

# Neglected suffering: The unmet need for palliative care in Cox's Bazar

MARCH 2018

## Acknowledgements

World Child Cancer and Fasiuddin Khan Research Foundation acknowledge the important contributions made by the people and organizations who supported the data collection for this study, including OBAT Helpers, PalCHASE, Médecins Sans Frontières, BRAC, International Committee of the Red Cross (ICRC), and Handicap International. Most importantly, we would like to thank those community members who participated in this research and provided the rich evidence and experience on which this report is based.

Special thanks to Jason Nickerson (*Bruyere Research Institute, Canada*), Mila Petrova (*University of Cambridge*), Richard A. Powell and Brett Sutton (*PalCHASE*) for their extensive insights and review of the content of the report.

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Cover: Cox's Bazar, Bangladesh:  
October 11, 2017. Djohan Shahrin / Shutterstock

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Published by World Child Cancer  
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London  
United Kingdom SW8 1RP  
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www.worldchildcancer.org  
Registered charity no. 1084729  
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World Child Cancer mission is to improve the diagnosis, accessibility of treatment and quality of support for children with cancer, and their families, in the developing world. Our work in Bangladesh focuses on improving the quality of life for children with life-limiting conditions, including children with cancer. We have supported the mainstreaming of paediatric cases in the 'Palliative Care Rapid Situational Analysis in Rohingya Refugees' as we believe that every child, regardless of where they live, has to receive the best possible treatment and care to realise their ambitions and dreams.

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# Introduction

**T**aslim was a 4-year old girl in Cox's Bazar refugee camp, Bangladesh, suffering from eye cancer. When her cancer first appeared, Taslim had surgery to remove her tumour. Initially, it looked like this may have cured her. But just two months later, Taslim developed headaches and pain. Sadly, the cancer had returned and spread.

When our team met Taslim, she was in severe pain. She desperately needed palliative care, including medicine to relieve her pain. But there was no morphine – the best treatment for her pain – available at the local health facility. In desperation, Taslim's father took her to a distant government hospital. Like the health facility, the hospital could not provide adequate pain relief. Tragically, Taslim died at this hospital only days later without the right care and support that she and her family so urgently needed.

Taslim's story is not unique. We hear many stories like this of children and adults around the world facing humanitarian emergencies – children and adults who cannot be relieved of the burden of suffering from disease or trauma because of a lack of medicine or supplies, or the absence of health workers who know what care to provide; and families who watch their loved ones in severe distress unaware of how they can help.

We know that large numbers of people facing chronic or life-threatening illness go unreached by humanitarian health systems; and many of those who could have been provided essential palliative care and pain relief will die, unreported and uncared for. The imperative to save lives in humanitarian emergencies has often meant that the suffering of those who cannot be cured is neglected or forgotten. This is the distressing reality in most humanitarian crises. The refugee crisis happening right now in Bangladesh is no exception.

Palliative care enables patients and their families facing life-threatening illness, with physical, emotional, social or spiritual distress, to be supported in their journey. They can access the right medicines, equipment, and

doctors, nurses, social workers and others who are trained in how to help. Solutions exist that we know can aid children and adults to live with greater quality of life, eased from the burden of avoidable pain and suffering.

Over in another part of the refugee camp, Mojidor is a 10-year old Rohingya boy with bone cancer. When he was diagnosed at the camp field hospital, Mojidor and his mother cried all night fearing he would soon die. Mojidor has two little sisters. His father is missing. We found Mojidor in a tent lying on a mat, unable to move or walk because of his pain. In the past, Mojidor was a typical football-loving boy. His nickname was 'bhuissya' meaning 'buffalo'. We started pain treatment, and now Mojidor can walk and even smiles a little. Palliative care has improved the quality of Mojidor's life and given much needed comfort to his family.

