Have you ever walked a mile in their shoes? (2)



Rohingya patients report on health services since the pandemic began

Edition 6, 31st May 2020

Despite widespread documentation of Rohingya dissatisfaction with available health services, problems continue to be reported in the relationship of trust between affected communities and humanitarians. Since mid-March, community-based research reflected in the COVID-19 Explained series has uncovered a wide-spread and highly concerning rumour that anyone who enters a camp health facility with COVID-19 symptoms will be killed as the only way to contain the virus. This rumour, combined with the common perception that health facilities do not have the capacity to provide adequate health care, have likely contributed to the 50% drop in the overall medical-consultation rate across the camps over the past six weeks (EWARS 03/05/2020). Often, these experiences are attributed to misperceptions of healthcare or rumours instead of actual reports and accounts of people's interactions with medical professionals or experiences at clinics. Throughout COVID-19 Consultations, Rohingya have repeatedly pointed to their perceived and actual experiences of treatment within and at health facilities in the camps as a major source of distrust. Rather than engage in larger questions about the perception of medicine, treatment or healthcare, this edition focuses on people's recent reported experiences and interactions with humanitarian health care staff since the pandemic began and explores how they came to their conclusions about their experiences. In light of the confirmed outbreak in the camps, it is increasingly important to explore the variables that shape Rohingva's health seeking behaviour and implement solutions where trust is being harmed. Given that among the first confirmed cases, people have attempted to escape, hide, and generally evade healthcare practitioners, there is clearly still room for all parties to improve in trust through the provision of better services - not simply through marketing strategies.

This report follows on from the findings of past <u>COVID-19 Explained Editions</u> and <u>Health Behaviours and COVID-19.</u> For this edition, 56 key informants were requested to provide detailed accounts of their recent experiences of medical consultations and treatments. These experiences were analysed and their findings presented here according to the same qualitative data analysis methods and standards as other COVID-19 Explained editions. Additionally, six illustrated story boards were developed from the interviews and developed separately as an illustrated companion report. It is the hoped that in response to the question "what do these stories mean," we can find answers by diving deeper into the singular stories and experiences of the people we serve.

- Among 56 interviews with key informants immediately following their visits to health facilities, participants reported 27 positive, 23 negative and 6 neutral experiences. Despite this, rumours and negative perceptions are delaying some people from seeking treatment because they assume that the clinic cannot help them, or if they are suspected to be infected with COVID-19, they will be taken away.
- The five variables found to have the greatest impact on the perception of healthcare were 1) Staff behaviour and use of respectful language; 2) Perceived quality of the consultation in terms of whether the patient had been provided with basic care, such as temperature check, blood pressure, and physical examination; 3) Rohingya's ability to communicate effectively with healthcare staff in language they understand; 4) The explanation of systems and rules of the medical facility to patients; and 5) Clear communication about where to fill prescriptions.
- Patients' experiences, trust, and perception of healthcare services will undoubtedly improve if healthcare providers pay attention to five variables within facilities. Both good and bad experiences of healthcare facilities were reported based on differences in those factors and all already have operational solutions being implemented in various medical facilities in the camps to varying degrees. This edition recommends health actors take patients' perceptions as a serious and key factor that impacts people's willingness to test and seek treatment for COVID-19 and other illnesses and is a key issue in ensuring accountability to affected populations.
- It also recommends that simply taking more and continuous detailed accounts of patients' experiences in different facilities allows for sector-wide problems and solutions to be identified and scaled up. These approaches can be integrated within existing health community feedback mechanisms and stronger monitoring of health facilities is clearly needed to mitigate and respond to negative experiences when they do occur. It should be noted that of the 56 interviews, many were sufficiently detailed to constitute formal complaints if that have been the purpose or intent of this exercise.





