facility offering **level 1 critical care** serving the Rohingya camps

Limited capacity for curative and life-saving care → **high mortality rates**

Operational Priority
Integration of palliative care (PC), particularly, end of life care



METHODS

Inclusion criteria

- Inpatients: Neonates/children < 15 years old with a **life threatening illness,** and their families
- Community-based follow-up: families residing close to the health facility

Based on MSF PC guidelines

- **Locally** adapted protocols
- Care pathways
- Documentation forms

Integration activities

- Identification of PC **focal points** from each discipline
- Advocacy for access to **morphine**
- Training sessions

Qualitative Studies

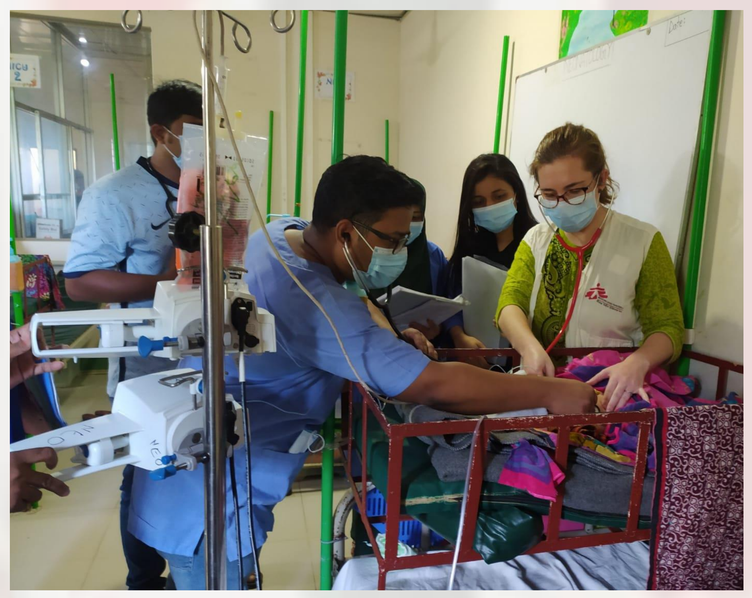
- **Ethnographic Study** to understand the moral experiences of staff involved in the program. March-August 2021
- **Rapid qualitative evaluation** of caregiver experiences. December 2021.
- **A literature review** and two case studies experience in India and Bangladesh "Access to opioids for palliative care in low and middle-income countries" June 2022

CHALLENGES AND STRATEGIES

- Staff **misunderstanding** about PC related concepts "Palliative care is when we have nothing to do"
  - Formal PC trainings
  - **Multidisciplinary** daily bedside clinical mentoring and debriefing of complex cases.

- Breaking bad news and **communication** with families
  - Training on breaking bad news using the **SPIKES** protocol for Doctors, Health Promotion, Mental Health, Interpreters
  - Bedside modeling of effective communication (rehearsing ahead of time)
  - Communication training using role-playing
  - Translators available 24/7

- **Barriers to accessing morphine**
  . Connected with other actors to explore strategies to access morphine locally and apply for a narcotic license



- **Family preference** to take child home: by understanding caregiver preferences we adapted hospital-based practices:

  Private space
  24h Open visitation, without limiting the number of visitants
  Facilitating visits by **religious leaders and traditional healers**
  Bereavement support

CONCLUSION

- Emphasize that palliative care is **Active Care**
- Guidelines, **locally-adapted** protocols/pathways, **multidisciplinary bedside** clinical mentoring → essential to building staff confidence with PC decision-making.
- **Anthropological /Qualitative Assessments** →critical to understanding local perspectives on illness and death, before **AND** during the implementation process

For MSF, Palliative Care Knows No Borders

MEDECINS SANS FRONTIERES