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“Their suffering also plagues us”: a narrative ethnographic exploration of humanitarian healthcare workers’ moral experiences of providing pediatric palliative care in Cox’s Bazar, Bangladesh

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Abstract

This focused ethnography was conducted between March-August 2021 at the Médecins Sans Frontières (MSF) Goyalmara Mother–Child Hospital in Cox’s Bazar, Bangladesh, which serves the Rohingya refugee and Bangladeshi host community. Data collection involved participant-observation, individual interviews (22), focus group discussions (5), and analysis of protocols and other documents. In this paper, we present three composite stories which explore the meaning of empathy to international, Bangladeshi, and Rohingya MSF staff and their moral experiences of attempting to provide empathetic palliative care to children and their families in a humanitarian context.

Empathy, as well as related Bangla concepts such as *shohanubhuti* and *shohomormita*, were central to how MSF staff understood good palliative care. These concepts informed how MSF staff experienced their relationships with the children and caregivers receiving palliative care. In the story “their suffering also plagues us”, Haawa (pseudonym) tries to support a woman whose newborn baby is dying. In “if it were my child”, the team struggles when Layla’s (pseudonym) parents decide to leave the hospital. Finally, in the story “becoming a mechanical person”, the team wrestles with how to maintain empathy as they share difficult news with a family.

Innovative approaches to education and mentorship are needed to ensure that humanitarian healthcare workers have the capacity to engage empathetically with their patients. Considering the moral experiences of front-line staff and incorporating local empathy-like concepts and practices may contribute to the development of organizational strategies that are more relevant in diverse humanitarian crisis contexts.

Keywords Empathy, Compassion, Composite stories, Focused ethnography, Humanitarian action, Palliative care, Moral experience, Rohingya refugees

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Two roads

There are two roads you can take from the airport in Cox's Bazar, Bangladesh to Goyalmara Mother–Child Hospital. One option is to take Marine Drive, which curves gently along the white sand beaches lining the Bay of Bengal. Verdant hills rise to your left and the sun shimmers off the surface of the water to your right. The road was recently paved so the ride is smooth and peaceful. Along the way you pass beach resorts, full of Bangladeshis and humanitarian aid workers enjoying their vacations. People walk along the side of the road drinking from freshly cut coconuts. As you approach the coastal village of Shamlapur, the sharply curved silhouettes of fishing boats punctuate the horizon. At this point, you turn inland. Signs along the road decorated with photos of elephants indicate that you have entered Teknaf Wildlife Reserve. After another 30 min or so of twists and turns, the corrugated roof of the aptly nicknamed "Goyalmara Green-Roof Hospital" emerges in the distance.

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The alternative route is to take the N1 highway, passing through the heart of the "mega-camp", a maze of bamboo and tarpaulin dwellings where the majority of the nearly one million Rohingya refugees who fled to Bangladesh are currently living (United Nations Office for the Coordination of Humanitarian Affairs (2023) 2023). This road leads you through crowded markets overflowing with fresh mangoes, squawking chickens, and motorized rickshaw drivers trying to find a place to park. As time passes, you notice buildings along the side of the road labeled with the logos of various United Nations and non-governmental organizations (NGOs): World Food Programme, World Vision, Save the Children, BRAC (a large Bangladeshi international NGO), and others. It begins as a trickle and exponentially increases until everything you see seems connected to the humanitarian response. As you approach the town of Ukhiya, you catch sight of the endless blue and white painted fence posts strung with razor wire that starkly delineate the 'Rohingya camps' from the 'host community'. Your progress is slowed by caravans of trucks overloaded with bamboo poles harvested from what remains of the wildlife reserve. The wood will be used to build new dwellings for Rohingya families, or to rebuild those destroyed in the fires that frequently ravage the camps (Gocumlu 2021).

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The sights and sounds experienced along Marine Drive are very different from those of the N1 highway. A journey beside sun dappled beaches produces a very different interpretation of a place than a journey accompanied by razor wire fences. Cox's Bazar may represent a vacation destination, protracted humanitarian crisis, homeland that has been rapidly transformed, site of employment opportunities, place of refuge, or site of exile and confinement, depending on your perspective. What follows is an exploration of empathy in humanitarian palliative care, of how different journeys and life experiences shape our ability to see and understand an experience, a situation, a place, from another's perspective, and the challenges to enact empathy in a humanitarian crisis.

Methodology

This focused ethnography (Wall 2015) is based on data collected as part of an operational research study for the medical humanitarian organization Médecins Sans Frontières (MSF)(Yantzi et al. 2023). The aim of the study was to explore MSF staff's moral experiences of providing palliative and end of life care to children in order to understand how MSF's commitment to integrate palliative and end of life care relates to the values, priorities, and pressures experienced by staff. In this paper, we explore the meaning of empathy to Rohingya, Bangladeshi, and international MSF staff and their moral experiences of attempting to provide empathetic palliative care to children and their families in a humanitarian context.

The theoretical underpinnings of the study include Kleinman (1999, 2006) and Hunt and Carnevale's (2011) work on moral experience, defined as a person's lived experience of situations that may fall anywhere on the spectrum of right-wrong, good-bad or just-unjust (Hunt and Carnevale 2011). Moral experience comprises what matters most to people, and their interpretation of situations where those values are realized or thwarted (Kleinman 2006; Hunt and Carnevale 2011). According to Hunt and Carnevale (Hunt and Carnevale 2011), moral experience is shaped by what Taylor refers to as "horizons of significance" (Taylor 1991), or the social, cultural, and historical processes that inform the way we interpret experience. It is important to acknowledge that the methodological and theoretical orientations of this study draw heavily on European and North American sources. It is unavoidable that these influenced the findings and how they are presented; however, we have chosen to approach the topic through the lens of moral experience because this theoretical framework is expansive rather than limiting, and it acknowledges the influence of cultural context and interpretation on what people and communities consider morally important.

Empathy is a complex and highly debated concept in the literature (Guidi and Traversa 2021). Within healthcare, a common definition of empathy is "the ability to observe emotions in others, the ability to feel those emotions, and finally the ability to respond to those emotions" (Finset 2010). Empathy is sometimes subdivided into the concepts of cognitive empathy, or "the ability to perceive emotions in others", and affective empathy, or "the emotional engagement that occurs when confronted with the suffering of another person" (Guidi and Traversa 2021; Jeffrey 2016). Empathy is often distinguished from sympathy, a more general "fellow feeling" (Jeffrey 2016), or "feeling for" another person (Guidi and Traversa 2021). In a Canadian study focused on the experiences of adults receiving palliative care for terminal cancer, sympathy was negatively perceived as superficial and associated with pity, whereas empathy and particularly compassion were valued(Sinclair et al. 2017). This negative perception of sympathy and positive perception of empathy is widely shared in the palliative care community. Participants in the Canadian study saw empathy as involving relational engagement, while compassion was understood to be more action-oriented "to address the suffering and needs of a person" (Sinclair et al. 2017). Some scholars conceptualize empathy as a precursor to compassionate action (Sinclair et al. 2017; Riess 2017), however others argue that empathy has behavioural and moral components, whereby a person communicates their understanding of another person's experience, confirms the accuracy of this understanding, and acts in ways to relieve their suffering (Jeffrey 2016; Riess 2017).

We use the term empathy throughout the paper to refer to a constellation of "empathy-like" phenomena (Hollan 2017) that MSF staff both explicitly and implicitly invoke. Descriptions and illustrative examples of the Bangla concepts of *shohanubhuti, shohomormita* and *maya* included in this paper were provided by first-language Bangla speaking co-authors. We recognize that certain usages and examples may not fit neatly within formal definitions of empathy put forward by philosophers, neuroscientists, and psychologists; however, empathy was the term most consistently used by staff. As anthropologist Douglas Hollan argues, "our research definitions of empathy must remain open and flexible enough to capture the varieties of empathic processes and expressions we find around the world, rather than arbitrarily exclude forms that may fall outside these relatively arbitrary (and perhaps ethnocentric) definitions" (Hollan 2017).

Study context

Fieldwork for the study took place between March and August 2021 at the MSF Goyalmara Mother–Child Hospital in Cox's Bazar, Bangladesh where the first author was working as a researcher, nurse educator, palliative care program lead, and briefly as neonatology nurse manager. She was hired to both conduct this study and to establish a palliative care program in the neonatal and pediatric departments in order to fulfill MSF-Spain's strategic objectives related to person-centered care.

