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Palliative Care - not a Luxury, but a Human Right and an Essential Element of Universal Health Coverage (UHC)

Bridging the Gap of Informal to Formal Palliative Care Provision at The Rohingya Refugee Camps

Palliative Care matters in Humanitarian Crises

By Farzana Khan

Two years back, October 2017, I joined a medical camp at Rohingya refugee camps and found that there existed no palliative care. That surprise helped crystallize my values and my vision. I believe in a world where health innovation is for everyone – where no human being dies with a suffering that can be prevented. But what I found was a world still shaped by inequity. That discovery was one of the most important steps in my journey to humanitarian camps. I decided to be an advocate for the community who needed my help. I knew I had to face reality and struggle. However, I like to find hope when life feels pretty hopeless. Palliative care matters in humanitarian crises because it matters to people in humanitarian crises. This is something - this is a message that I have chosen to give to you, who are reading this article. There is no doubt that palliative care is unpopular within the culture of humanitarian aid.

The view of the camps around Cox's Bazar, the world's largest refugee settlement. Photo: EU Civil Protection and Humanitarian Aid/flickr, CC BY-NC-ND 2.0

A brief History of Rohingya Refugees in Cox's Bazar

As I sat down to look back at the last three years to connect the dots, I went through lots of readings as well. The brief history that I have jotted down from books, newspapers and journal papers are like this: This is not a new one. Bangladesh has been hosting Rohingya refugees for more than three decades. The Rohingyas are a Muslim ethnic-minority group based in Myanmar's Rakhine State. According to many historians, they are descendants of Arab traders and other groups who, in the 15th century, migrated to Rakhine, previously called the Kingdom of Arakan. After 350 years of independent existence the Burmese conquered Rakhine State in 1784. This annexation was short lived as the territory was occupied by the British in 1824 and made a part of the British Indian Empire. In 1948 Myanmar (previously named as Burma) became independent from the British Indian Empire. The current conflict took place in Rakhine state of Myanmar. This is separated from the rest of Myanmar by barren mountain range. Today the Rohingyas are about 1.1 million Muslim citizens of the Rakhine state but are not

recognised legally as one of the 135 ethnic groups. They are considered as illegal immigrants. They are denied basic human rights with no access to education, medicine, or other government services.

Out of the total refugee population in Cox's Bazar, 700 000 people have arrived in the district since August 2017 - 80% of them women and children. The majority required immediate humanitarian support. Photo: EU Civil Protection and Humanitarian Aid/flickr, CC BY-NC-ND 2.0

An Ethnic Cleansing

Things got worse when militants attacked security forces in northern Rakhine State on August 25, 2017. In response, the Myanmar army launched a ruthless campaign against the Rohingyas fashioned in the style of the Japanese war tactic—"burn all, kill all, destroy all". The army and its collaborators slaughtered thousands of civilians, raped girls and women while family members were tortured and killed, and burned their houses, forcing hundreds of thousands to flee their homes.

In a world where so many borders are closed, Bangladesh, itself a poor country and one of the world's most densely populated, welcomed the Rohingyas by opening its border. Since August 2017, over 750,000 Rohingyas have crossed into Bangladesh. For Bangladesh, the Rohingya refugee influx is not a new phenomenon. Different media reports confirm that between 1974 and 2016, more than 260,000 Rohingyas fled Rakhine. Bangladesh and its people have shown the best of humanity and saved many thousands of lives by providing shelter to the Rohingya

community. The country has allocated 5,000 acres of land for temporary shelters, provided food, deployed mobile medical teams, and carried out large-scale immunisation campaigns. However, palliative care was totally absent in the refugee camps.

Ambitious Project of the Fasiuddin Khan Research Foundation

Well I started the work with my own organization Fasiuddin Khan Research Foundation (FKRF) that bears my father's name. The FKRF wants to stand for something and that is palliative care in vulnerable areas. Just to note, the spirit of FKRF lies in four words: Rectify, Pacify, Modify and Reify. *Rectify* means to correct something or to set something right. The word *Pacify* tells us to bring or restore to a state of peace or tranquility. By *Modify*, we mean to make minor changes to something and the last syllable *Reify* helps us making something real or making something concrete. At FKRF we've tried to capture that insight that lays in phrase "Rectify, Pacify, Modify and Reify". Our customers are neglected human beings. We don't believe in rumination of what you always have, it's about rethinking, reframing and innovation. The FKRF has been really ambitious.

The FKRF is a local non-profit that works in vulnerable settings like refugee camps and urban slums. We started working in Rohingya refugee camps for people who were displaced. Before starting the work we did a needs assessment (reliefweb, 2018).When we wanted to explore about their needs, they wanted exact medicines for their pain and other symptoms with proper doses. These people are historically marginalized even in their own country, so sufferings belong to them for a long time or almost their whole life. When you think about health care in refugee camps and people with incurable diseases, there is always disproportionate suffering in this community. And so we've decided and committed to provide palliative care for these people. And we started that for cancer patients, for HIV, for non-communicable diseases, for drug resistant tuberculosis and many more incurable diseases.