Key Findings & Recommendations

¹ Assessments and analysis reports that discuss health seeking behaviour of Rohingya: MSNA 10/2019, UNHCR 11/2019, WFP REVA2 05/2019, IOM 04/20, ACAPS 04/20



Methodology

From 20th of April to the 10th of May 2020, a team of 15 (7 females and 8 males) Rohingya field researchers trained in qualitative research with the support of two Bengali IOM CwC staff members conducted 56 Key Informant Interviews (KII) and eight participant observations of Rohingya refugees who had had personally sought medical support from a participating health clinic or hospital within the camps using a semi-structured questionnaire (see demographic breakdown in table 1). Agencies operating the clinics were notified and invited to participate in the study and provided with access to the primary data related to their facilities to understand how facilities' services are experienced by patients. KIIs aimed to investigate respondent experience at health facilities with a focus on social interactions with facility staff. Personal information related to staff or patient names was not gathered during the study. The organizations that elected to take part in this study were MSF, IOM (and partner organizations). Information from other clinics was collected in a non-targeted manner when KIIs shared stories of recent visits to other facilities.

A purposive sampling approach was employed with the aim of interviewing an even number of female and male respondents with representatives across all major age groups that had visited participating clinics within the timeframe. Field researchers also aimed to interview some respondents with non COVID-19 health care needs (pregnant women, NCDs such as diabetes etc.), and some that displayed COVID-19 symptoms (e.g. fever, cold-flu like symptoms) to allow for the possibility for observations to be made between experiences by health issue. Data was collected by IOM and discussed with the Rohingya facilitators who conducted the interviews as part of the analysis. Interviews were recorded with consent, transcribed and checked by Rohingya volunteers and Bengali staff. Any interviews that showed bias, included leading questions or were not sufficiently detailed were removed from the sample.² Data was then analysed by ACAPS using qualitative data analysis software through matrices. This report is a part of a series on Rohingya's perceptions of the COVID-19 response led by IOM's CwC team in collaboration with ACAPS (see here).

The focus was on the collection of detailed descriptions of interactions to illuminate where trust is being built or damaged, as opposed to statistical sampling. The information collected aims to provide participating operational agencies detailed information about their own clinics and the response as a whole an overview of key detriments of trust in the response's health care system.

The symptoms reported throughout the report are reflections of the informants themselves, not medical professionals, as is the perception of whether or not they received adequate medical attention or advice.

Table 1: Demographics of the KII by population group, gender, age range and whether the informant was seeking health care due to sick child (excl. participation observations).

Population Group	Gender	Older person (60+)	Adult (31- 59)	Youth (18-30)	Age not specified	With sick child	Total no. of KIIs
Host Community	Female	1	2	0	0	2	3
	Male	0	0	1	0	0	1
Rohingya	Female	4	14	12	0	8	30
	Male	4	11	5	1	7	21
	Mixed	0	1	0	0	0	1
Total		9	28	18	1	17	56

Data collection ethics during COVID-19: All staff have received training on how to protect themselves and those they are interviewing from undue risk of COVID-19 transmission. The use of trained Rohingya field researchers in the camps and Bangladeshi CwC staff from the host community enabled data to be collected face to face; however, strict physical distancing and hygiene rules were applied to ensure the safety of researchers and participants. For this edition, only KIIs were conducted and enumerators were asked to gather information in areas nearby their residence to reduce unnecessary travel. Meetings between researchers outside of the camps and the facilitators were kept to a minimum (two total) and involved physical distancing and other relevant protector measures. Additionally, all staff and enumerators have had training on child protection, PSEA, consent and data protection protocols. Consent was gained per key informant and data was anonymised; names of staff or respondents were collected.

To promote greater access to lifesaving information, the enumerators have also be trained in providing crucial information on COVID-19 to the respondents after the conclusion of each interview to ensure this information is shared throughout the community.

² A total of 5 interviews were removed from the total number of KIIs conducted and were not analysed as they lacked sufficient detail or showed signs of response bias due to the participant-observation methodology utilized in some interviews.



Limitations

This edition is not a representative sample of all health service providers or patient experiences within the camps. Notably, the service heavily preferred by Rohingya, private clinics, was omitted due to time and other research constraints.

As the analysis focused on humanitarian run health facilities within the refugee camps, only 4 host community informants participated because these facilities are not commonly used by the local population despite the service also being available to them.