Palliative care is an emerging priority within the humanitarian aid sector (Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises: A WHO guide. 2018; Sphere 2018), however organizations, including MSF, have faced a number of challenges including a tendency to prioritize life-saving interventions, lack of access to adapted guidelines and technical support, inaccessibility and fears related to opioids, and the cultural specificity of death and dying (Hunt et al. 2020). At time of the study, access to palliative care in the Rohingya camps was very limited (Doherty et al. 2020). In 2021, the International Organization on Migration was in the early phases of developing a program in collaboration with the Fasiuddin Khan Research Foundation that integrates palliative care into routine primary care (Halder et al. 2026), but services were only available in certain camps and opioid access was sporadic.

At the time of data collection, MSF staff had some familiarity with basic concepts in palliative care and significant experience caring for newborns and children at end of life but limited formal training or experience with a palliative care approach. Palliative care services in Bangladesh are sparse, available primarily in Dhaka at Bangladesh Medical University[1] (Worldwide hospice palliative care alliance 2020; Doherty and Thabet 2018; Kashmeeri et al. 2024), and misconceptions about palliative care are prevalent among physicians (Biswas et al. 2021). In July and August, towards the end of the data collection period, the first author provided formal training sessions and put in place a care pathway for patients in need of palliative care (Yantzi et al. 2023). COVID-19 lockdowns, transmission precautions, and anxieties were important factors shaping the context at the time.

When we refer to "MSF staff", we are not describing a homogeneous group of people but rather an assemblage of individuals from diverse communities including Rohingya health promoters who are themselves refugees living in the camps; health assistants and other staff hired from the local community whose lives have been turned upside down by the Rohingya refugee crisis and subsequent humanitarian response; nurses, doctors and midwives from Dhaka and other distant regions of Bangladesh; and internationally recruited nurses, doctors, midwives, pharmacists and others, representing nearly every continent who come and go in continuous rotation. Internationally recruited staff are often involved in leading training and other activities meant to improve the quality of care and ensure that project activities are aligned with organizational priorities and values.

While English was the language of work at Goyalmara, many Bangladeshi and Rohingya staff had limited English proficiency, and among the internationally recruited staff at the time, the first author was the only native English speaker. Relationships between Bangladeshi staff and patients and families were complicated by the fact that many of the staff, particularly doctors and nurses, did not speak Rohingya or the local Chittagonian dialect of Bangla. As is common in most humanitarian contexts, partial fluency and communication across diverse dialects complicated every act of communication at Goyalmara.

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[1] Formerly known as Bangabandhu Sheikh Mujib Medical University

Data collection

Data consisted of information from individual interviews, focus group discussions (FGDs), and field notes. Institutional guidelines, reports, and other documents were collected to provide additional context for the study. We conducted a total of 22 individual semi-structured interviews with MSF nurses (4), doctors (7), mental health staff (3), health promotion staff (3), midwives (2), a medical translator (1), health assistant (1) and pharmacist (1). Additionally, we conducted 5 FGDs with nurses, health promotion, and mental health staff, involving a total of 18 staff. Overall, 37 unique individuals took part in an FGD or interview, because 3 individuals took part in both an interview and FGD. Among the 37 participants, 30 Bangladeshi, 2 Rohingya, and 5 internationally recruited staff took part in the study. Topic guides included questions focused on participants' perceptions of palliative care, definitions of good care at end of life, their professional role related to palliative care, experiences of decision-making processes, and elicitation of patient stories they perceived as difficult, troubling, rewarding, or meaningful. Interviews and FGDs were conducted in English, Bangla, or Rohingya by the first author and a Bangladeshi co-author. One interview was conducted in Rohingya with the assistance of a trained translator. All interviews and FGDs were audio-recorded, transcribed verbatim and simultaneously translated to English as needed. The first author documented 102 pages of field notes based on participant-observation activities during her fieldwork. Details regarding the overall study methodology, analytic approach, and context can be found in the first publication based on this research (Yantzi et al. 2023).

Ethics approval was obtained from the Bangladesh University of Health Sciences Ethics Review Committee (ID: BUHS/ERC/EA/21/31), the MSF Ethics Review Board (ID: 20,109), and the Hamilton Integrated Research Ethics Board (ID: 16,746). Clinical trial number: not applicable. The study was conducted in accordance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, which is the research ethics standard in Canada (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada 2022). Staff were offered the option to decline inclusion of any information about them in field notes. All individual interview and FGD participants gave prior written informed consent. The names used in the composite stories are pseudonyms.

Analytic approach

Data analysis for the overall study followed a modified version of the Qualitative Analysis Guide of Leuven (QUAGOL) (Yantzi et al. 2023; Casterlé et al. 2012). The first author wrote narrative summaries of each interview and FGD transcript, and based on these summaries, developed an inductive list of concepts relevant to the research question. These concepts were used to develop a codebook, which was iteratively refined during the coding process based on analytic discussions with the research team. All data were coded in NVivo qualitative data analysis software (Release 1.6.2).

During this analytic process, a significant volume of data was coded as "sympathy and empathy", and it became clear that these concepts were central to staff's understanding of palliative care and their moral experiences of providing it to patients. We were particularly interested in the staff's use of the English phrase "sympathy and empathy" in interviews conducted in Bangla, where the two words seemed to be tied together as a linked construct. Based on the experience of Bangladeshi co-authors, it is quite common in healthcare settings in Bangladesh for people to use certain English words and phrases when the English term is more familiar, the Bangla term too complex or formal, or in cases when there is no suitable Bangla equivalent; however, the word "empathy" is not commonly used in other healthcare settings in Bangladesh. The staff's use of this phrase pointed to the unique "local moral context" (Hunt and Carnevale 2011) that exists in every humanitarian project where local concepts, values, and discourses interact with those of diverse internationally recruited staff, and the values and priorities of the humanitarian organization.

The approach that we use in this manuscript is informed by Arthur Frank's socio-narratology, described in his book *Letting Stories Breathe* (Frank 2010), and ethnographic writing exercises suggested by anthropologist Kirin Narayan (Narayan 2012). We explore staff's moral experiences using three stories which are composites of multiple participant narratives and ethnographic scenes. The composite stories are meant to provoke questions and reflection rather than present a single closed interpretation. Inspired by Narrative Medicine, our use of storytelling is intended to facilitate an "empathic encounter" (Guidi and Traversa 2021) between the reader and humanitarian healthcare workers as they struggle to offer empathetic palliative care. The composite stories are written in the first person, portraying the study themes in the context of situations that the first author experienced, observed, and documented in field notes. As Corman suggests, this approach "clearly situates my voice as the author of these accounts through my use of the first-person and presence throughout them" (Corman 2021).

We chose composite stories for both methodological and ethical reasons. Composite actors and narratives are often used in ethnography to protect participant confidentiality (Corman 2021; Narayan 1999). Yim and

Schwartz-Shea argue that the use of composite characters is particularly useful in protecting "internal confidentiality", whereby members of the community where the research took place may be able to recognize each other (Yim and Schwartz-Shea 2022). Given the sensitivity of the research context and topic, as well as the close-knit nature of the MSF community, this precaution was warranted.

The process for developing the composite stories was as follows: the first author began by reading and re-reading all data that had been coded as "sympathy and empathy" while considering analytic questions which were developed based on the moral experience literature and in discussion with co-authors (e.g. what is at stake when staff do/do not/can/cannot offer empathetic palliative care?) Based on this initial review, the first author identified a list of codes that participants either explicitly or implicitly linked to "sympathy and empathy". These data were read and re-read while considering the analytic questions. The first author engaged in analytic discussions with co-authors, memo-writing, and mind-mapping exercises to develop the themes to be explored in the composite stories. She discussed tentative interpretations with co-authors and explored the meaning and significance of Bangla concepts in individual conversations with Bangladeshi co-authors. Co-authors including a Bangladeshi doctor, a Bangladeshi nurse who conducted the Bangla interviews, and a Bangladeshi nurse who was neonatology supervisor at Goyalmara at the time of the fieldwork, reviewed the composite stories and manuscript to ensure that the stories authentically reflect the context and experiences of MSF staff without inadvertently disclosing identities. Pseudonyms were carefully chosen in consultation with Bangladeshi co-authors.

