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### **Displaced population groups' access to mental health services in Bangladesh and Uganda**

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**Displaced population groups' access to mental health services in Bangladesh and Uganda**

**Fariba Alamgir<sup>1</sup>, Kate Pincock<sup>2</sup>, Khadija Mitu<sup>3</sup>, Rachel Hiller<sup>4</sup> and Munguleni Dalmatius<sup>5</sup>**

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**Abstract**

The psychosocial vulnerabilities of refugees and significant need for mental health services in humanitarian settings have received increased attention in recent years. Based on qualitative research with Rohingya refugees in Bangladesh and South Sudanese refugees in Uganda, and service providers in each context, this paper identifies hitherto underexplored factors that shape access to mental healthcare, as well as barriers and opportunities for improving mental health support. The paper finds multiple barriers that limit access to formal care, including distance, cost, lack of family support, poor health, communication challenges, perception of service propriety, and poor quality of services. Tensions between cultural understandings of mental health and shifting gender norms and roles in displacement also shape mental health vulnerability and service access in each setting. Gaps in existing services are identified, as are recommendations as to how community expertise and knowledge might be integrated within formal psychosocial support services for refugees

**Keywords:** Mental health, access, refugee, displacement.

## 1. Introduction

The psychosocial vulnerabilities of refugees, especially in contexts of protracted displacement, have received increased attention in recent years. There is evidence that dealing with trauma is an important dimension of peacebuilding and reconciliation for affected communities as well as for helping refugees to rebuild their own lives (Gitau 2017). Yet whilst mental health has attracted global attention and interventions, troubling statistics continue to emerge from humanitarian settings. In Bangladesh, the daily stressors of life in the refugee camps of Cox's Bazar, on top of ongoing statelessness and a long history of exposure to violence, have an extraordinarily negative impact on the mental health of Rohingya refugees (Riley et al. 2017; Milton et al. 2017). In Uganda, among refugee groups, the number of suicides doubled in 2019 compared to the previous year, and one in five households in Arua, which hosts a large number of South Sudanese refugees, contained a family member who was suffering mental distress (UNHCR 2019a).

The significant need for mental health services in humanitarian settings is widely recognised. However, there are a wide range of challenges to ensuring adequate support. While constraints on funding cause serious problems, these are not the only limitations. Promoting sustainable and equitable mental health assistance that benefits the refugees requires better understanding of the social, economic, cultural and psychological factors influencing refugees' access to services, among other issues. Extant research and interventions around mental health largely fail to engage with gender and cultural differences as factors shaping access to mental health service.

This working paper engages with some of these gaps in knowledge by presenting findings of research carried out among Rohingya refugees in Bangladesh and South Sudanese refugees in Uganda. By carrying out qualitative research with both displacees and healthcare providers working in these settings, we explored factors that shape displacees' access to mental healthcare and identified barriers and opportunities for improving mental health provision and support. It aims to bridge the gap between communities and formal practices, leading to more gender-sensitive programming, better targeting of healthcare interventions, and deeper understanding amongst healthcare providers and humanitarian actors working in other sectors about refugees' views, practices and challenges related to accessing mental health care.

We first provide a brief overview of the two research contexts: establishing the drivers of mental health difficulties amongst refugee populations; and the recognised challenges around mental health service access. The project methodology is then presented, followed by a discussion of the findings from each country context. The paper ends with key headline findings and recommendations.

### 1.1 The Rohingyas in Bangladesh

Bangladesh has witnessed a fluctuating, but recurrent, influx of Rohingyas from Myanmar since the 1970s. In August 2017, due to an outbreak of violence in Rakhine state led by the Myanmar government, more than 700,000 Rohingyas entered Bangladesh. Presently, an estimated 1.2 million Rohingya refugees are living in refugee camps in Cox's Bazar in

Bangladesh. Bangladesh has not ratified the 1951 Convention relating to the Status of Refugees and is not a signatory to the 1967 Protocol. The 'National Strategy on Myanmar Refugees and Undocumented Myanmar Nationals' adopted in 2014 is predicated upon security concerns and managed encampment, restricting Rohingyas' mobility and integration. While most international humanitarian agencies are advocating for Rohingyas' integration, particularly, into the employment market and educational institutions in order to promote self-reliance, the Bangladesh government is continuing with its restrictive policy and framework providing only emergency and temporary assistance. Working within this temporary relief assistance framework pose significant challenges for the humanitarian agencies in operationalising longer-term and sustainable programmes to promote wellbeing and resilience at the individual and community level.