The information outlined in this report does not represent the official views of IOM or ACAPS in Bangladesh. It reflects an analysis of the views of Rohingya refugees living in camps. It should not be read as a definitive account of the Rohingya's or host community perceptions on COVID-19, and their perceptions of health provision across all camps.

What shapes perceptions of health care?

Among 56 key informants, roughly 40% (23) recounted their recent personal interaction with health services in the camps in a positive light and would recommend those services to family and friends. However, almost half of the key informants (27) explained that that they would not recommend the clinic or hospital they visited to their family and friends due to their recent negative experience. There were also six informants whose overall opinion of their experience was neutral, summarising their experience using both positive and negative elements, and did not have as strong opinions on whether they would return or share their experiences. The fact that negative experiences lie in the majority of patient's experiences is concerning, especially that these are the stories more likely to be widely shared.

Five key social factors were identified as playing a critical role in shaping the respondent's experience as either positive or negative. These variables were found to consistently shape the informant's opinion of the facility and the rationale behind whether or not they would recommend this facility to friends and family. These include:

- Staff behaviour;
- Quality of consultations with doctors;
- Communication with health care staff, especially doctors;
- Clear systems and rules in place, followed by both patients and staff;
- Clear communication about where and how to fill prescriptions.

Patients who reported rude and disrespectful behaviour towards them by health care staff and staff in support roles such as guards and registration staff were the most distressing and common problem identified among these experiences.

It should be noted that the majority of those who labelled their overall experience in the health facility as positive received some form of medication or more 'tangible' treatment – something that people perceive to be associated with better treatment. However, when asked what made their experience positive, the vast majority put greater emphasis on communication and positive social interactions with support staff and doctors than their medical treatment. Those who felt that they were respected and had their problems listened to were more likely to recommend the clinic to their family and friends. Of the 30 informants that reported receiving medication, nine were mostly unhappy with their experience and would not recommend the clinic to their family and friends. Informants attributed this to the way in which they were treated by staff at the clinic. They all labelled their interactions with support staff as rude and disrespectful and over half also explained that their consultation with the doctor was inadequate. As a result, they explained that they did not trust the diagnosis, medical advice or treatment prescribed by the doctor and sought alternate treatment at private clinics because they felt they had not been checked properly nor given the opportunity to explain their symptoms.



1. Staff Behaviour

The way staff behave and interact with patients was seen as the most important factor contributing to overall satisfaction with the facility by all respondents. Disrespectful and discriminatory behaviour such as offensive language and shouting was commonly reported. Support staff, particularly guards, registration staff and others were most likely to behave this way. A minority (7 of 27 negative reports) mentioned the doctor was also rude and disrespectful.

Negative - Positive +

Twenty-four key informants cited being disrespected, shouted at and discriminated against by support staff such as guards, registration staff and others in supporting roles at clinics or hospitals.

"The women volunteers sent me away. When I tried to go with my child they called me mad. They said 'Is she crazy? How can we explain. If you can't control them, then why have you brought them here? Rohingya give birth to a lot of children. If you can't control them, then keep them inside of you."

~Rohingya female youth seeking medical treatment for her young child with a fever Kind, respectful and helpful behaviour from support staff was discussed by **Twenty key informants** as one of the main reasons for them recounting their experience positively.

"The doctors and staffs from the clinic asked questions very politely to the patients about their suffering and they also did blood test to the patients in two places. All the patients were treated properly by the doctors irrespective of whether they were poor or rich people."

~Rohingya adult female with diabetes

2. Quality of consultations with the doctors

Informants explained that their consultations with doctors were satisfactory when they felt they were listened to, were able to communicate their symptoms and understood the diagnosis and medical advice given by the doctor. They also expressed their appreciation when doctors conducted minor tests to check their weight or blood pressure, taking this as evidence of the doctor or facility's investment in their care and recovery. Those who did not have an opportunity to speak to a doctor were more likely to distrust the diagnosis and treatment prescribed because they were not convinced that the doctor understood their issues – this largely contributed to the negative perception of the quality of care.

Negative -

Thirteen key informants felt as though they were not given the opportunity to explain their condition and that the doctor did not take sufficient time to listen to and check their symptoms.