In certain cases, the contextual details of several situations were merged for narrative effect and to convey themes that emerged in our analysis. Characters are composites of staff, patients and family members who took part in or are described in interviews, FGDs or field notes. All dialogue is taken directly from focus group and interview transcripts with minor revisions to enhance clarity. Individual interview and FGD identification codes are included following quotations for transparency (e.g. FGD-01). Individual interview identification codes correspond with the participant's professional role (e.g. mental health team (MH), health promotion team (HP), Nurse (NUR), Doctor (MD), IS (internationally recruited staff)). Dialogue that was originally spoken in Bangla or Rohingya is indicated by italics while dialogue that took place in English is indicated without italics.

A note from the ethnographer

While this piece of work is based on the contributions of a team of co-authors, I (first author) was the ethnographer, engaging in participant observation at Goyalamara Hospital, and leading the planning, data collection, analysis, and writing processes. Therefore, it is important to share aspects of my positionality that have shaped this study. Importantly, I was both ethnographer and internationally recruited staff during the period of fieldwork. If I had not been conducting this study, I very well could have been a participant. My moral experiences of providing and mentoring others as they provided palliative care are inextricably linked with those of the study participants as is evident in the narratives that follow. My positionality and various roles at Goyalmara clearly impacted staff's perceptions of me and my interpretation of the findings. Key features of my identity that are relevant to this study include that I am a pediatric critical care nurse and that I worked at a tertiary medical center in Canada prior to and following the period of fieldwork. Other MSF internationally recruited staff likely perceived me as an insider to MSF given my prior experience with the organization in the Central African Republic, but as a Canadian woman of European descent, I was a visible outsider in the Bangladeshi context. While I attempted to learn, I speak very little Bangla and I do not speak Rohingya, therefore the involvement of Bangladeshi co-authors was critical to all phases of the study, including to support translation and interpretation of findings. I will share reflections on the impact my positionality later in this paper and these reflections are explored in more detail in my doctoral dissertation.

Strengths and limitations

As described in the previous section, the composite stories and interpretations in this manuscript are shaped by the ethnographer's positionality and perspective. This manuscript offers one lens to explore humanitarian health care workers' moral experience of empathy; however, the extensive involvement of a diverse group of co-authors with lived experience of the context builds confidence in the findings. Trustworthiness is strengthened by the richness of the data, and triangulation of interview and FGD data with observation and document analysis. Negative cases, or data that contradicted initial interpretations, were explored which added nuance to the findings. Additionally, the ethnographer's prolonged period of fieldwork and ongoing engagement with the study context enhanced rigour. The first author had the opportunity to revisit Cox's Bazar in 2023 and 2024 to discuss emerging findings and their implications with MSF staff, including staff who had been working at Goyalmara since 2020–2021, staff who arrived since that time, and MSF colleagues involved in person-centered approach initiatives. The composite stories have been iteratively revised based on their feedback.

The data for this study were collected in a particular temporal and geographic context. The moral experiences of humanitarian healthcare workers related to empathy at other times and in other places would certainly be different; however, the composite stories and interpretations provoke questions and reflections that are useful to consider in other humanitarian contexts.

Findings

A vision of empathy

When describing their vision of what matters when caring for children and families with palliative care needs, MSF staff employed four terms almost interchangeably: sympathy, empathy, and the Bangla terms *shohanubhuti* (সহানুভূতি) and *shohomormita* (সহমর্মিতা). Staff did not seem to make a clear distinction between the English concepts of sympathy and empathy, and in fact often expressed them as a pair such as in the following FGD: “Sympathy *and* empathy*, we know these two words. These are the two words which we can take as a role of nursing in this case... so the pain they have, the cries and sufferings, we as nurses, our words, messages, behaviour should be like we have* sympathy *or* empathy *for them”* (FGD-04).

In a smaller number of examples, staff used the Bangla terms *shohanubhuti* or *shohomormita. Shohanubhuti* (সহানুভূতি) is a compound word deriving from *shoho* (you and I) and *anubhuti* (feeling). In the healthcare context, it implies a shared feeling of sadness or compassion when witnessing another person’s suffering and is based on a sense of shared humanity. S*hohanubhuti* may or may not linger for a long time, but it is not usually an overwhelming emotion. Depending on the individual, it can be a transient feeling that still leaves an impression, or the person may revisit the memory or the feeling from time to time if something reminds them of that moment. A member of the MSF health promotion team explained *shohanubhuti* this way: “*when a person’s heart is broken... if we talk to them with shohanubhuti or* sympathy *and* empathy*, then it is actually effective*” (FGD-02). She implies that *shohanubhuti*, sympathy, and empathy have similar meanings and that they can be outwardly demonstrated, for example, by talking to patients and their families with *shohanubhuti*. When the first author returned to Bangladesh in 2023 to share preliminary findings with MSF staff and obtain their feedback, a nurse and health promotion team member described sympathy, empathy, and *shohanubhuti* as synonyms.

Another compound word, *shohomormita* (সহমর্মিতা) is composed of *shoho* (you and I) and *mormita* (heartfelt sorrow). An MSF mental health counselor described his team’s emotional reaction to the death of a young boy infected with rabies saying, “*they had shohomormita”* for the boy (FGD-01). *Shohomormita* involves hearing about a tragedy and feeling that it could have happened to you or those you love. There is a sense of being compelled to respond in some way. Both *shohomormita* and *shohanbhuti* are relatively formal concepts, which may explain why certain MSF staff instead used English terms like sympathy and empathy.

The meaning and moral significance of these empathy-like phenomena were most clearly described by a nurse who said, *“when I present myself in their place, then they will understand that I can feel their pain inside me. Then a good feeling will work inside them. In this way, I have to put myself in their place. As a mother, as a father, we have to understand that place, then they will trust us”* (FGD-04). MSF staff saw empathy as rooted in their shared humanity with patients and their families. Staff described being emotionally affected by suffering as an inherent human characteristic and something that connected them with others who are suffering. A mental health counselor described this when they said, *“we all are human beings, and we all have feelings that works within us. We feel the grief too”* (MH-03). Staff described how their personal experiences and shared identities as mothers, fathers, sisters, and brothers enabled them to imagine themselves in the child or parents’ place. Several internationally recruited staff felt that the capacity “to be in the place of the family” (IS-01) was a necessary component of palliative care and something that needed to be encouraged among the staff.

Understandably, imagining themselves in the parents’ shoes often resulted in a strong emotional reaction among staff. As a member of the health promotion team explained, “when I see them and the mothers, oh my God, she or he might be my brother and sister. You know, my mother, father, or relatives, they will die like this” (HP-02). Similarly, a nurse explained that “we have a brother, we have a sister. If we recognize the patient in my own place… it was a horrible situation for me. It was so much emotional, psychologically affect us” (NUR-02). Yet several staff felt that being emotionally affected by their patients’ and families’ experiences was a necessary part of their work. As a mental health counsellor articulated, “*as a human being we must feel suffering, this is necessary. I will not be able to support them until I understand their pain.*” (FGD-01).

The outcomes of these imaginative and emotional reactions were two-fold. Firstly, staff explained that their ability to imagine themselves in the parents’ position compelled them to treat the child and family as they would treat their own family member. As one nurse explained, “I thought he is my cousin, he is my father, she is my mother, he is my child. I always keep that in my mind” (NUR-01). Secondly, staff described the importance of outward displays of sympathy and empathy through their words and behaviour as a tool to communicate with families. As the nurse quoted earlier said, “*our* *words, messages, behaviour should be like the way we have that* sympathy *or* empathy *for them*" (FGD-04). Another nurse explained that "we should offer our services with empathy and sympathy" meaning that we should "*tell them the truth in a humble voice, not in a harsh voice*" (FGD-05). Staff believed that the impact of this empathetic communication and behaviour was that families would understand that staff took part in their grief, and consequently, families would listen to and trust the staff. As a nurse explained, "*we have to gain their trust. If I talk to them in a good way, if I make them understand better, they will believe me…they believe what I am saying as the truth*" (FGD-04).