Humanitarian agencies recognize the immense mental health needs among the population due to their traumatic exposure to violence and flight, and also because of the experience of poverty, restrictions on mobility and livelihood, and congested and poor living conditions in the camps (IOM 2018). Moreover, protection vulnerabilities and human rights violations are adversely affecting Rohingya refugees' mental health (Riley et al. 2019). There are significant differences in signs of distress and stressors based on gender and age (ACF 2017 in Tay et al. 2018). A study focusing on the impact of integrating mental health treatment within the primary health care system found more females than males to be diagnosed with mental disorders by primary health care physicians (Tarannum et al. 2019). While adolescent girls feel safer in Bangladesh, they nevertheless express high levels of feelings of insecurity and fear of violence, abduction, criminality including trafficking and forced labour (Plan International & Monash GPS 2018). Corna et al. (2019) also highlighted Rohingya women's need for maternal mental health support to improve wellbeing, child development and family resilience.

To tackle diverse concerns related to mental health, humanitarian agencies and the government have adopted the Mental Health and Psychosocial Support (MHPSS) framework that conceptualises and organizes mental health responses according to a pyramid of interventions comprising a multi-layered system of complementary services to address a range of needs (Tay et al. 2018, UNHCR 2019). While the interventions at the bottom two layers of the pyramid focus on strengthening security and support at the community level, the third layer consists of psychosocial support delivered by community volunteers or outreach workers provided with training and supervision, and the top layer consists of clinical interventions provided by professionals (that is, psychologists, clinical psychologists and psychiatrists). In 2017, a Mental Health Working Group led by IOM and UNHCR was established. By 2020, this included 75 organizations working on MHPSS.

Studies suggest that MHPSS interventions have evolved significantly through the implementation of varied and innovative strategies since 2017. In the Rohingya refugee context, there are organisations that focus on mental health activities (i.e. management of mental disorders through counselling and psychiatric care) or psychosocial activities which underscores the connection between psychological functioning and social factors (for instance providing skill training, education, livelihood opportunities and recreational facilities, and promoting security, legal and protection services). Several organisations combine both. However, available services and resources are inadequate to support the large number of people with mental health needs (Sullivan et al. 2019). Moreover, available services are

shrinking due to a significant financing gap. In 2021, the Covid-19 pandemic increased humanitarian needs by compounding socio-economic and health challenges, while the funding coverage for appealed response plan dropped from 75% in 2019 to 60% (Global Humanitarian Overview 2022)<sup>1</sup>.

## 1.2 The South Sudanese in Uganda

Following decades of violent religious and ethno-political conflict, in July 2011 South Sudan declared its secession and independence from Sudan. However, in 2013, fighting broke out again – this time in South Sudan, between rival factions in the Sudan People’s Liberation Army. Over the following year, inter-factional violence between these groups killed more than 10,000 people and displaced more than a million (International Crisis Group 2014). By October 2019, 2.2 million people were displaced. The majority of refugees from South Sudan are currently in Uganda, with the vast majority in the West Nile district. Those regions with the most refugees are Yumbe (230,000), Adjumani (209,000) and Arua (172,000) (UNHCR 2019). These are also the closest settlements to the border of South Sudan. These regions have also been hosting Sudanese refugees since the 1980s and have taken in further influxes of Congolese refugees since the 1990s.