Even when there is no cure and it seems like there is little hope, for patients like Mojidor and Taslim there is so much that can and should be done. This imperative is echoed in *The Lancet* Commission on Global Access to Palliative Care and Pain Relief and the stark statistic that 25.5 million people die with serious health-related suffering that requires palliative care. That a significant health response in Bangladesh has been mobilized in this crisis is commendable. That unrelieved pain and suffering remain a common occurrence should be an incentive to action and a reminder of the enormous benefit palliative approaches can bring. The Government of Bangladesh, humanitarian agencies and local health workers have a moral and health imperative to invest in policies and programmes that ensure no child or adult lives or dies in severe distress in Cox's Bazar. Relieving the burden of pain, suffering and anguish associated with disease and illness must be a priority in this humanitarian crisis.

In November 2017, a palliative care rapid situational analysis was conducted amongst Rohingya refugees living in temporary settlements in Cox's Bazar. This the first assessment of palliative care conducted during an unfolding humanitarian crisis.

# In Ukhia camps, Cox's Bazar:

## What are the GAPS?

## What can health actors DO?

*73 per cent of people with chronic or life-threatening illness live with pain and do not receive the pain treatment they need.*



Pain treatment, including oral morphine, must be made available to all patients with preventable pain.

*58 per cent of people with chronic or life-threatening illness do not receive the care they seek for their presenting symptoms.*



Health care workers should be trained to routinely assess and manage pain or other symptoms.

*Health facilities do not provide palliative care and there is no community-based palliative care service.*



Comprehensive plans for the management of chronic disease should be developed and include community-based palliative care services.

*Children with chronic or life-threatening illness face unique challenges. Families with a sick child are struggling to provide for their basic needs.*



Home-based palliative care services should be developed to support children and families.

Health care workers should be trained to support the unique needs of children requiring palliative care.

*60 per cent of patients have had to stop taking medicines because they cannot afford to pay.*



Palliative care should be provided free at the point of use or with limited out-of-pocket payment.

*Physical disability stops patients accessing the medical supplies they need.*



Essential medicines and supplies such as catheters, diapers and wheelchairs need to be available and accessible, including to those with physical disabilities.

*94 per cent of caregivers have not received any training in how best to care for their family member.*



Caregivers should receive training on how to provide optimal care; and psychosocial support to manage the emotional stress of caregiving.

# Unknown and unseen: a humanitarian crisis within a crisis

**B**etween August and November 2017, a military offensive forced 623,000 people, most of them Rohingya Muslims, to flee Rakhine State in Myanmar into the Cox's Bazar District of Bangladesh (1). Many witnessed the killing of family members or sustained violence-related injuries during the military raids. They travelled long distances on foot to find safety, arriving exhausted and traumatized. Scores of children were separated from their families in the chaos of leaving their homes. Those forced to flee settled in overcrowded tent camps in the border areas in southeast Bangladesh, where an estimated 213,000 Rohingya from Myanmar were already living.

Today, they endure extreme living conditions, with poor hygiene, a lack of basic supplies including food and clean water, and a lack of resources and access to health care. There is no reliable count of the number of people who have died in the camps – the World Health Organisation has officially recorded over 300 deaths in Bangladesh's refugee camps. Forty per cent are children under five. But the real toll is almost certainly far higher (2). Poor hygiene and dirty drinking water heighten the risk of diseases like cholera, typhoid and shigella. Crowding and low immunisation coverage brings the threat of measles and rubella. Pneumonia and diphtheria are already significant causes of mortality, particularly in children; and thousands of children are being treated for severe acute malnutrition.

Humanitarian aid agencies and local health services are on the ground providing food, water, shelter, immunisations and hygiene kits to stop the spread of disease. There is a focus on preventing and treating acute and curative disease; on ensuring mothers delivering babies in the camps get appropriate antenatal care; and on supporting the mental health of traumatized families.