Unfortunately, there appeared to be a gap between the way that empathy was discussed at Goyalmara and the reality at the bedside. Alongside beautiful descriptions of the value of empathy in palliative care and situations where staff listened to and connected with the experiences of their patients, were instances in which their ideals related to empathy were thwarted, limited, or even potentially harmful. The way staff used the English terms "sympathy and empathy" interchangeably and as a linguistic set, hinted at a lack of clarity amongst the staff regarding what was being asked of them. As one nurse explained during an FGD, *"what seems to me is that actually we know very little about palliative care. Not too much. If we know a little more about these things… what is palliative care? For what purpose is it given, where is it given? Moreover, especially when we say* sympathy, *how do we actually show* sympathy, empathy *when someone has reached their last moment? I think this is an important issue"* (FGD-03).

Using three composite stories, we explore how staff's values related to empathy were realized and thwarted in their everyday work while providing palliative and end of life care at Goyalmara Hospital.

Stories of empathy realized and empathy thwarted

Story 1: Their suffering also plagues us

As I speed walk along the pothole filled dirt road between the office and the hospital, I overtake a group of nurses as they carefully sidestep mud puddles and piles of goat excrement. A dog, resting peacefully in the middle of the road raises its head, considers me, and lays his head back down, clearly unimpressed by my presence. The rice paddy to my right is swollen with water from last night's rain and looks to be within inches of overflowing its banks. A man walks knee deep in the muddy water, transplanting fistfuls of rice stalks in a meticulous grid-pattern. As I hurry along, sweat gathers on my upper lip and I breathe hard under my blue paper mask. It's only 8 a.m. and not so hot, but the oppressive humidity of an impending storm causes me to sweat, nonetheless.

I enter the neonatology department, brushing the mud off my sandals on the mat in the doorway. The nurses sitting at the table in front of me smile as I walk into the room. A nurse wearing a peach-coloured hijab jumps up and beckons me into the adjacent neonatal intensive care unit (NICU). As the doors open, a wall of musty heat hits me. Nine mothers and nearly as many female relatives are lounging on narrow beds packed into the small room. Many are waving brightly coloured fans, and I notice a woman wiping sweat from her forehead with the edge of her abaya[2]. Nine oxygen concentrators produce a wall of white-noise and add to the oppressive heat in the room.

In the far corner, two women are anxiously watching a pale, limp baby lying in the crib at the foot of the bed. The doctor informs me that the baby has severe hypoxic brain injury and that over the past hour they have had to intervene many times to restart his breathing. As time goes on, these periods of apnea are increasing in frequency, and the medical team has decided that it is time to stop. The baby is still breathing. Barely.

Haawa[3], one of the Rohingya health promoters, asks the mother and mother-in-law if they would like to use the private room down the hallway. They nod quietly and the mother gathers the baby into her arms. As we walk down the hallway, I see Haawa put her arm gently around the mother-in-law's waist. As we enter the private room and the door closes behind us, the two women begin to wail. I feel my throat tighten. Haawa is standing beside the mother-in-law with her hands resting on her shoulders when the woman slides down onto the floor, unable to maintain an upright position. Haawa kneels on the floor beside her, supporting her weight as the woman collapses against her. She murmurs "*Apu* (sister), *I am here with you. If I were in your place, I would also be like this*" (FGD-04)[4]. The mother sits on the chair in front of me, holding the baby as he hovers in that liminal space between life and death. I am kneeling in front of her, holding her hand and trying to make sure she does not lose her grip on the baby. Then the mother reaches for me and buries her face in my shoulder. My heart aches as I feel her tears soak through the fabric of my dress.

Later, as Haawa and I are walking back to the nurses' station she tells me how grateful she is that despite the COVID visitation rules, we made it possible for the family to spend time together "*until the child's last breath*" (MH-03). She says that the family was "*thanking the hospital repeatedly, because many hospitals may say there is nothing to do at this time, you should take the baby home*". Instead, "*we could support the mother til the last minute*"

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[2] Abaya: a loose-fitting full-length robe worn by some Muslim women

[3] All names are pseudonyms

[4] Interview or focus group discussion transcript numbers have been included in the composite stories for transparency purposes

(MH-03). As the family was leaving, the mother had said to her: "*I received a lot of support and felt courageous by staying among you and I have found an environment that has reduced my suffering because of the trust we have in you*" (MH-03). In that moment, Haawa says, "*my feeling was very good, I felt like we were doing something for the patient, we were doing something for some family, then it seemed that palliative care was really very important*" (MH-03).

I am painfully aware that the NICU staff are exposed to an incredible amount of death and loss, sometimes experiencing multiple infant deaths in a single day so I ask Haawa how she is feeling. She acknowledges that she is feeling sad but says, "*by being saddened by their grief, we will also be able to make them understand that their suffering also plagues us*" (FGD-03). She shares with me that she lost her own baby girl many years ago shortly after birth. She explains, "when baby born, I see maybe this is my baby. If the baby is not crying, this mother will lose one baby. At that time, I feel I am a mother, I have also a baby… then I think all mothers will be thinking the same as me" (MW-01). She admits that sometimes the things she sees at work make it difficult for her to sleep.

Story 1: Reflection and analysis

What effect then does empathy have? What good does it do for healthcare workers' throats to tighten and eyes to sting? Could the grieving mother-in-law feel *shohanubhuti* in Haawa's hand on her back?

For Haawa, it was important for the grieving family to "understand that their suffering also plagues us"; it was not enough for her to feel empathy, but rather it was the family's perception of her empathy that mattered. For many staff, empathy was demonstrated through physical acts of connection: a hand on the shoulder, an arm around a mother's waist. These acts demonstrated that "I am here with you" and gave the family the courage to face an impossible situation.

Haawa and other MSF staff saw their own grief as a necessary therapeutic tool. Haawa's statement that "their suffering also plagues us" goes well beyond common definitions of empathy in which the healthcare worker seeks to understand the mother's experience. How can healthcare workers have empathy without being plagued by the suffering they witness?

In the story, Haawa struggles to differentiate her own experience from that of the mother. Her experience of loss gave her a window into the mother's experience that perhaps enabled her to connect with the mother, but the story also raises concerns of staff re-traumatization. An interview participant shared that it is important for staff to distinguish, "when [they are] with the patient and when in the personal life, to differentiate those two things" (MH-01). The ability to maintain a distinction between their experiences at work and their life outside of work, and between themselves and their patients, may be critical skills for healthcare workers to develop; however, experiences of personal trauma may undermine staff's ability to do this. When experiences at work conjure up painful personal memories, work and personal life, self and other, may merge. This is a significant possibility for locally hired staff in humanitarian interventions given that they are likely to have their own experiences of loss and trauma.

Story 2: If it was my child

"Rachel Apu[5], did you know that baby Layla has arrived in PICU?" I look up from my laptop where I'm preparing a presentation for this afternoon's training. Little Layla is about 12-months old and a bit of a celebrity among the staff. She has an inoperable congenital heart defect that lands her back in the pediatric intensive care unit (PICU) periodically with respiratory distress and low oxygen levels. Unfortunately, the heart failure caused by her heart defect is worsening, so we have been seeing more of her recently.

I decide to take a break from my computer and walk over to the PICU to check on her. As I enter the unit, I spot nurse Shimul cuddling Layla in his lap. She is breathing very fast but seems content as she gazes up at the enamoured nurse.

Over the next few days Layla's breathing becomes more laboured and her oxygen levels begin to drop. By the end the week, she is lethargic and no longer opening her eyes. She is now receiving the maximum respiratory support we can offer and all the available medications for her heart failure, but her condition is only getting worse. While we knew that this day was coming, we struggle to accept that Layla is dying.

As I sit at the nurses' station poring over a patient register, I notice that Jeem from the health promotion team has just finished having a conversation with Layla's parents. He slowly walks over and sits beside me at the nurses' station. He is quiet for a few moments, then says dejectedly, "how the child is breathing, it feels very bad to me. This is a child. She cannot express but she has the feeling of pain" (MH-01). He explains that watching the baby struggling to breathe had reminded him of his own experiences of feeling out of breath during a difficult hike or when it is very hot during Ramadan, yet he knows that the child's suffering is exponentially worse. "Oh God, I can't imagine, I can't imagine" (MH-01) he murmurs.