South Sudanese refugees report ‘overthinking’, ethnic conflict, and child abuse as the most pressing concerns and challenges they face in refugee camps, followed by family separation, drug abuse, poverty and unaccompanied minors – all issues that have significant adverse effects on mental health (Adaku et al 2016, Tol et al. 2020). Unlike Bangladesh, Uganda’s refugee policy allows for an integrated approach to services, with refugees able to move beyond the settlements and use the same hospitals and facilities as the host population. However, in practice, South Sudanese refugees are unable to afford these costs, struggle to overcome language and cultural differences, or do not know where to go to get the help they need (Morof et al. 2014). Local mental health services in rural regions such as Arua are also limited, and not specialised to respond to the specific struggles that refugees may be experiencing. Refugees largely rely on the limited mental health services available in the settlements; under the UNHCR’s MHPSS strategy, interventions are scaled-up and are integrated into sub-sectors, rather than treated as a ‘standalone’ issue (UNHCR 2019) in the same way seen in Bangladesh. Yet with Uganda’s refugee response subject to significant underfunding, services providing general counselling are limited and specialised psychiatric services are largely non-existent, with over two-thirds of refugees in some settlements reporting being unable to access MHPSS at all (UNHCR 2019b).

## 1.4 Methodology

Recognizing that women and men’s access to mental health services may be affected by gender-specific barriers both at the community level and in institutional provision (Goodman et al 2004), our research was designed to focus on exploring cultural norms around mental health and gender. The semi-structured interviews with the Rohingya and South Sudanese

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<sup>1</sup> <https://gho.unocha.org/rohingya>

men and women explored the following: factors that influence their access to formal care; how they overcome barriers to care; local idioms and conceptualisation of mental illnesses; and community-based practices around treatment. Our research also engaged with service providers to explore how they are currently engaging with refugee mental health, their perceptions about gendered needs, practices and access, what challenges they experience in undertaking interventions, and what they understood to be the challenges facing refugees.

This collaborative research project was funded by UKRI-GCRF under Bath University's internal scheme. The team included research investigators from University of Bath (UK), University of Chittagong (Bangladesh) and Oxford Refugee Studies Centre (UK), and researchers from partner organizations – INCIDIN Bangladesh and Shepherds Associates Uganda. In both contexts, refugees were recruited as peer researchers. In Bangladesh, data was collected in one of the camps in Cox's Bazar district. A total of 30 qualitative interviews were conducted with adult men (15) and women (15) who had accessed formal mental health care practice. A total of 20 interviews were carried out with service providers (clinical psychologists, psychologists, medical officers, Mental Health focal persons, lay counsellors, safe space programme managers and community volunteers). In Uganda, fieldwork was carried out in two anonymized zones of Rhino camp in the Arua region. In total, 22 qualitative interviews were conducted with adult males (12) and female (10) who suffered from symptoms attributed to mental illnesses but who had not necessarily accessed formal support. A further 15 interviews were conducted by the Ugandan partner organisation with service providers equivalent to those who were interviewed in Bangladesh. Data collection was carried out between February and July 2020 and was disrupted due to the spread of Covid-19 and associated restrictions.

In the Ugandan context, two of the peer researchers were from the Dinka community and two from the Nuer community. In Bangladesh, data was collected by two Bangladeshi researchers who graduated from the University of Chittagong in Anthropology. In addition, five Rohingya refugees worked as research assistants. They were recruited on a daily basis as per the rules set by the camp authority. All researchers were trained in interview techniques and research ethics, and then participated in reviewing, expanding and translating an interview schedule. Ethical approval for the research was provided by the University of Bath and the relevant ethical protocols of the university were followed. Permission to undertake the research in Uganda was granted by the Office of the Prime Minister (Arua Branch) and UNHCR. In Bangladesh, permission to conduct the research was received from RRRC (Refugee Relief and Repatriation Commissioner) office in Cox's Bazar and also from CIC (Camp in Charge) office at the camp level.

Analysis of data was undertaken collectively by the research investigators in discussion with all the researchers involved in the team. Due to the differences in availability of formal services in the two contexts, there was a significant difference in the kind of participants we interacted with, and the type of data gathered- on access barriers to care. These led to variation in themes and findings that emerged through analysis. In Bangladesh, the scale of support is broader in comparison to the Ugandan context. There were 18 organisations (government, international and national organisations) that were carrying out diverse MHPSS interventions including specialised care in the Rohingya refugee camp in Bangladesh where we conducted our fieldwork. Two refugee researchers in our team had previously worked as volunteers in various organizations including health organizations. These made it possible to identify and



interview the Rohingyas who accessed formal care as was planned in our research proposal. Hence, the data gathered in the Rohingya context illustrated detailed information related to refugees' experience, perceptions and access barriers with regard to formal support. By contrast, the interventions in Uganda were very limited, and also people had little access to care facilities because of faraway locations. In most cases, the South Sudanese participants accessed formal care to address their afflictions only once or a few times, and then discontinued. They had comparatively limited experience with accessing the humanitarian mental health system, and in the context of limited interventions targeting mental health care in the camps the data they provided mostly concerned their own and community responses.