But there is a neglected crisis within this rapidly evolving humanitarian emergency. There are likely thousands of children and adults

facing chronic or life-threatening illness who are not receiving the care they desperately need. Those with HIV, cancer, diabetes and other non-communicable diseases remain unseen and their needs are largely if not wholly going unmet.

Humanitarian health workers aim to save lives and relieve suffering. But the imperative to treat those with acute and curable conditions – whilst crucial – often means that the needs of people who cannot be cured are set aside. (3,4). Dying or seriously ill patients with incurable disease have been left unattended or cared for by health workers who are unsure how to help them – or worse, who treat them as if they were already dead. This leads to pain, suffering and severe anguish for patients and their families (5). This is the distressing reality in most humanitarian crises. The refugee crisis happening right now in Bangladesh is no exception.

Palliative care in humanitarian crises has been given little focus or research investment. Understanding who and how many would benefit from palliative care; building evidence about how to implement effective programs; and monitoring progress towards reducing the burden of preventable pain and suffering in humanitarian crises is a moral and health imperative.

Palliative care has equally been neglected in development settings, in particular in low-income settings. Yet the mobilisation of medical care and humanitarian assistance in this crisis must bring into sharp relief the missed opportunity to meet an urgent and pressing need, especially with so many terrible dimensions of suffering. This crisis should also remind us of the minimum standards that we commit to adhere to; and the human rights that underpin such standards. Palliative care has a rightful place in an essential package of medical care. We should never accept – in crises or in routine care – that intolerable suffering is something to address as an afterthought.

# Palliative care: what is it and who needs it?

Palliative care is an approach that improves the quality of life of children and adults and their families facing chronic or life-threatening illness. This suffering may be physical, emotional, social or spiritual. Palliative care is best provided from the time of diagnosis. It continues throughout a person’s life and after they die, through bereavement care for distressed family members. Palliative care may be provided in combination with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy. It includes those investigations needed to better understand and manage distressing clinical complications (6).

Palliative care for children is closely related to adult palliative care but has some unique characteristics. It involves the active total care of the child’s body, mind and spirit and provision of support to the family.

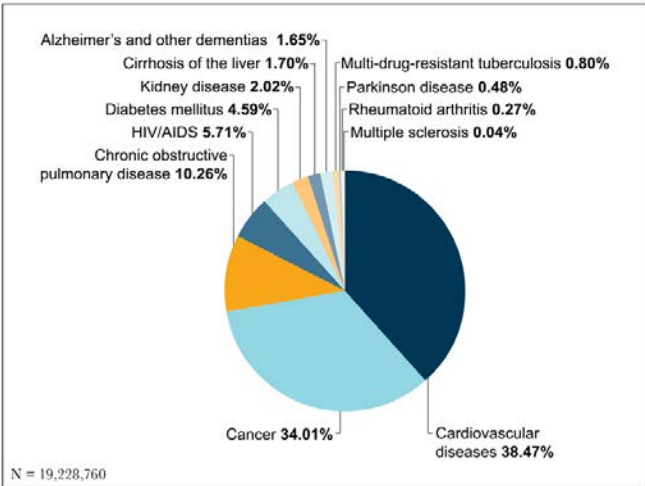
Solutions exist that we know can aid children and adults to live with greater quality of life, eased from the burden of avoidable suffering.

These solutions are effective, inexpensive and can be implemented even where resources are limited. *The Lancet* Commission on Palliative Care and Pain Relief has proposed an Essential Package which includes tools – medicines, equipment, and health and social care workers trained in how to help—for providing essential and affordable palliative care interventions in low-resource settings (7). (Appendix A)

Globally, forty to sixty per cent of people could benefit from palliative care (8). Adults facing chronic illness including heart disease, cancer, chronic respiratory conditions, HIV and AIDS, and diabetes; and children with congenital anomalies and neonatal conditions, malnutrition, meningitis, and HIV and AIDS, could experience better quality of life with palliative care services (Figure 1).