Jeem then informs me that the family has decided they want to take Layla home. I am surprised because the family had agreed yesterday to stay in hospital so we could

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[5] Apu is a Bangla word that means elder sister, but it may be used to refer to any woman who is older in age in both formal and informal settings

better manage Layla's symptoms. While sending her home could be a good option, we don't have any home-based follow-up services to offer to the family, and I'm concerned that Layla will suffer. I send Layla's treating doctor, Dr. Moyna, a quick WhatsApp message, asking her to come over and speak with the family.

The parents sit huddled on the small bed around Layla while Dr. Moyna, Shimul, and Jeem stand in a circle, towering above them. I sit uselessly at the nurses' station observing the "counseling" (NUR-02) taking place, unable to understand the blend of Rohingya, Chittagonian, and Bangla flying back and forth. The parents stare at the floor, not saying a word. Later, Aleef from the mental health team joins them at the bedside. Over the course of the day, the team spends what feels like hours trying to "convince" (MD-05, MD-01, FGD-02) Layla's parents to stay. In the end, they decide to leave, and the team is devastated.

I sit with the team at the nurses' station. The frustration, and grief are palpable. Shimul shakes his head, "I am so upset when the mothers decide to go to home. Ultimately, we are counseling them to keep them here, but they don't agree. We failed to counsel the mother. When we failed, we have nothing. It is too much of a shock" (NUR-02). Jeem adds, "*if it was my child, as a father, I would want to continue treatment as long as my child is alive*" (MH-02). I try to probe a little further, to understand what made this situation so difficult for the staff. Shimul explains that "*we took care of the baby for many days. Patients don't usually want to stay that long. She was here for so long… we felt maya* (tenderness and affection) *towards the baby*" (NUR-03).

After the others have left, Aleef quietly shares with me that the father was receiving constant phone calls from his parents demanding that he and his wife return home so she could care for their other children. He described how the father was torn between his parents who were demanding they come home, his wife who was exhausted, grieving, and wanted to be with her family, and the needs of his dying child. "He is in the oven, he is under too much pressure, the father," Aleef said. "When I was in the shoes of the father, I was talking with the father, I feel like this man actually, whoever is suffering, this man is in a very, very complicated situation" (MH-01).

Story 2: Reflection and analysis

In the story, Jeem drew on his own experiences of breathlessness as a starting point to imagine Layla's suffering, yet he acknowledged that their experiences were not the same. In fact, rather than claiming to understand Layla's experience, he said, "I can't imagine". He could empathize with her while remembering that he is not Layla; however, he struggled to do this for Layla's parents. Rather than attempting to understand the situation from their perspective, he placed himself in the situation and imagined what he would do: "*I would want to continue treatment*". In contrast, Aleef went beyond imagining and listened to the father's story, which gave him a clearer understanding of the father's experience. During one FGD, while her colleagues were describing the importance of empathy in palliative care, a nurse argued that *"no matter what I say, I can never go in [the mother's] place. So, I will definitely take care of the baby, but it is better if we do it after hearing from the mother… No matter what we say, no one can take the mother's place"* (FGD-04). This nurse's comment highlights the limits of one's ability to understand another's experience. When empathy is inaccurate or incomplete, staff may feel they need to "convince" (MD-05, MD-01, FGD-02) families to do what they would do in the situation, rather than supporting the family's wishes. Their efforts to persuade rather than collaborate may also have been connected to the staff's lack of experience with a palliative care approach.

The staff wanted to protect Layla, and their *maya* for her made it all that much more painful when they felt unable to do so. *Maya* is a Bangla concept that exists somewhere at the intersection of tenderness, affection, warmth, nostalgia, and attachment. It implies aching or a feeling of being pulled towards something or someone. Staff described feeling *maya* for certain patients, perhaps due to prolonged hospital stays, perceived vulnerability, or an undefinable endearing quality. While conceptually different from empathy, it is relevant that staff described having more *maya* for certain patients. The suffering of certain patients provokes a stronger emotional response, and similarly, staff have an easier time imagining themselves in the position of certain people. Empathy can motivate ethical action, yet the challenge with empathy is that it is partial. We often have greater empathy for those close to us and like us. At times, MSF staff struggled to engage empathetically across the many barriers that separated them from both the Rohingya and host community families. Pervasive mistrust combined with the inability of most MSF doctors and nurses to speak Rohingya complicated their efforts towards empathy.

Story 3: Becoming a mechanical person

It was a Sunday, the first day of the work week. The rainy season was coming to an end, and the humidity was so thick that it was hard to tell if it was lightly raining or about to rain. I had just received a call that our patient and his mother had arrived for our meeting. As I sat waiting at the desk outside the outpatient department, taking a moment to breathe and read the patient's file, a little boy ambled up to me with a broad smile on his face. He took my hand and began speaking to me quickly and confidently in Rohingya, seemingly unaware that I did not understand. I assumed that he was the patient we were meeting because both our patient and this smiling boy in front of me had Down's syndrome.

Once Dr. Azaan, the medical translator Shornali, and the mental health counselor Bely arrived, Bely beckoned to the mother who was sitting on a wooden bench at the back of the open-air waiting area. We walked single file down the narrow bamboo hallway into a small room with flimsy walls covered with colourful watercolour paintings depicting palm trees and beaches. We arranged the wooden chairs in a circle and Shornali pointed to where the mother and child could have a seat.

After Shornali introduced each of us, Dr. Azaan began speaking in Bangla, pausing every now and then so that Shornali could give a summary in Rohingya. The mother nodded and murmured as she listened, her voice muffled by the black niqab covering her face. I could not understand exactly what was being said but picked out the occasional *"bacche"* (child), "*dukhito"* (sorry) and a smattering of English words that enabled me to follow the main flow of the conversation. After I heard the words "leukemia", "treatment *nai*" (there is no treatment), and a series of *dukhito*'s, the mother began crying loudly. The little boy looked up at his mother with curiosity and a furrowed brow. After a few moments, Shornali said that the mother was asking if MSF could send her son to Dhaka for treatment. Dr. Azaan replied that unfortunately this was not possible.

As the mother continued to cry more softly, Shornali and Bely talked to her in gentle tones. At one point I noticed that Dr. Azaan was no longer paying attention and was leaning over the desk beside him, filling out the palliative care program forms I had recently created. I groaned inwardly, wishing he would listen attentively and fill out the forms later. Then his cell phone started loudly ringing. As he went to answer the call, I whispered to him, "can it wait?" He quickly hung up, set the phone on the table, and replied, "Sorry, it's the ER". After a few minutes and a cacophony of alerts from his phone, he left to respond to a crisis in the ER.

Afterwards, I sat with the translator and mental health counselor for a few minutes. We had been working on a practice of having interdisciplinary family meetings when we needed to share difficult news, and I wanted to see how the team felt about the process. Shornali said, "*I was instructed to explain these words to a mother. This was very difficult for me to tell her that a healthy child of hers would die like this, because he was healthy then, he was talking. After doing everything I have to tell her what would happen to her child, there is no treatment. I had to tell her that he would die. This was actually a difficult situation for me*" (FGD-01). She went on to clarify that it was her "empathy" (FGD-01) that made it difficult to speak those words, seeing the impact of her words reflected on the mother's face.

Later as I walked down the narrow corridor between the NICU and PICU, I saw Dr. Azaan and another physician, Dr. Chadni, standing in the corner talking. I asked how he felt about the family meeting, and he said, "when we are breaking that news, it's really difficult for us because the patient party didn't realize we empathize. Sometimes yes, I am feeling sad but it's not in my mouth because I have to see more patients" (MD-03). Dr. Chadni added that she often wonders, "am I becoming a mechanical person or something like that? That I am working here only for money, or I have no emotion or nothing? But then I realize no, we actually, we get used to it, seeing the death day by day, and we need to move on. If we broke down, at that time we can't manage another patient" (MD-04).

Story 3: Reflection and analysis

For many staff, having empathy implied "feeling sad" or being emotionally affected by their patient and family's suffering. While empathy was not necessarily understood to equal losing emotional control, it did imply a certain emotional responsiveness that was perceived as risky. Empathy for the patient and family's suffering, and the frank injustice of the situation, was perceived to make their work more difficult. Although tertiary specialist services were theoretically available in Dhaka, access was constrained by multiple layers of limitation. Movement and administrative restrictions affecting Rohingya refugees, together with the resource intensity and prolonged nature of leukemia treatment, posed substantial barriers to referral. In this clinical context—where transfer was unlikely to provide meaningful survival benefit—facilitating referral was not feasible. For MSF staff, being attuned to the mother's emotional response made the act of speaking the words "there is no treatment" even more difficult to do. As a result, MSF staff experienced a simultaneous need to associate and dissociate from their patient's and family's suffering.