Earlier in the work I spent much time in the camps to familiarize myself further to humanitarian setting and the context. This included meetings with key personnel and stakeholders, periods of observation while joining medical camps for acute treatment, speaking to staff and listening to patients and families. During this time I learned more about how humanitarian health sector works, gained an understanding of the incurable patients journey and spoke to wide range of staff at all levels of international and national humanitarian organizations working on the field. Engagement with the community leaders is ongoing and was not confined to the induction period.

Rohinyga Children in Kha Maung Seik Maungdaw North 2012. Photo by Carine Weiss

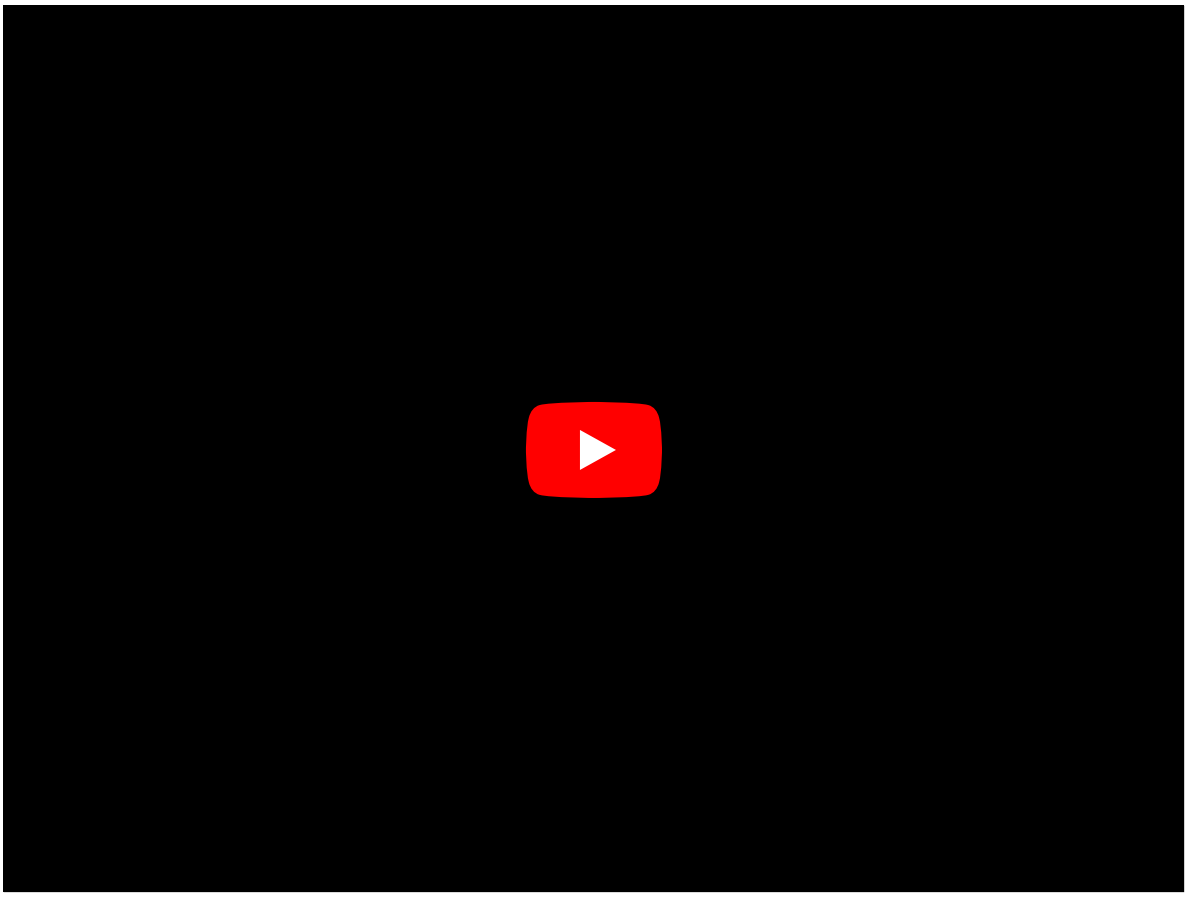
Community Health Workers are Palliative Care Assistants

There is no easy solution to the incurability in humanitarian crisis. Distinguishing between mainstream health services and social services is never straightforward, and responsibility often cuts across different state agencies. This calls for a coordinated palliative care approach. In Bangladesh, this has been done at the local level through Worldwide Hospice Palliative Care Alliances (WHPCA)-funded project in urban slums, where I had been actively involved earlier.

The FKRF started with community health workers (CHWs) to work in the camps. CHWs are non-clinical workers who come from the communities of the patients they serve, whose job is to help patients live healthier lives, as well as to help providers better understand and respond to patient needs. After providing 10 days theoretical training on palliative care to CHWs we call them Palliative Care Assistants (PCAs). Afterwards they would get 6 moths in-service training. PCAs really became the backbone of the organization. They did almost all of the skill-based routine tasks. They did it extremely well. With the result, we had high productivity, high quality services at very low cost. A growing body of evidence shows that social, economic and cultural factors can impact an individual's ability to build and maintain health, and community health workers can change the paradigm of medical care. Careful construction of the right care models, CHWs can contribute enormous value to patients, communities, and health systems alike.