The majority of those needing palliative care live in low- and middle-income countries. Sadly, very few are able to access the care they need in these settings because such services are only just beginning or do not exist at all.

## ADULTS



## CHILDREN

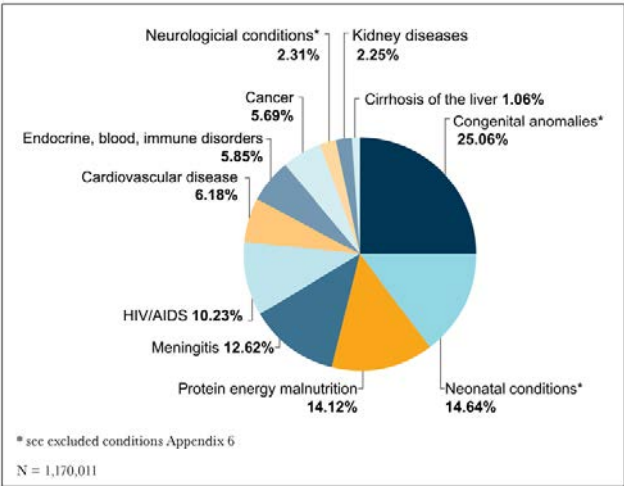


Figure 1. Distribution of adults and children in need of palliative care at the end of life by disease. (Used with permission Global Atlas of Palliative Care at the End of Life (World Hospice and Palliative Care Association, 2014))

# The relief of suffering in Cox's Bazar: where are the gaps?

In November 2017, a palliative care rapid situational analysis was conducted amongst Rohingya refugees living in temporary settlements in Cox's Bazar. This the first assessment of palliative care conducted during an unfolding humanitarian crisis.

The following groups were interviewed to understand their illness and care experiences and the availability of medicines, medical supplies and services:

- Children and adults living with chronic or life-threatening illness (including cancer, HIV and AIDS, severe physical disabilities and other serious medical conditions).
- Family members and caregivers.
- Health facilities in the Cox's Bazar District.
- Retail pharmacies in and around the Rohingya refugee settlements.

## Pain and symptom relief

In Cox's Bazar, 73 percent of people with chronic or life-threatening illness live with pain. Almost half have received no pain relief; and those that have been given basic pain medicines including paracetamol or non-steroidal anti-inflammatories have had very little relief (Figure 2). No-one has received opioid pain medicines such as oral morphine –the first line of treatment for moderate or severe pain.

This is partly due to a severe lack of opioid pain medications in stock at local health facilities and pharmacies particularly inside the refugee camps. Doctors lack knowledge of how to use pain medicines or hold beliefs that opioids can be misused and are reluctant to prescribe them. There are also regulatory barriers. Most pharmacies employ sales people with limited or no formal training in the field of pharmacy.