"After taking [the medication], they didn't even ask about our feelings and told us to go to the home. I returned from the hospital at 5 pm. But I didn't feel better after their treatment. They spoke to us respectfully, but we didn't get good quality care. Now, I am feeling better after taking medication from another doctor who treats people in Kutupalong Bazar but it costed 35,000 BDT."

~Rohingya adult women sought health care due to symptoms of severe diarrhea

Positive +

Adequate consultation with a doctor was identified by **thirteen key informants** as a key factor that increased their trust and overall satisfaction in the facility.

"The doctor asked me everything. He talked with me more than 10 minutes and behaved with me very cordially. I liked the way they treated me. I felt very confident that the doctor understood my disease and gave me medicines according to my illness."

~Rohingya male youth seeking assistance for fever, body aches and cough



3. Ability to communicate and understand health care staff, especially doctors.

Not being able to communicate with health care staff, especially the doctor, in the language in which patients feel confident they can explain their symptoms and understand the advice and instructions being given by staff was specifically identified as a source of stress. This led to patients' distrusting the facility's ability to adequately diagnose and treat their illness. On the contrary, of those who expressed trust and satisfaction in the facility and with facility staff explained that language played an important role in their ability to seek adequate health care. They reported that this was because they were able to explain themselves fully and understand medical advice and instructions provided by facility staff and the reasons behind them. Some key informants also highlighted that support staff will often use their misunderstanding of Bangla as a justification for speaking rudely to them, implying that they are worthless and uneducated. This decreases their confidence in reporting issues and actively engaging with health facility staff.

Negative -

Five informants specifically mentioned language as a barrier when communicating with staff at the facility.

"I didn't understand her [ICU nurse] properly because she spoke in Chittagonian language and mixed with our language.

Interviewer: Did you tell her that you don't understand their language?

"No, we feel shy to ask them again repeatedly. Doctors spoke to us in Bangla language about patient experiences. We couldn't understand any word that they said to us, and they went away without a proper explanation"

"Rohingya adult male, his son was recently rushed to emergency with severe breathing problems

Positive +

Six informants mentioned how important it was that they were able to communicate with the staff at the facility especially the doctor either directly or through a translator.

"No one from the clinic spoke to us disrespectfully. We were respected from when we entered the facility to when we left. And also, the expatriates from that clinic can speak three kinds of languages such as Burmese, Rohingya and Ferai language (English). Everyone can speak to them with whatever language they wish. Although I can speak a little English, I can speak Burmese fluently. So, I felt very glad as I could explain by myself.

Interviewer: What would you tell your family or friends if they want to go that facility?

"I would explain to them all about the treatment I received from there and I was also ready to take them to that facility if they needed."

~Rohingya female youth recent visited the clinic for treatment for Hepatitis–C

4. Clear systems and rules in place, followed by both patients and staff

Inconsistency in the enforcement of clinic and hospital rules, such as opening hours and standard procedures when entering the clinic, by support staff, as well as a lack of communication on how patients are triaged created confusion and frustration. Many informants also spoke of not understanding how the triage system works, noticing that some were arriving late yet getting seen before those who had arrived early. Some even explained that patients who have family who work at the clinic are more likely to be seen than those who do not. This issue was raised more often by those who expressed an overall dissatisfaction in the service they received at the health facility. The opposite was reported among informants that had a more positive experience. They were more likely to be able to clearly describe the rules and the processes of the facility that they had visited. For example, many spoke of the clear queues that involved a ticket number representing their place in the queue. Many also spoke of staff being able to clearly explain some of the more operational aspects of the facility and why it was important that they were followed. The clear order and set rules of the facility contributed to people's satisfaction with the clinic. Many of these people were happy to wait in queues when the facility was busy if there was a clear system in place that they understood.

Negative -

Ten informants explained that they were denied entry by a guard or turned away by registration staff with limited to no explanation. Few were able to negotiate their way through.

"We went at 9 am and sat there for about two hours but the child was not allowed to enter. The guard who was at the entranceit's not good he didn't let people in and he didn't let my little son enter. If he would have let my child enter, others would not have said anything. Even though we came from far away, he wouldn't let my son in. The guard didn't reply even when we ask why we couldn't go in. He just says that we can't enter. So, my child had to wait outside until I came out."