Frustration Continues

Two years have passed and the aid sector finds itself shifting from emergency response to dealing with a protracted crisis. The dimensions of the response are changing as the months pass by. As the refugee crisis prolongs, longer-term health needs also become a pressing concern. The camps are now home to nearly one million Rohingya, including previous generations of refugees who fled their homes in Myanmar's Rakhaine State. There are slim prospects of a quick return home, as the UN says Rakhaine State is not yet safe for the Rohingya, who have faced generations of marginalization. Most of the refugees say they won't go back until their rights are guaranteed. Till then, the FKRF had been the only organization, working hard to provide palliative care as best as it can. At the same time 'The New Humanitarian' contacted me **to make a short video** on palliative care performance in the Rohingya camps – 'The Healer in Rohingya Camps' (The New Humanitarian 2019). I used to sit with the patients because I have similar experiences while working before in urban slums. I felt in connection with patients and their families. There would be small child or young boy or old lady who has got so much faith in me; I tried to give my best for them. I believe it is ourselves we are helping. It is ourselves we are healing.



The New Humanitarian (TNH) | The Healer

Empathy, not sympathy

Here I would like to share two patients story with you.

First, Nur Banu's story

A 48 years old lady with neck malignancy was referred to the FKRF by MSF. The FKRF team first visited her on 29th January, 2018. She had a stage 4 cancer wound with severe pain. I had to start Tramadol, which belongs to WHO analgesic step 2 or weak opioid, to treat her severe pain, because morphine was not available in Cox's Bazar. But her pain didn't go away. So I prescribed and bought oral morphine, that is the golden drug of choice for severe pain, from Dhaka and carried that to Cox's Bazar. After starting morphine she experienced a lot of pain relief.

She and her husband left their two little sons in Myanmar. At the end of her life, one month before death, we had a discussion with the family whether they should sent her back to meet the children. The family agreed to do so. But Nur Banu said that she wouldn't go back, because the palliative care team was taking so much care of her, which she might not have in Myanmar. After 15 days suddenly she had changed her mind and decided to go back to her country. We gave her few morphine tablets and other medicines. The family had arranged late night boat journey. After reaching home, she had lived for 7 days. The family later informed us she was very happy seeing her children again. However, at the last moments she had pain.

Secondly, Shohida Akter's Story

This little girl with an unknown congenital disease, may be of muscular or neurological origin, I'm not certain - loves to read. She cannot stand or walk, however, her mother & friends help her to go to a nearby school. If her mother tells her not to go to school, she would start crying. She would crawl herself over the ground and reach the school. Her handwriting is excellent. We found her one and half years later with moderate pain all over her body. After receiving pain treatment, her pain was relieved. Her 18 years old brother has the same disease, who also had a history of starting slowly and for the last few years his condition remains the same.

Few months later one PCA went to visit her. Shohida requested the PCA, "please tell madam that I don't have any pain now. The only problem is that I can't move, stand or walk. Can she do something for me!"

I felt helpless, as I didn't know how to treat her. I wish an expert on this condition might be able to help her. I tried, but failed to get help from any expert for clinical advice for Shohida.

She has reached a point where she is no longer able to walk. This awareness might not her change the path but we want people to know about them and their diseases to support research and see the meaning in her life and all children affected by life-limiting conditions. I

can see the human capacity for hope is so strong that even when you're told there is no hope somehow you still manage to experience it. Otherwise, how could Shohida and Kefayetullah be still smiling!

23rd January, 2020: Formal Palliative Care Provision in Ten Primary Health Centres in Rohingya Refugee Camps have been started. Photo: © Farzana Khan & FKRF Team

Light at the end of the Tunnel

The FKRF has started working in 10 camps including two upazilla health complexes Ukhia and Teknaf with International Organization for Migration (IOM) award from January 1st, 2020. However, in the middle of January we got to know that the NGO Bureau of Bangladesh has denied providing registration to the FKRF, because this is a small organization with only few

workers. Obviously IOM cannot give work order to an organization that doesn't have 'NGO status', as this is a bar from our government. That was a huge blow to the FKRF, in particular to Palliative Care Activities in the Rohingya Camps!

Then a magical thing happened. IOM decided to take palliative care into their activities and took over all our 38 staffs through EnRoute. IOM also appointed me as health consultant for palliative care. At the moment, all palliative care staffs are working in four IOM based Severe Acute Respiratory Illness- Isolation Treatment Centres (SARI-ITCs).

Conclusion

Palliative care needs to be extended in all facilities in humanitarian context. Now, how do you create compassion or extension? How do you make people or organization own the problem? Do you want to do something about it? I'm sure readers are able to find the right solutions to these issues.

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