Staff described both consciously suppressing their emotions and subconsciously becoming habituated to the suffering they witnessed. In the story, Dr. Chadni described a more passive process of habituation: "we get used to it, seeing the death day by day" (MD-04), whereas Dr. Azaan felt he had to actively suppress his emotional reactions because he had to "see more patients" (MD-03). As a result, his empathy was not always perceptible on his face or in the way he spoke to patients and families. A health assistant similarly described in an interview that, *"I too got sometimes emotional. Then I control my own mind. I tell myself that I am a servant"* (HA-01). In other cases, staff described pressure or even ridicule from other staff when they openly expressed grief during their clinical duties. One nurse described a situation where they became tearful while caring for a seriously ill child and a doctor "counselled me to grow up, be strong. They asked me, is it your first day?" (FGD-05). In contrast, a member of the mental health team described how their colleagues demonstrated professionalism by maintaining their ability to express emotion: "After all of this they are not like stone. They still feel, they still have emotion, they feel frustrated, they feel anger. So as professional, I think it's very good, they are in a right track" (MH-01).

Importantly, while staff saw getting "used to" (MD-04) the suffering they witnessed as necessary to continue their work, they experienced it as a fundamentally dehumanizing process. To be "mechanical" implies abnormality or being not fully human. In fact, the public perception of the unfeeling doctor or nurse was itself a source of distress for staff, as one nurse described in an interview: "Many people saying that we are emotionless person. As patients' attendants crying, I have no feelings… So it is, this word actually sometimes affects [me] because I am not emotionless, I have emotions but as a professional, professionally I am not able to show emotion. If I get emotion, that time who will provide care?" [NUR-01].

The humanitarian sector, organizations, and individuals in positions of leadership sometimes offer contradictory messaging about emotional responsiveness and the role of empathy in humanitarian response. Staff must be empathetic while also prioritizing documentation and data. They are asked to offer person-centered care while grappling with significant human resource constraints. While empathy is not the same as "having emotion", it does involve emotional engagement. As Dr. Azaan experienced, the extreme workload of humanitarian response does not often give healthcare workers the emotional space to recover after their empathetic engagement with patients and families before they are called upon to respond to the next crisis.

A note from the ethnographer: reflecting on my role

As is evident in each of the three composite stories, I (first author) was far from a detached observer during the fieldwork for this study. I crafted the composite stories to illustrate themes that emerged from our analysis concerning the moral experiences of staff; their experiences of offering care with empathy, and of having their values related to empathy thwarted. However, as a character in the stories, my own moral experiences are intertwined. As I prepared this manuscript and responded to feedback from co-authors, I grappled with the ways my identities have impacted my interpretations, the limits of my own empathy, and how I may have influenced the staff's moral experience related to empathy.

In the story "becoming a mechanical person", my frustrated reaction when I noticed Dr. Azaan focusing on the documents and taking phone calls during the family meeting hints at the limits of my own empathy. While Dr. Azaan's actions may have seemed insensitive to me, they may also have been his way of coping with an interaction that was simply too emotionally difficult. The processes of iteratively listening to audio-recordings, reading transcripts, and crafting the composite stories have enabled me to develop greater empathy for my colleagues' experiences and the challenges they face in enacting organizational priorities related to palliative care and person-centered care. A key assumption of more recent person-centered initiatives in MSF is that in order to create a supportive and empathic culture that recognizes the full humanity of patients and families, it is necessary to create such a culture for staff (Médecins Sans Frontières 2024). My hope is that this work may be a small contribution towards building that culture of empathy.

At one point in my fieldnotes, I described how it felt as though there was a "veil" between myself and the patients, families, and many staff, due to my inability to speak Rohingya or Bangla beyond a few simple phrases. While this certainly limited my ability to directly understand data collected in Bangla and Rohingya, I was fortunate to have Bangla-speaking co-authors who are fluent in English and understand the Canadian context from which I come. They offered contextual insights beyond simple transliterations of transcripts and helped me to understand why an English term like empathy was used by MSF staff. I have been particularly cautious when describing the meaning and significance of the Bangla concepts of *shohomormita, shohanubhuti,* and *maya* because as a non-Bangla speaker, the full meaning of these words is not available to me. The explorations of these concepts in this manuscript are based on extensive conversations with Bangladeshi co-authors and were revised several times based on their feedback. By bringing together our blend of insider and outsider perspectives of the unique local moral context of an MSF project, I hope we have been able to represent it with authenticity.

Discussion

Situating empathy in humanitarian action

In his seminal work on humanitarian ethics, Slim outlines the origins and ethical foundations of humanitarian action including the centrality of concepts such as sympathy, empathy, and compassion to the humanitarian ethical stance (Slim 2015). Similarly, humanitarian ethics scholar Bouvier asserts that compassion is at the heart of humanitarian action (Bouvier 2018). Slim traces the foundations of humanitarian action back to the work of philosophers such as Hume who described sympathy as "the universal emotion through which we identify ourselves with others in distress" (Slim 2015), as well as Levinas and Ricoeur who emphasized the importance of the face-to-face encounter with the suffering other as the origin of our sense of responsibility to act in response to that suffering (Slim 2015). Slim equates empathy with intersubjectivity, or “the ability to move between our own and others’ experience” and argues that due to the activity of mirror neurons in our brain, “physical identification with people suffering seems to be neurologically and emotionally hard-wired” (Slim 2015).

While humanitarian ethics draw heavily on Western philosophy, it is clear that empathy is not an exclusively “Western” concept (Fassin 2011). Fassin argues that Western morality “has no monopoly on concern for the misfortune of others” (Fassin 2011), citing the importance of similar concepts in Confucianism, Buddhism, Islam, and Judaism. In fact, Bangladeshi anthropologist Zaman suggests that the Global South may “have more potential to promote and practise free-flowing compassion among community members” due the strong values placed on privacy and individualism in Western cultures (Zaman et al. 2018). Empathy-like phenomenon such as *shohanubhuti* and *shohomormita* are valued in Bangladesh and are invoked by local charitable and humanitarian organizations to inspire and guide their work (Rana 2020; Shoptorshi Samaddar 2020; Sahanubhuti About us 2024). The origin story of the Bangladeshi organization Sohomormita Foundation is an interaction between founder Parvez Hasan and an impoverished woman and her two children on the streets of Dhaka. Hasan described that he could “feel the pain of those children as he himself lived through similar struggles during his childhood”, which inspired him to establish the foundation which aims to “spread empathy” (Rana 2020).

Mirroring movements calling for person-centered care within the healthcare sector more generally, there has been a parallel, if somewhat delayed, movement in the humanitarian health sector. Empathy, and empathy-like phenomena such as sympathy and compassion, are often considered key components of person-centered care (Sinclair et al. 2017; King and Hoppe 2013; Santana et al. 2018), defined as healthcare that moves “beyond the delivery of services to more explicitly consider the preferences, needs, and values of the persons receiving those services” (Sinclair et al. 2017). Within MSF, this has manifested as the adoption of a people-centered approach or person-centered care initiatives in various entities within the MSF movement. These initiatives are aimed at “humanizing healthcare” (MSF OCP n.d.), and identify compassion and empathy as key components of person-centered care (MSF OCBA n.d.). Similar initiatives in other humanitarian aid organizations reflect a broader movement within the sector. According to the International Committee of the Red Cross, “people-centric programing”, requires staff who are “genuinely engaged, interested, capable, and compassionate" (Nepal and Klein-Kelly 2023).