Studies reveal that diagnostic criteria, explanatory models, experiences and outcomes differ cross-culturally (Kleinman 1987). Littlewood (1990) also argued that the concept of selfhood varies across cultures; therefore, local categories and conceptualizations of mental illnesses may differ from Western psychiatric ones. Although our study focused on exploring access barriers, to contextualise people's practice and perceptions we explored local idioms and cultural ways of explaining the causes and experiences of illness. We began the interviews by asking how the participants feel inside to explore their narratives of sufferings. This conversation was followed by questions such as what the conditions they were suffering from were called in their languages, perceived causes of their illness, treatment practices and access to formal care. The following sections presents our analysis of both people's and service providers' views, practices and experience.

## **2. Mental Health Service Access in Displacement: The Case of the Rohingyas in Bangladesh**

### **2.1 Drivers of mental health problems**

Poverty or lack of money, shortage of food, poor living conditions (overcrowded living spaces and broken or shabby shelters), loss of home and land, lack of livelihood, lack of social networks, settling girl's weddings, insecurity or protection vulnerabilities, and uncertainty with the future are found as major stress factors among the Rohingyas. While some of these stressors, such as poverty and lack of livelihood, are found among the poorer population groups in both developed and developing countries, in the case of refugees these are compounded with structural constraints, disruptions, uprootedness and loss.

The Rohingya participants who developed mental health conditions after displacement (N=9) spoke more about their grief, experience of violence, worries and struggles in their present living conditions to describe their sufferings or factors that influence their mental health problems. A woman (48 years) participant stated, "I think about our home that we left behind. I try not to think but still I see our home in my dreams sometimes. My body trembles and I wake up to find that we are in a different place." Narratives from refugee participants frequently indicated feelings of yearning for home and land in Myanmar and helplessness due to the disruption of social ties, past social networks, and support of extended families, which were central in their pre-displacement life. Some repeatedly mentioned about violence in Myanmar and harrowing experiences when they fled.

The service providers often tended to homogenize people's sufferings and stated that while at the beginning, a higher rate of post-traumatic stress disorder (PTSD) was observed, in recent times, more people are suffering from obsessive compulsive disorder (OCD), depression and anxiety. The commonly expressed view by service providers was that women's mental health vulnerabilities, risks, and need for support were higher than those of men. The underlying causes of women suffering more mental health problems are domestic violence, demands for dowry, early marriage and pregnancy, fear of sexual harassment, sexual abuse and polygamy among men. Similar views were expressed in female group discussions. As one participant stated, "In Myanmar, there was no peace, but we had peace in terms of having sufficient food to eat and also within marital relations. Here, we live in peace (without fear of persecution), but many are suffering from '*bou-jamaier jindegani loyee oshanti*' (distress from not having peace in marital relation)". In Myanmar it was difficult to enter multiple marriages due to government prohibition. The number of polygamous marriages has increased since the displacement, as the rules about granting permission are flexible and measures to control such practices by the camp authority are often difficult to enforce for multiple reasons. The women participants who had daughters feared for their daughters' security because of the increasing incidents of kidnapping and trafficking. On the one hand, getting their daughters' marriages settled is considered very important given the insecurities due to their changed living condition; on the other hand, as their property has been lost and social networks of support have been disrupted, in displacement they feel at a loss with arranging marriages and dowries. None of the women participants were involved in any livelihood activities. Women were engaged in household work in their everyday lives in varying degrees, and not being able to perform daily chores properly because of their illness was a major concern for most of them, as they feared this would eventually result in being devalued by family members.

Women participants also emphasized the impact of violence induced by community leaders on their mental health. Three women participants described the effects of injustice and unfairness on their mental health after being verbally and physically abused by community members. Their narratives highlighted that ensuring people's access to authority to claim justice in cases of violence within community is important for protection and people's agency. Feelings of insecurity, fear of harassment, conflict within the community ('no harmony among the Rohingyas'), not knowing '*rasta-ghat*' i.e. ways of seeking support or where to seek support were also mentioned by women as underlying causes of their distress. According to the service providers, violence induced by the armed groups inside the camps are sources of fear and sleeplessness for both men and women.