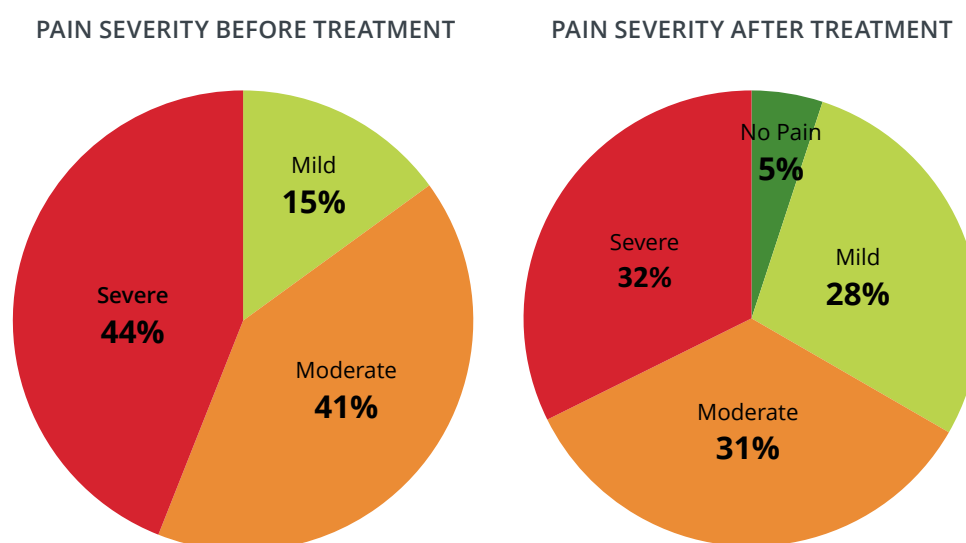


Figure 2. Pain severity before and after treatment



Most people with life-threatening diseases suffer physical symptoms in addition to pain such as fever, or have trouble sleeping and no appetite (Figure 3). These symptoms can be treated, but few facilities are assessing these symptoms or providing symptomatic care and the right medications are frequently unavailable

from local pharmacies. Fifty-eight per cent of people with chronic or life-threatening illness have not received the care they seek for their presenting symptoms. The World Health Organisation has published protocols for the treatment of symptoms in palliative care for children and adults (9,10).

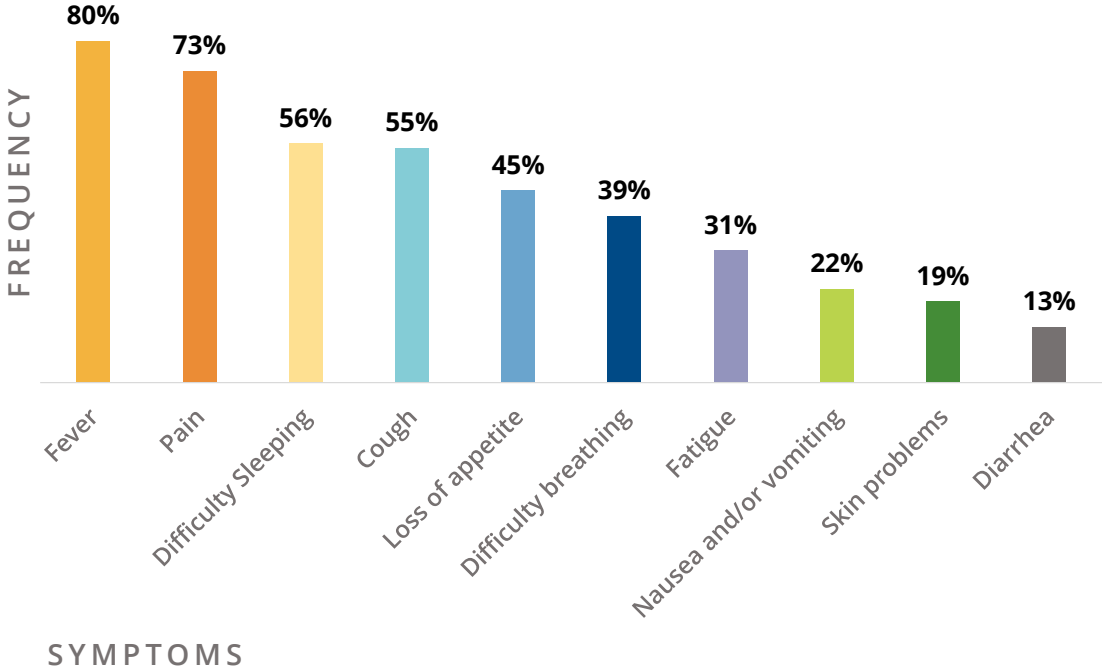


Figure 3. Commonly reported physical symptoms

## Access to the right health care

Visits to health facilities for those with chronic or life-threatening illness are common. Reasons for seeking health care include management of pain; management of acute symptoms such as diarrhea or fever; or for other problems related to their condition. Despite reasonable access these visits are frequently unsuccessful from the patient or caregiver’s perspective. Health facilities are unable to treat the needs of these patients in fewer than half of such visits.

