https://www.doctorswithoutborders.ca/article/living-limbo-rohingya-refugees-bangladesh-three-years-after-main-exodus

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

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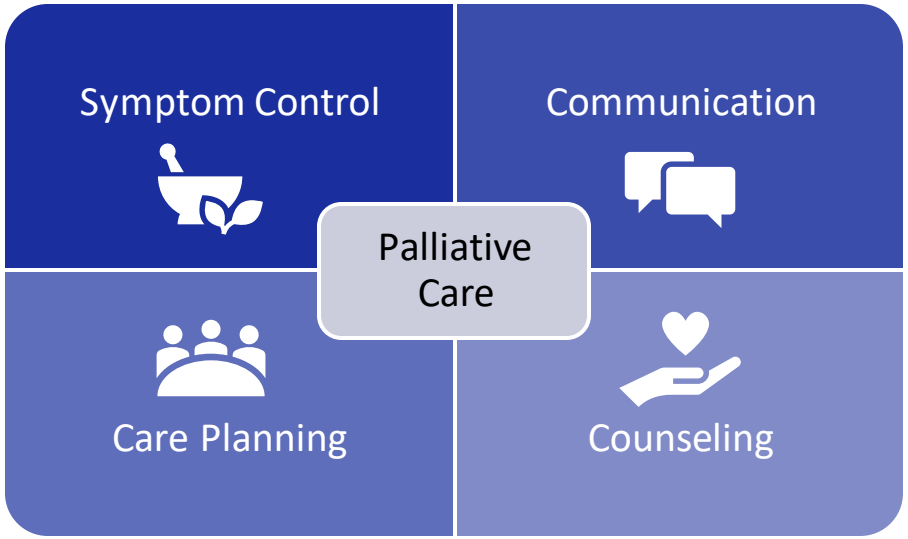
Conflict of Interest:
The author has declared no conflict of interest.

Integrating Palliative Care at Goyalmara Mother-Child Hospital

https://www.msf.org/bangladesh-rohingya-crisis-update-may-2019



https://www.unicef.org/bangladesh/en/stories/three-years-rohingya-refugee-crisis

https://www.doctorswithoutborders.ca/article/living-limbo-rohingya-refugees-bangladesh-three-years-after-main-exodus

Study Aims

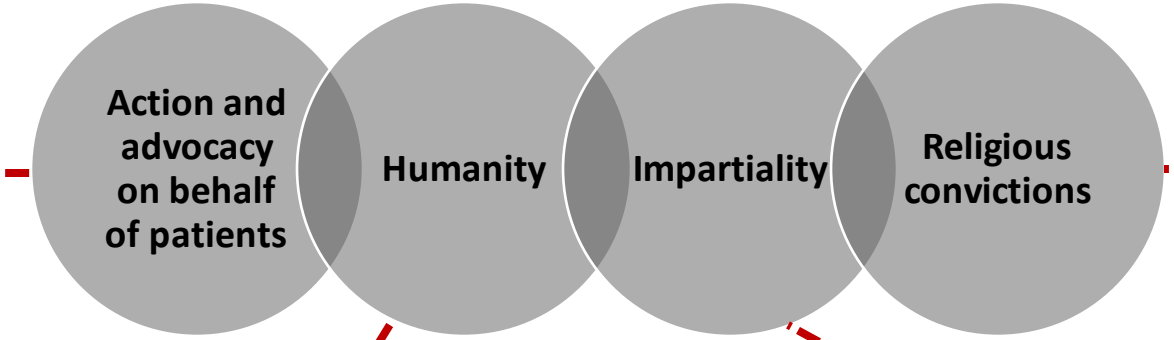
1. To document and describe the lived experience of providing palliative and end of life care in Goyalmara Hospital in order to inform program implementation and preparation of staff in this and wider MSF contexts.
2. To understand the ethical implications on staff of integrating palliative and end of life care into holistic care.

Methodology

- Focused ethnography informed by moral experiences theoretical framework (Hunt & Carnevale, 2011)
- Ethics approval received from the MSF and Bangladesh University of Health Sciences Ethics Review Boards
- Interviews conducted in English, Bangla and Rohingya, audio-recorded, transcribed
- Constructivist analytic approach using narrative summaries and qualitative coding in Nvivo 11 (de Casterlé et al., 2011)

What values guided MSF staff as they provided end of life care?