~Older Rohingya man, sought health care due to body aches and stomach pain with his son who had an unknown itchy rash

Positive +

Noting the importance of understanding the system and processes of the health facility was identified in **eleven informants** that reported positive experiences.

"They opened the door of the gate in the morning at 07:00 AM - 07:30 AM. Doctors arrived to the Hospital before 08:00 AM. The gate-man opens the gate according to their schedule. Nowadays, patients enter through the gate after they are sprayed and they wash their hands with soap. Patients have to wear masks and sit with social distance because of the virus. Their systems work very well. And then people enter and sit on the benches. There they put numbers on every single bench such as 1, 2, 3, 4 and 5... There are separate rooms and doctors for different diseases..."

~Older Rohingya man, regular patient suffering from chronic illnesses



5. Clear communication about where and how to fill prescriptions

Medicine availability in clinics and hospitals is a challenge. When prescribed medicine was not available, patients needed to either find a clinic within the camps with stock, wait for the clinic to replenish their stocks or pay for the medicine outside the camps. This was a major barrier for patients who reported a lack of support or guidance by the clinics when shortages occurred. Some informants also mentioned having trouble filling prescriptions as they cite being told that only one person from a family can receive medicine, regardless of the prescription.

Negative -

Thirteen informants specifically identified having trouble filling their prescription through the pharmacy attached to the facility either due to availability of medication or specific rules that reduce the amount of medication that is able to be distributed at once regardless of prescription.

"After they arrived, they wrote 4, 5, 6 items of medicine on a paper but they distributed only 2 Items of medicine. Why did they not give the rest of the items?"

~Rohingya male with child suffering from fever

"I'm suffering back pain, neck pain and leg pain. For this, they provided me medicine. At this time they said "Now we are providing medicine for elderly people and children." And I was moved to the corner. When I was standing there, they said 'You can leave'"

~Rohingya female suffering from body aches

Positive +

Seventeen informants explained that they would recommend the facility after their recent visited as they felt satisfactory medical advice and treatment was provided.

"Interviewer: Do you think you got 'good care'?

Informant: Yes. I was not spoken roughly or disrespectfully and was given medicine immediately when I said my child had diarrhea. Since the clinic started, they have given priority to diarrhea patients." ~Rohingya adult male, went to clinic with his son who had diarrhea

Other challenges reported by patients

was in a serious condition

Beyond the five main variables reported above, other issues were reported that had a lesser, but noteworthy impact on perceptions and experiences of health care. These factors were not reported as the main reasons behind patient-provider relationship, but are contributing factors to dissatisfaction and poor perceptions of health clinics.

A) Rumours and general negative perceptions of health clinics were reported by many and though all still sought treatment, a minority explained that they delayed seeking help until it was almost too late due to the negative stories they heard about the facilities in the camps.

"I should have gone there while the mother was giving birth but unfortunately I didn't admit her to the clinic because of what my neighbours said. The neighbours told me that your grandson will die if you admit her to the clinic to give birth that's why I didn't go but now I know it was really my fault.

This was how I found out that the clinic is really good, and I will tell people about my experience. I will tell them clearly what I observed there. If I convey wrong information about that clinic, people who are in need will not go there."

"Rohingya male youth, recently required emergency assistance because newborn

B) Waiting in long lines in the sun to enter the health facility due to the current COVID-19 physical distancing measures was reported as a challenge and contributed to informants' dissatisfaction with the service provided. On some occasions people reported that they were in too much pain to wait in lines and sought medical support outside the camps to avoid this.

"The people of hospital were not allowing the patient close to them even. They were asked to stay away and sit here and there. They don't care about the people. They were taking a few people inside and letting a few out. I waited there for one and half hours. I couldn't tolerate the pain more. So, I decided to go to the pharmacy in Pan Bazar."

~Rohingya male youth recently went to the clinic severe body aches and cramping, and a headache

C) Short operating hours of clinics were also expressed as a challenge, with many explaining that it is difficult to visit the clinic when they need to within the opening hours as they often clash with various aid distributions. Additionally, if someone in their family falls ill outside of opening hours many people reported not knowing what services are available to them.