Palliative care services are completely absent from local health facilities. Health care workers are overwhelmed with patients needing acute medical care and are struggling to address complex problems associated with chronic or life-threatening diseases. Health care plans to comprehensively manage chronic conditions have not yet been established in the Rohingya settlements and there is no community-based palliative care service available.

## Children needing palliative care

Cancer, drug-resistant tuberculosis and serious physical disabilities are seen amongst the children in Cox’s Bazar. Many of these children also have intellectual or developmental disabilities.

Children requiring palliative care face unique challenges. Providing high quality palliative care for children requires additional skills and training. Children with life-limiting conditions often spend time in hospital and experience separation from family and friends. Children

may require additional support during hospitalization due to the psychological stress that this brings.

Families with a sick child are struggling to provide basic needs such as food, medicines and transport to health facilities. A family’s financial resources are often severely strained during hospitalization due to loss of income and other indirect costs, even if the medical care is free or low-cost.

## Essential medicines and medical supplies

People with life-limiting illness need medical supplies and medicines for symptoms other than pain to support their care and quality of life (Figures 4 and 5). Despite availability of medical supplies and medicines at health facilities in the camps, more than 60 per cent of patients have had to stop taking essential medications

because they cannot afford to pay. Physical disability also means that patients cannot receive the medical supplies or medicines they need – they and their caregivers struggle to reach distribution points to collect needed supplies.

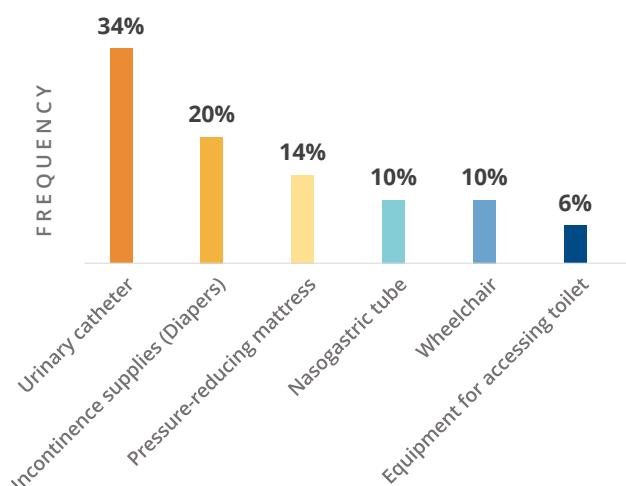


Figure 4. Medical supply needs

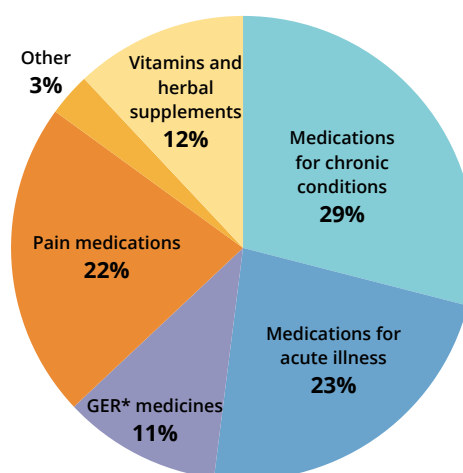


Figure 5. Medication needs  
\*Gastro-oesophageal reflux

# Supporting caregivers

Caregivers are nearly always family members who provide hours of assistance every day bathing, administering medications and feeding. Caregivers also provide emotional support and care. They are a vital support in helping people get to health facilities. Many caregivers are women with the majority also having young children to look after. Caring for a sick person is

a demanding and difficult role physically, socially and financially and can create immense sadness and anxiety for the caregiver (Figure 6).

Most caregivers (94 per cent) have not received any training on how to care for their family member or been given any psychosocial support to help them cope.