"Doctors have made the effort, everyone has tried hard enough from their respective roles"
(Focus Group Discussion-01, Mental Health Counselor)



"Now above all we have the belief, those of us who are Muslims, that we are just a medium. Birth and death are controlled by the One" (Focus Group Discussion-04, Nurse)

"I have to put myself in their place… then they will trust us" (Focus Group Discussion-04, Nurse)

"In our ethics everybody is same. There is no difference, age, sex, religion, races... what I am doing right now, I will do [for] my relatives also" (Interview, Nurse-01)

"I have found peace in the peace of the patient's mother"
(Focus Group Discussion-02, Health Promotion Team)

MEDECINS SANS FRONTIERES

SCIENTIFIC DAYS

Conceptual Ambiguity

Palliative care as withdrawal of treatment

"We have nothing to do" (Interview, National Staff Doctor-01)

Sense of Powerlessness

"When this palliative care term comes to us, I am helpless like the mother…with my hands many babies are recovered, but I cannot help her baby" (Interview, National Staff Doctor-02)

Communication Challenges

- Rohingya experiences of healthcare oppression
- Language/cultural differences
- Absence of translators on night shifts

Action and advocacy on behalf of patients

Humanity

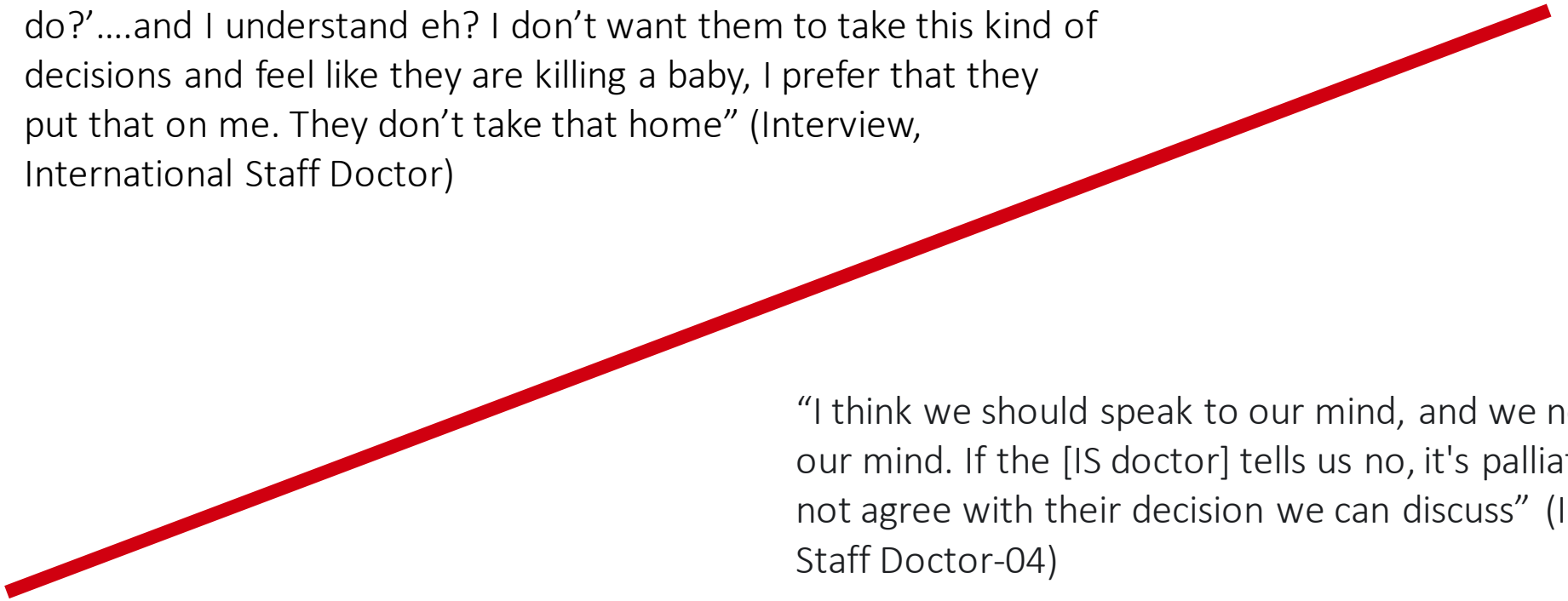
Mistrust and Misunderstanding

"If the patient party hears about palliative care, they are afraid. They don't want to understand why we are not giving the treatment…They said why we don't try our best, why we do not continue the treatment?" (Interview, Mental Health Counselor-01)

International Doctors as ‘Captains of the Ship’

Action and Advocacy on behalf of patients

“The staff keep looking at me like, ‘what do you want to do?’….and I understand eh? I don’t want them to take this kind of decisions and feel like they are killing a baby, I prefer that they put that on me. They don’t take that home” (Interview, International Staff Doctor)

