Discussing disability

Delivering services to people living with a disability in the camps can be challenging. While some Rohingya people may have been living with their disability for a long time, the violence in Myanmar has required many refugees to adapt to new physical and mental injuries. Physical and cultural limitations mean that people living with a disability may find it difficult to access mainstream education or other humanitarian services such as health centres or women- or child-friendly spaces. They are less likely to be included in community activities, and therefore less likely to learn a language other than Rohingya. Their isolation also reduces their access to information or feedback and complaint systems. This makes communicating with them in their preferred language crucial to allow them to access the support services they need.

**Mental and intellectual disabilities**

The Rohingya culture distinguishes between the brain (mogos/demag), the mind-soul (dilor/foran), and the physical body (jism). There is considerable stigma (bodnam) related to psychological conditions. Rohingya people refer to many mental conditions as faul, a general term meaning ‘madness’ or ‘lunacy’. Therefore, it is sometimes easier to explain physical disabilities (gaar mazuri) rather than mental conditions (dhemaki khomzuri) or intellectual disabilities (zehen-khomzuri).

While the Rohingya language includes vocabulary to describe emotions, feelings, and thoughts, many of these terms are adopted from other languages, mainly Urdu. Many Rohingya people are not familiar with these terms.

**Talking about disability**

As the Rohingya community has not had sustained access to medical care, there is generally a low level of health-related understanding among the community. Many medical conditions related to disability have no Rohingya translation and others share a term with a related, but medically different, condition. For example, the Rohingya word for stroke (boyare maijje) is the same term used for general paralysis (whether describing long- or short-term paralysis).

Many commonly understood physical disabilities do have a distinct term: for example deafness (nafaang) and blindness (aandha). A person who has a physical disability is sometimes referred to as jismi khomzuri.

Someone who has a mental disability is called demaki-khomzuri, which translates as ‘low intelligence’. Both of these terms, and the majority of terms used to describe disability, are negative and stigmatising.

Many symptoms or complications associated with a physical disability do have Rohingya equivalents. For example, numbness (besut on), fluid retention (fula aish’she), muscle tightness (gusto doro on), and insomnia (gum zai no’faron).

Many people living with a disability are now able to access regular rehabilitation (dubara gom goron) for the first time, from agencies working in the camps. These rehabilitation exercises are sometimes called frektis taken from the English ‘practice’.
Of jinns and winds

Historically, many cultures blur the line between spirituality and medicine. In Rohingya culture, illnesses and diseases are sometimes thought to be the workings or supernatural entities (zin-fori). People may explain a variety of mental conditions by saying people are possessed by spirits (asor’e dhoron). For example, the term for paralysis – boyare maijje – literally means ‘to be hit by the wind.’ But who is doing the hitting? Many Rohingya people believe that jinns hit humans with winds to make them immobile. Many Rohingya people still see disability as a test from God, particularly if it is psychological and/or intellectual in nature. A woman is considered particularly vulnerable to attacks by a jinn during menstruation, childbirth, and for 40 days after the birth. The belief is that if a jinn attacks the newborn child, they may develop a mental or physical disability. Because of this, Rohingya people commonly seek help from traditional healers and religious leaders, rather than health professionals, if they believe their child has a disability.

Types of pain

The general word for ‘pain’ in Rohingya is bish. It is associated with physical pain rather than mental or emotional pain, which people describe as hoshto, meaning ‘difficulty.’ The Rohingya language differentiates between different types of physical pain. Aching or prolonged, dull pain is horani, which literally means ‘to bite.’ Shooting or stabbing pain is sissiyani, and tingling or pins-and-needles is zinzinon. Though these specific terms exist in the Rohingya language, many Rohingya patients use the general word for pain (bish) instead. Prompting patients with these specific words will help health practitioners and health interpreters to identify sources and types of pain.

Concerns of the Rohingya community:

Health and medical services

Rohingya people have raised different concerns during listening group discussions. In the last 18 months, access to health and medical services are amongst the top five concerns raised by the Rohingya community who attend these discussions. And, in the last six months, the proportion of concerns raised on the topic has been rising, compared with other areas. Given that this topic is in the top five, we’ve decided to focus on it for this edition of What Matters?

Health and medical service-related concerns have been raised particularly by people in camps 22, 23, 24 and 25. In all these camps, people mentioned that they need more health facilities, especially easily accessible services within their blocks, and better treatment for different kinds of diseases. They also asked for an emergency medical service. Rohingya people mentioned that there are some health complexes run by NGOs where they usually go if they become sick, but they have to wait in the queue for a long time to get treatment from the doctor. Participants also said that after taking medicines given by the doctor, they don’t get better. Some male participants said that, whatever the sickness is, doctors only prescribe Napa (paracetamol) as medicine. Female participants couldn’t name the medicines that they were being given by the doctor, but they also believed that they receive the same medicine for all kinds of sicknesses and they are not getting better after taking it.

To try to get better treatment, some community members go to the MSF (Médecins Sans Frontières) or district hospital outside the camp. As they need transportation to go to these places, many people can’t afford it, and they feel that they have no other options to get better treatment.

In the four camps where most concerns were raised, there are some similarities in terms of key issues of concern. In camps 22, 24 and 25 people were concerned about the outbreak of contagious diseases like chickenpox and were requesting treatment for that disease. In camps 22, 23 and 25 people were concerned about increasing prevalence of skin diseases and wanted support to get proper treatment for these. In camps 22 and 25, water born diseases were raised as a concern.

Source: Feedback from 10,364 listening group meetings from December 2017 to May 2019 from 24 camps (Camp 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 22, 23, 24, 25 and 26) collected by Bangladesh Betar, ACF, IOM and DRC, together with FGDs conducted by BBC Media Action in camp 9 with 18-25 years and 26+ years men and women, in camp 12 with 18+ men and women.
However, communities in some camps raised more unique concerns:

**In camp 22,** people mentioned that they needed more nutritious food to ensure their wellbeing. They said that lack of money was a barrier to eating well. Malnutrition has become a concerning issue in this camp. Feedback suggests that people feel it would be helpful if there was a nutritionist stationed in the medical facility – they feel that they need to know how to prepare more nutritious food.

**In camp 23,** people demanded better treatment for eye-related complications, antenatal care facilities and also mentioned the need for nutritious food. Though no more data was found from this camp, in camp 12, female participants mentioned that some people in their community are facing vision problems but there is no access to optical treatment. Some female participants also said that they need to know more information about the nutrients of different foods.

**In camp 24,** Rohingya people raised issues regarding psychological illness and their treatment. They also wanted to know about the process of preparing saline when they are suffering from diarrhea.

**In camp 25,** people raised concerns about their children's physical and mental wellbeing and requested more women-friendly and child-friendly spaces. They wanted to know how to keep children safe from pneumonia and requested knowledge about antenatal care, postnatal care and different kinds of vaccines for children.

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I feel weak as I could not eat properly. Also, we cannot give nutritious food to the pregnant women. So, we need to know, what do we need to eat to get strong?

~ Woman, camp 12
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If you have any comments, questions or suggestions regarding *What Matters?*, you are welcome to get in touch with the team by emailing info@cxbfeedback.org

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