Simultaneously, in recent years there has been increasing recognition of the importance of palliative care in humanitarian response, as demonstrated by the publication of a WHO guide (Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises: A WHO guide. 2018) and inclusion of palliative care as a minimum standard in humanitarian interventions (Sphere 2018). The emergence of palliative care as a humanitarian priority, within MSF and the sector as a whole, is likely due in part to its alignment with person-centered care and other similar initiatives (MSF OCBA n.d.); Ocba 2019). Advocates for palliative care in the humanitarian sector often employ the language of empathy and compassion to describe both why palliative care is needed and how it should be provided. In one study describing the moral experiences of humanitarian health professionals caring for patients who were dying or likely to die, compassion was described as one of the underlying ethical commitments throughout the participants narratives (Hunt et al. 2018). Their recognition of a shared humanity with people who are suffering in humanitarian crises “demanded an empathetic, holistic and tangible response”, which led many participants to advocate for the integration of palliative care in humanitarian interventions (Hunt et al. 2018). Coghlan and colleagues similarly argue that “palliative care brings fundamental value in helping the humanitarian system recover its historical consciousness of humanity, empathy, solidarity, and witness” (Coghlan et al. 2024). In the story “their suffering also plagues us”, Haawa’s statement “I am here with you” is an act of accompaniment that is both the heart of palliative care and foundational to MSF’s principle of témoignage or witnessing. MSF speaks out on a global stage based on experiences of “being near and listening” to those who are suffering in humanitarian crises (MSF 1995). Discourses of empathy and empathy-like phenomena within the humanitarian aid sector, as well as local empathy-like phenomena, function as important horizons of significance against which MSF staff interpret their experiences with patients and define what it means to give good palliative care.

The limits of empathy

Fassin (Fassin 2011) offers an important critique of what he calls the “new moral economy, centered on humanitarian reason” (p. 7), which focuses on the suffering and misfortune of others and uses empathy and compassion to mobilize a response. He asks the provocative question, “what, ultimately is gained, and what lost, when we use the terms of suffering to speak of inequality, when we invoke trauma rather than recognizing violence… more generally when we mobilize compassion rather than justice?” (p. 8). While empathy and related concepts such as compassion are perhaps the origin of our sense of ethical responsibility to respond, they are a challenge for motivating sustained responses to humanitarian disasters in distant parts of the world (Slim 2015). In her ethnography of Islamic charity in Egypt, Mittermaier explores an Islamic "nonhumanitarian ethics" in which people give to God rather than giving to the poor (Mittermaier 2019). In this way, responding to the suffering of others is a divine obligation rather than dependent on the affective response of the giver. Mittermaier argues that this nonhumanitarian ethics addresses the unequal distribution of compassion and relieves the receiver of the obligation to perform their suffering (Mittermaier 2019).

Palliative care in humanitarian medicine is complicated by the reality that there are people with conditions considered life-limiting in a humanitarian crisis who could survive in a stable or high-resource context. In humanitarian palliative care, an emphasis on empathy without a simultaneous recognition of injustice risks substituting an emotional response for advocacy on behalf of patients. As Zaman argues, unless compassion is "tied to concrete action, it runs the risk of being or becoming a rather fragile set of exhortatory rhetorics" (Zaman et al. 2018). For the little boy and his mother who were receiving news of his leukemia diagnosis, empathy did not make up for the systemic injustice resulting in his lack of access to treatment for a potentially treatable cancer. Yet the same family meeting without empathy would certainly have been a more haunting, traumatic, and dehumanizing experience for the mother, child, and staff. As Dr. Chadni suggests, humanitarian healthcare without empathy and emotional engagement risks becoming "mechanical". Despite the valid critique of empathy as a motivating force for humanitarian action, we would argue that empathy continues to play an important role, particularly in the micro-level interpersonal interactions of humanitarian healthcare, and humanitarian palliative care more specifically. Empathy is key to creating therapeutic relationships between staff, patients and families, and those connections are often an important source of meaning and purpose for healthcare workers (Larson and Yao 2005).

While MSF staff saw empathy as important in their interactions with patients and families, their values related to empathy were often challenged by the limits of their ability to understand the other. In the story "if it was my child", Jeem imagines *himself* in the parents' situation rather than trying to understand *their* experience of *their* situation and concludes "*I would want to continue treatment*". One major critique of empathy, or what Davis calls "empathy culture", is that we cannot truly know another's experience. She argues that people often conflate their own emotions and experience with those of the other person and forget that "to be in the shoes of an Other still leaves you with your own feet" (Davis 2023).

While we are never fully able to understand another's experience, this may be even more true in humanitarian crises where staff are often interacting with people facing suffering at the extremes of human experience. Additionally, humanitarian healthcare workers often provide care to people across racial, ethnic, and linguistic differences, and while humanitarian aid organizations and their staff strive for the ideal of impartiality (Association 2018; (MSF n.d.), they are not immune to biases that limit their ability to understand the experience of others (Davis 2023). Slim similarly acknowledges that sympathy, empathy, and compassion are influenced by our proximity and similarity to the suffering person or community (Slim 2015). In Cox's Bazar, local host community sympathy for Rohingya refugees was initially very high but has declined over time for a variety of reasons including the protracted nature of the crisis, disparities in humanitarian support, perceived security risks, and increased cost of living (Kamruzzaman et al. 2024). These tensions and resentments may undermine humanitarian healthcare workers' ability to empathize with patients and families. The vast social distance separating internationally recruited staff and the Rohingya community may make it difficult for internationally recruited staff to imagine themselves in the position of patients and families. The ethnographer was unable to imagine herself in the position of the mother in this story because, as a Canadian woman, she was very unlikely to ever have a family member receiving care in a humanitarian field hospital.

Several scholars of empathy have argued that while sympathy and compassion are more automatic or reactive responses, empathy involves skills in moral sensitivity and empathic accuracy that can be taught (Jeffrey 2016; Maxwell 2008), skills aimed at "getting judgements about the others' subjective experience right" (Jeffrey 2016). Halpern, a physician and researcher who has written extensively about empathy, argues that empathy involves an engaged curiosity where "the basic stance is one in which the physician recognizes that he or she does not fully understand and has more to learn about the patient's situated experience" (Halpern 2014). Halpern suggests the importance of "decentering" in clinical empathy, whereby the healthcare worker uses their own emotional responses as clues while attempting to "step aside from" their own emotional point of view to explore the patient's experience (Halpern 2001). Carnevale similarly proposes the concept of empathic attunement which involves healthcare workers taking a "position of humility towards the unique particularity of a person's subjective experience". This approach involves allowing the healthcare worker's initial perception of the patient's experience to be continually modified through proximity and openness to the other person (Carnevale 2009).

Like Davis, Halpern, and Carnevale, an MSF nurse challenged her colleagues to remember that "*no one can take the mother's place*" (FGD-04). She and Aleef highlight the importance of "*hearing from the mother*" (FGD-04), of dialogue to confirm and deepen their understanding of the other person's experience. Empathic attunement is critical as healthcare workers are often involved in making decisions regarding what is in the best interests of children receiving palliative care (Carnevale 2009). As discussed in a previously published paper based on this focused ethnography, MSF staff felt compelled to "do their best" for their patients (Yantzi et al. 2023). If staff lack the capacity for empathic attunement, they may make decisions based on their own moral experience of the situation, or what they would do "if it was my child" (MH-02), rather than based on what matters to the child and family. Given the heightened moral complexity of humanitarian palliative care, it is critical that capacities related to empathic accuracy, empathic attunement, and moral sensitivity are developed and sustained in humanitarian healthcare workers.

Being moved by their patients

Halpern argues that "by allowing patients to move them, physicians gain access to a source of understanding illness and suffering that can make them more effective healers"(Halpern 2001). Yet despite the importance MSF staff gave to what could be referred to as affective empathy, being emotionally moved by their patients' suffering was also seen at times as risky or a sign of weakness. Expressing emotion was sometimes associated with a lack of professionalism and some staff described feeling the need to hide their emotions from colleagues for fear of judgement or ridicule. This is consistent with research that explores the "hidden curriculum" in medical education which may lead to a decline in empathy among new doctors as they learn to distance themselves from their patients in order to act in ways they believe are "professional" (Howick et al. 2023). As Kleinman explains, people become "moral in the eyes of a particular group" when they embody what is considered good and desirable within that group (Kleinman 2006). In the local moral context of Goyalmara Hospital, staff seemed to feel caught between the competing moral demands of professionalism which was sometimes interpreted as emotional distance and control, and moral demands connected with palliative and person-centered care initiatives which valued empathy and emotional responsiveness.