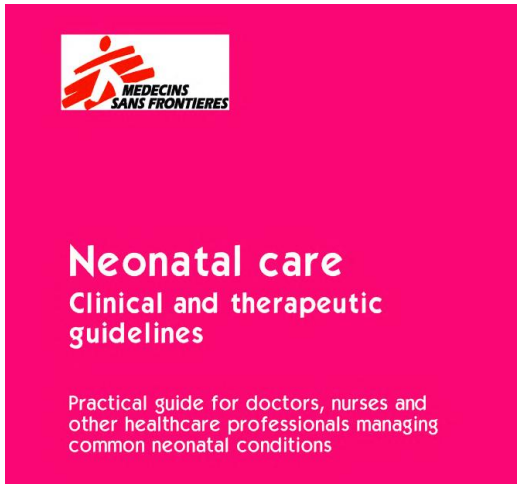


“I think we should speak to our mind, and we need to listen to our mind. If the [IS doctor] tells us no, it's palliative care, if we do not agree with their decision we can discuss” (Interview, National Staff Doctor-04)

Protocols & Guidelines: ‘the thing that is going to remain’

- International staff turnover and shifting approaches to palliative care led to frustration and undermined national staff confidence to make decisions

> “Every time we are putting some patient in palliative care we are talking with the [IS doctor] and we are giving eventually what he or she wants to give…and each [IS doctor] is telling us another thinking, so it’s very difficult” (Interview, National Staff Doctor-03)



- Guidelines were used by national staff to support their point of view in discussions with international staff
- Some national staff viewed guidelines as overly rigidly, not contextually adapted, and not always applicable to the patient at hand

Non-physician participation in decision-making

Nurses

- Felt decision-making was more inclusive in MSF than other facilities
- Described importance of their engagement
- Perceived obligation to follow medical orders
- Minimal active participation by nurses observed

Health Promotion Team, Mental Health Counsellors & Translators

- Primary role related to communicating decisions to families
- Emerging recognition of their knowledge of patient/caregiver preferences and relevance to decision-making

"Still I have to perform CPR, since I am a nurse and I have to obey the orders of the doctors. It feels so bad at that time that the baby is dying, there is nothing left, yet we are continuing CPR" (Focus Group Discussion-04, Nurse)

Palliative care and systemic injustice

Photo by Rachel Yantzi

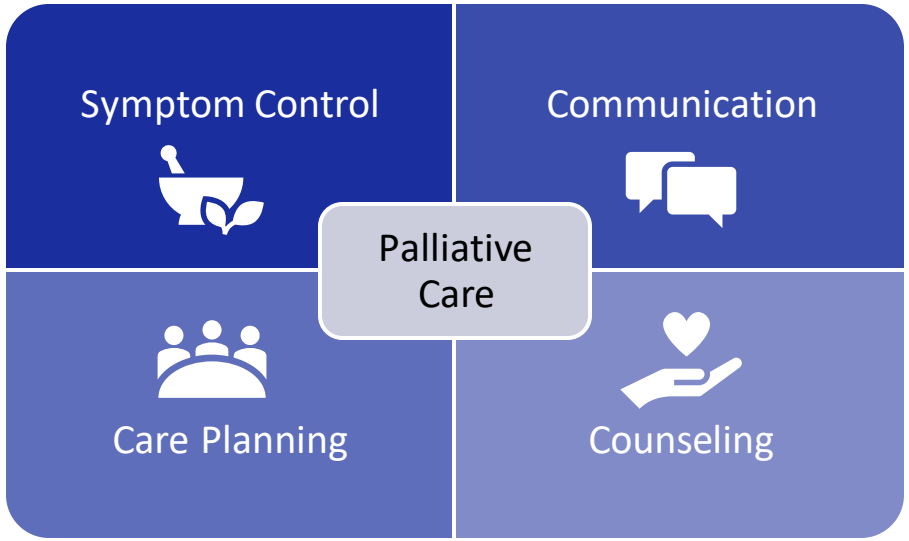
- Staff expressed distress when palliative care was the only option for potentially curable conditions
- Lack of clarity, consistency and transparency surrounding referral decisions
- Differential care pathways for Bangladeshi and Rohingya patients