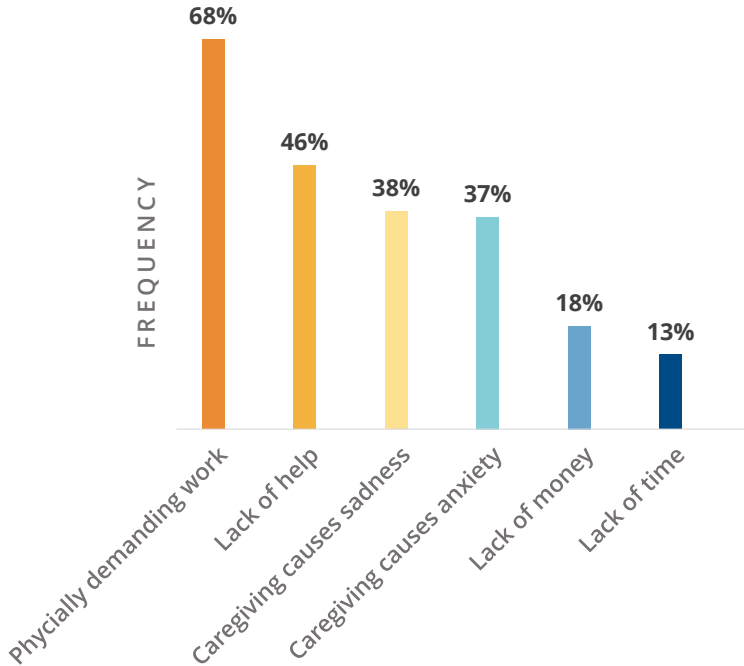


Figure 6. Problems reported by caregivers related to providing care for the sick person



*Monia is a 46-year-old woman with advanced breast cancer. She went to a local NGO-run hospital hoping to receive surgery, but she could not afford the cost of the procedure. She returned home to her tent.*

*Monia was suffering from severe pain when our team met her.*

*We guided her to a nearby clinic, hoping she could get treatment for her pain. She was given only paracetamol.*

*Monia returned home with severe pain and now she does not know how she will get any pain relief. There are no palliative care services available and no clinics where physicians feel comfortable to prescribe the oral morphine which she desperately needs to control her pain.*

**Home-based palliative care services could help to support Monia and ensure she receives the pain treatment she needs.**

# Recommendations

There are significant unmet health and social care needs for people and families living with chronic or life-threatening illness in Cox's Bazar. Yet there is so much that could be done to give hope and relieve suffering. The Government of Bangladesh, humanitarian

agencies and local health workers have a moral and health imperative to invest in policies and programmes that ensure no child or adult lives or dies in severe distress.

**Priority must be given to:**



## Pain and symptom relief

- 1. Pain treatment, including oral morphine, must be made available to all patients with preventable pain.** Morphine is manufactured in Bangladesh and is readily available at palliative care health facilities in Dhaka. The World Health Organisation provides guidelines to assist health care organizations to improve opioid availability, while ensuring safe storage and dispensing (10,13).
- 2. Health care workers should be trained to routinely assess and manage pain and other symptoms using WHO Pain Guidelines.** This training should include information on how to appropriately prescribe opioids.



## Access to the right health care

- 3. Comprehensive plans for the management of chronic diseases should be developed for the Rohingya refugees and host population in Cox's Bazar.**
- 4. Community-based palliative care services should be developed and implemented for the Rohingya refugees and host populations.** Community health workers equipped with palliative care training can provide essential services in the home.



## Children needing palliative care

- 5. Home-based palliative care services should be developed to support children and families facing chronic or life-threatening conditions.** Providing palliative care for children at home can improve the quality of life for children and their families and is especially desirable for children with physical disabilities where transportation is often challenging.
- 6. Support for basic needs (e.g. food, clean water, transportation, shelter) should be provided to families who have a child with a life-threatening condition.** This is a key component of palliative care in resource-limited settings and should be incorporated into pediatric palliative care planning.