While conceptually different from affective empathy, the Bangla concept of *maya*, involving tenderness, affection, and attachment, has related connotations of emotional engagement. In an ethnography of aging and gender in West Bengal, India, Lamb found that the concept of *maya* played an important role in aging, death, and dying. Lamb initially thought of *maya* as a positive emotion, but her interlocuters clarified that the pull of *maya* can be problematic because it "causes immense pain and suffering" at end of life when loved ones are separated from each other (Lamb 2000). Similarly, in the novel *Parable of the Sower,* Butler's heroine Lauren Olamina suffers from hyper-empathy syndrome, causing her to fully experience the pain and suffering that she sees in others. In an apocalyptic landscape full of thieves intent on hurting her, hyper-empathy incapacitates her in key moments when she needs to defend herself and her friends (Butler 2012). For Lauren, empathy is a dangerous, potentially fatal character flaw.

Humanitarian crises can resemble apocalyptic landscapes and for humanitarian healthcare workers, being emotionally responsive to human suffering due to affective empathy, or the pull of *maya,* may feel like an Achilles heel. As Dr. Chadni said, "if we broke down, at that time we can't manage another patient" (MD-04). It is clear that a balance is needed between detachment, where healthcare workers suppress and control their emotions (Halpern 2001) to the point of presenting to patients and families as unfeeling, and being "plagued" by their patient's suffering. As Bouvier argues, certain forms of empathy or interpretations of the concept may contribute to secondary trauma, burnout, and compassion fatigue among humanitarian aid workers (Bouvier 2018).

Jeffrey argues that when empathy is self-focused, when the healthcare worker imagines *themselves* in the patient's situation, or as Jeem said, *"if it was my child"*, not only can this approach result in inaccurate interpretations of the person's experience, but this personal identification can lead to healthcare worker distress and burnout (Jeffrey 2016). Similar to Halpern's concept of decentering (Halpern 2001), Jeffrey suggests that what is needed is an other-oriented perspective, where the healthcare worker imagines what it is like for the patient undergoing the patient's experience; all the while maintaining a clear distinction between themselves and the patient (Jeffrey 2016, 2020).

What does it mean though for Haawa to maintain a clear distinction between the mother and herself when she herself is a refugee, when she herself has lost a child? The reality of humanitarian contexts is that locally hired humanitarian aid workers have often suffered some of the same traumas as their patients and families. For those who have not, the day-to-day exposure to suffering in their workplace may be highly traumatic. Jeffrey acknowledges that maintaining this other-focused orientation is a complex task requiring "mental flexibility, an ability to regulate one's emotions" (Jeffrey 2016). Particularly in humanitarian contexts where healthcare workers often have their own unresolved experiences of trauma which make it difficult to maintain this differentiation, psychoeducation, psychological support, and efforts to build these capacities are needed rather than merely asking staff to be more empathetic.

Towards empathies in humanitarian action

This narrative exploration has been an attempt, as Halpern suggests, “to study empathies in context rather than to defend a singular ideal for clinical empathy” (Halpern 2014). As Zaman argues, communities in the Global South have important insights to offer when it comes to empathy and compassion in palliative care (Zaman et al. 2018). Drawing on empathy-like phenomena from cultures and contexts where humanitarian organizations intervene, and the ways that communities offer care to people with serious illness or at end of life, may offer richer and more relevant understandings of empathic humanitarian palliative care. For example, drawing on the way empathy-like phenomena are understood within the compassionate community model of the Neighborhood Networks in Palliative Care developed in Kerala, India may be helpful in informing palliative care interventions in humanitarian contexts (Zaman et al. 2018). Or perhaps culturally specific concepts like *maya* may be helpful to contextualize discussions on the topic of humanitarian impartiality, considering the human tendency to have stronger feelings of attachment for certain patients and groups. Most importantly, by meaningfully engaging staff and communities from the contexts where humanitarian organizations operate, insights from diverse empathy-like phenomena may be incorporated into organizational or project-level strategies and initiatives to improve people-centered humanitarian action.

Conclusions and implications for humanitarian policy and practice

Empathy-like phenomena were central to how MSF staff understood good palliative care. These concepts informed how MSF staff experienced their relationships with the children and families receiving palliative care, and at times with each other. Humanitarian action takes place in what have been referred to as non-ideal moral contexts (O’Mathúna 2016; Tessman 2010), where empathy-like phenomena are crucial yet challenging to enact and sustain. In these “unconducive conditions”, Tessman argues that we must continue to strive for the ethical ideal because “to give up striving would be to announce one’s acceptance of injustice” (Tessman 2009). While the ethical ideal of equitable access to person-centered curative and palliative care offered with empathy may seem unrealistic in humanitarian crises, we must continue to strive for that ideal. As Bouvier argues, humanitarian crises are inherently dehumanizing for affected communities as well as humanitarian healthcare workers, and without an emphasis on compassion and empathy, humanitarian action itself may further perpetuate this dehumanization (Bouvier 2018).

Our aim in presenting the study findings through composite stories was to promote reflection rather than prescribe solutions; however, several implications for humanitarian policy and practice should be highlighted. As Kleinman argues, “ethical imagination and responsibility can, indeed must, be grounded in the turbulent waters of moral experience” (Kleinman 2006). In other words, humanitarian organizations’ ethical ideals related to person-centered care and palliative care must be grounded in the moral experience of those called upon to enact those ideals in practice. Particularly when organizations face challenges to make progress on complex strategic priorities such as person-centered care and palliative care, efforts to understand the challenges from the perspective of those on the ground are an important way forward. Considering the moral experiences of frontline humanitarian healthcare workers and incorporating local empathy-like concepts and practices may contribute to the development of organizational strategies that are more relevant in diverse humanitarian crisis contexts.

Development of empathy-related competencies including perspective taking, empathic attunement, and moral sensitivity should be considered a key component of any palliative care program, particularly in humanitarian crises. Within MSF-Spain, staff psychological support, debriefing mechanisms, communication skills, and learning activities aimed at building empathy-related competencies are key components of our palliative care integration strategy. Additionally, MSF has developed and plans to evaluate a package of support aimed at strengthening the culture of caring and empathy-related competences in MSF projects. This package of support includes a workshop that draws on narrative medicine and other participatory learning modalities (Médecins Sans Frontières 2024).

MSF staff’s use of phrases like “empathy and sympathy” highlight the risk of these terms becoming buzzwords, disconnected from the reality at the patient’s bedside. It is not enough to instruct humanitarian staff to be empathetic, innovative approaches to staff education, mentorship, and psychological support are needed to ensure that staff have the capacity to engage empathetically with their patients. Empathic engagement must be accompanied by concrete action and advocacy to both save lives and relieve suffering.

Abbreviations

FGD	Focus group discussion
MSF	Médecins Sans Frontières
NGO	Non-governmental Organization
NICU	Neonatal intensive care unit
PICU	Pediatric intensive care unit
QUAGOL	Qualitative Analysis Guide of Leuven

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Authors' contributions
RY, SB, AL, PKSG, and LS contributed to the study conceptualization and protocol preparation. RY led data collection with support from MD for Bangla interviews and focus group discussions. RY led the data analysis process under the supervision of her doctoral committee LS, MH, SM and OW, and with support from co-authors SB, PH, MD, KR, AL, GR, PKSG, and MJS. RY wrote the original draft of the manuscript and received substantive feedback from all authors. All authors read and approved the final manuscript.

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Data availability
Due to the sensitive nature of the data, appropriate requests to access the dataset can be sent to OCBA.ORcommittee@barcelona.msf.org.

Declarations

Ethics approval and consent to participate
Ethical approval was obtained from the Bangladesh University of Health Sciences Ethics Review Committee (ID: BUHS/ERC/EA/21/31), the MSF Ethics Review Board (ID: 20109), and the Hamilton Integrated Research Ethics Board (ID: 16746). The study was conducted in accordance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, which is the research ethics standard in Canada. Staff were offered the option to decline inclusion of any information about them in field notes. All individual interview and FGD participants gave prior written informed consent. The names used in the composite stories are pseudonyms.

Consent for publication
RY created all photographs submitted with this manuscript and gives permission for the journal to publish them as part of the article.

Competing interests
The authors have the following competing interests to declare: LS and SB are members of the MSF Ethics Review Board; however, were not involved with the review of this protocol. The authors have no other competing interests to declare.

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