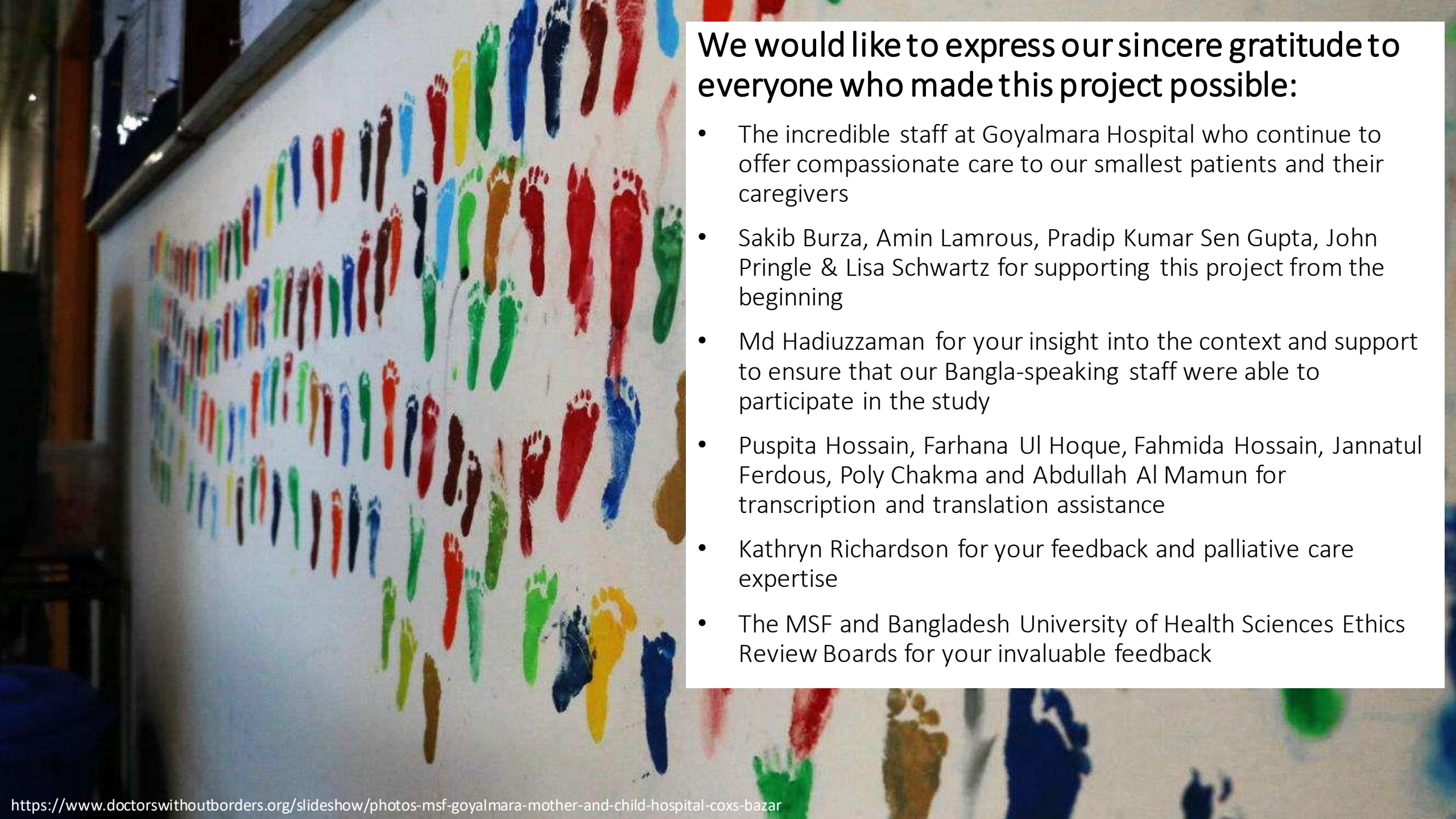
"You know that there is a solution in any other place but here you cannot offer them, so you feel more frustrated and not happy with the system and the, how you say, the lack of chances or the distribution of the resources" (Interview, International Doctor)

Conclusions

- Develop shared mental model of palliative care as active care
- Facilitate interdisciplinary decision-making and debriefing to address staff concerns
- Ensure clarity and transparency of referral and ceiling-of-care criteria
- Reassess and advocate for referral when appropriate to ensure that palliative care is not perceived as a substitute for curative care
- Ensure that medical tasks are not inappropriately delegated to non-medical staff and provide necessary training and support

"So that moment I found, this end-of-life care helps… It was a peaceful death, what else we could have asked from God?" (Interview, National Staff Doctor-02)





We would like to express our sincere gratitude to everyone who made this project possible:

- The incredible staff at Goyalmara Hospital who continue to offer compassionate care to our smallest patients and their caregivers
- Sakib Burza, Amin Lamrous, Pradip Kumar Sen Gupta, John Pringle & Lisa Schwartz for supporting this project from the beginning
- Md Hadiuzzaman for your insight into the context and support to ensure that our Bangla-speaking staff were able to participate in the study
- Puspita Hossain, Farhana Ul Hoque, Fahmida Hossain, Jannatul Ferdous, Poly Chakma and Abdullah Al Mamun for transcription and translation assistance
- Kathryn Richardson for your feedback and palliative care expertise
- The MSF and Bangladesh University of Health Sciences Ethics Review Boards for your invaluable feedback

https://www.doctorswithoutborders.org/slideshow/photos-msf-goyalmara-mother-and-child-hospital-coxs-bazar