"All the hospitals near my house stop their services at 2 pm but they close at 4 pm. They start their activities from 10 am and again stop them by 12 pm and go for lunch. There is also no 24 hours' hospital in this block. So, where we will go during our emergency?"



~Rohingya husband and wife, together they sought health care for husband's high blood pressure and fever

D) The cost of travel and current movement restrictions for those who need to seek support from a clinic or hospital located outside their camp of residence was reported as a challenge and a reason why people struggle to attend follow-up appointments.

"We have to spend 200 TK from here to there if transportation is available. If there is no transportation, we have to go on foot."

~Older Rohingya women with diabetes

Comparing experiences between demographic groups:

When comparing the experiences between those who had COVID-19 like symptoms and those with non-COVID-19 symptoms, 10 of the 16 who had a fever and other flu like symptoms reported that they had a negative experience. Though, according to the informants' description of events, this did not seem directly connected to their symptoms. Three reported facing difficulties and confusion when seeking support for suspected COVID-19 symptoms.

"Informant: After entering, we had to wash our hands with soap and had to sit 3 feet away from one another. They asked our names and told us to wait for a while.

Interviewer: What did they say?

Informant: They told that they would bring me somewhere in an ambulance because I was sneezing. Interviewer: What did you do?

Informant: I returned home silently because I was afraid.

~Rohingya female youth recently sought health care due to sore throat, cough and sneezing

"Finally, I went to the entrance and they asked me about symptoms of my child. I told them he was having fever, cough and sore throat when they were checking his fever with a gun machine. Suddenly the man started yelling at me, asking me why I didn't tell him my son's symptoms before he touched my son. He asked me to leave the hospital and pointed to the gate. I wanted to cry..."

From 56 KIs, 33 were females, 22 were males and 1 husband and wife, and there was a similar number of men (7) and women (10) who reported seeking healthcare for their children. When investigating to see if the findings indicate a difference in experience, no overwhelming differences were identified between patients experiences by gender. Similar proportions of positive and negative experiences and comparable reasons for those experiences were reported across demographic groups.

Twelve of 17 KIs seeking treatment for a sick child or grandchild reported having a negative experience. However, the available data makes it difficult to further unpack this and determine if it is a factor impacting overall experience. A minority of KIs explained that the reason they were denied entry was due to a facility rule where only one family member was allowed to enter. It seems that this rule is not consistently enforced, which causes confusion and discomfort among parents whose child is forced to seek healthcare alone.

"At first, they didn't allow me to enter with my child. And as I am suffering from pressure, I expected to take the medicines for my pressure diseases. But they told that only one person is allowed to take the medicines. And I explained them that my child is too young to tell about his diseases. And thus, this quarrel happened"

~Rohingya female with sick child that is suffering from fever and headaches

A deeper analysis of the current data, as well as additional data collection specifically looking at gender and other factors that impact people's experiences when seeking health care is needed to further unpack these issues.

What's in a story?

There is a risk that stories, quotes, and narratives can be anecdotal, non-representative, or prone to misappropriation. The research team of over 20 people has worked hard to include as many people in our consultations as possible. To date, over 540 people have participated in discussions for the COVID-19 Explained series since the response began, over 200 consultations were conducted and included in our data, and an estimated 600+ pages transcribed as a part of these interviews. Rather than being concerned with whether the findings are representative, we are more focused on conveying the day to day reality of living in the camps during the COVID-19 pandemic for the Rohingya. Therefore, this report is accompanied by an illustrated series of stories produced from this round of interviews. We hope that in reading these narratives in their full, it can help to better convey the full context of the lives of the people discussed in this report. As feedback about the process of producing COVID-19 Explained, many participants have said that simply sharing their stories has been a source of relief and have requested more of this activity — which they sometimes call "awareness raising" — the act of making us aware of them. Perhaps sharing just nine stories is also some service to them as much as it is awareness for us.

To view these stories, see COVID-19 Explained, Edition #6 Illustrated.