- 7. Health care workers should be trained to support the unique needs of children requiring palliative care, with specific emphasis on pain management in children.** This training should include the WHO guidelines for the use of opioids in children (10). Opioids can be used safely in children of all ages who have moderate to severe pain.



## Essential medicines and medical supplies

- 8. Palliative care medicines and services should be provided free at the point of use or with limited out-of-pocket payment for patients and families.** A community-based palliative care model implemented in the Rohingya settlements could provide medications and supplies free of cost.
- 9. Medical supplies such as catheters, diapers, nasogastric tubes, pressure-reducing mattresses and wheelchairs need to be made available and accessible.** Essential medical supplies are readily available in Bangladesh and locally produced items are more likely to be suitable than items imported from high-income countries. Health facilities and pharmacies should ensure these supplies are available.
- 10. The physical limitations of people with chronic and life-threatening illness need to be considered when determining how essential medications and supplies can be received.** Home-based palliative care services can assist with delivering such supplies.



## Caregivers

- 11. Caregivers should receive training on how to provide optimal care and psychosocial support to manage the emotional stress of caregiving.** Training equips caregivers with the knowledge and skills to provide the best care. Training can ensure caregivers are not injured providing physical care; can prevent caregiver burnout; and can help them manage the emotional stress of caregiving (11,12).

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# Appendix A. The Essential Package for Palliative Care and Pain Relief

## Medicines

- Amitriptyline
- Bisacodyl (Senna)
- Dexamethasone
- Diazepam
- Diphenhydramine (chlorpheniramine, cyclizine or dimenhydrinate)
- Fluconazole
- Fluoxetine or other selective serotonin-reuptake inhibitors (sertraline and citalopram)
- Furosemide
- Hyoscine butylbromide
- Haloperidol
- Ibuprofen (naproxen, diclofenac, or meloxicam)
- Lactulose (sorbitol or polyethylene glycol)
- Loperamide
- Metaclopramide
- Metronidazole
- Morphine (oral immediate-release and injectable)
- Naloxone parenteral
- Omeprazole
- Ondansetron
- Paracetamol
- Petroleum jelly

**The Essential Package** contains the inputs for safe and effective provision of essential palliative care and pain relief interventions to alleviate physical and psychological symptoms, including the medicines and equipment that can be safely prescribed or administered in a primary care setting. The list of essential medicines in the Essential Package is based on WHO's list of essential medicines, and considers the medicines, doses, and administration routes for palliative care for both adults and children.

Tasks often undertaken by specialised medical personnel in high-income countries can be performed by other specialised and general practitioners and nurses or by community health workers empowered with the necessary training and medical supervision to participate effectively in the delivery of palliative care and pain treatment at all levels of care, from the hospital to the home.

## Medical equipment

- Pressure-reducing mattress
- Nasogastric drainage or feeding tube
- Urinary catheters
- Opioid lock box
- Flashlight with rechargeable battery (if no access to electricity)
- Adult diapers (or cotton and plastic, if in extreme poverty)
- Oxygen

## Human resources

- Doctors (specialty and general, depending on level of care)
- Nurses (specialty and general)
- Social workers and counsellors
- Psychiatrist, psychologist, or counsellor (depending on level of care)
- Physical therapist
- Pharmacist
- Community health workers
- Clinical support staff (diagnostic imaging, laboratory technician, nutritionist)
- Non-clinical support staff (administration, cleaning)

With the key exception of morphine, the medicines in the Essential Package are available in most countries even if supply is limited. For morphine, an essential palliative care medicine, assuring safety and accessibility is complex.

The health services of the Essential Package must be complemented by interventions for the relief of social and spiritual suffering to preserve the dignity of patients, facilitate access to health interventions, and prevent financial hardship and impoverishment.

Adapted from *The Lancet* Commission Report (7).