Among men, those who had mental health conditions prior to displacement (N=11) were all engaged in different types of livelihood activities (farming or small business) and performed household responsibilities within a joint family structure. One male respondent (25 years old) who has been suffering from an illness since his childhood stated, "In Burma, I used to go to work in our paddy fields. I used to tend cows, goats, and chickens. I took care of our cattle shed." They contributed to their family labour and income, which was valued. After displacement, loss of their livelihood resources, lack of livelihood options and exclusion from livelihood opportunities appear as major problems causing distress to men. When we interviewed them, most men were working as day labourers on an irregular basis.

Men's mental health was adversely affected by unemployment and limited work opportunities, internal conflict-related violence, restrictions on mobility by the authority, uncertainty about repatriation, and any changes in the political situation that would impact their future. According to the Rohingya researchers and service providers, obtaining justice for the violence and displacement that the Rohingyas endured has mental health implications for the whole community. However, as men were more involved in political organizations, and they took part in meetings, campaigns and mobilizations, their concerns for repatriation and justice were explicit and communicated. A 48-year-old man stated, "I keep thinking about the future of our children and what we left behind us. We have demanded justice at the *duniyar adalat* ('worlds' court' meaning International Court of Justice), but we are worried as we still don't know what the outcome will be. It's been more than 3 years that we are living in Bangladesh! All these years we have been hoping that people of the world would help us so that we get justice and can go back to our land." Being repatriated to live in resettlement camps when their goal was to get back to their villages and homes was mentioned by men as a key concern. Men also experienced distress because of their loss of social status within the community and the loss of their traditional roles and authority within their families due to not having income-earning activities. To illustrate this, one Rohingya man made a statement which sounded ironic but powerful in communicating their predicament: "In Myanmar, there was peace as we owned a lot of land. We grew crops and earned enough. Here, I have to stand in the queue for food. I am nobody here".

## 2.2 Treatment Seeking Behavior and Practices

### Traditional and informal medical care

In the Rohingya language, mental disorder or illness is termed as '*demag er beram*'. '*Demag er beram*' includes conditions related to *demag* i.e. head or brain (for instance, *demag/matha khorof* i.e. spoilt head, *demager komti* i.e. suffering from having a weak brain), conditions attributed to mind or *dil* (such as *dil-or shirshiani* i.e. sensation of tremble inside, *dilor o-shanti* i.e. not having peace in mind, *dil-or pereshani* i.e. tension or worries) and conditions related to the soul i.e. *foran/mon* (such as *foran tontonai* i.e. heartache or yearning). One woman participant (47 years old) stated that she was abused by her husband and in-laws for years: in the beginning, for not being able to give them the dowry money; and later for being childless. She stated, "It was because of all those tortures that my head became 'short'. People with such a condition are called 'phaul' (mad). In the Burmese language this condition is also called 'aru'." Some also used the term *pet pura* which literally means belly-burn, but it is used to express the feeling of yearning, missing a place or a person intensely or longing for some place or someone. As such, people's narration of suffering reflects a complex interrelationship between mind, soul, body and head in defining mental illness. Our data align with Riley et. al's (2017) findings that the body-mind divide is not obvious in traditional ethno-psychological concepts of mental illnesses among the Rohingyas in the way it is recognized in the dominant western models in psychology.

Most of the participants (21 out of 30) reported as suffering from *demag er beram* or distress prior to their displacement. Apart from cases where mental illnesses were linked with physical torture induced by the Myanmar authority, domestic violence and accidents or injuries (N=8), mental illness is commonly attributed to spiritual causation and sorcery. However, two or more

models of explanation are often held simultaneously in explaining one's illness. For instance, a Rohingya woman (35 years old) stated that she fell ill worrying about raising her seven children after her husband died, and also because of being possessed by *jinn* (a supernatural entity).

In all but one of the cases, the Rohingya respondents sought community-level services which include the traditional healers known as *baidya* and religious specialists known as *hujur*, *fakir* and *peer*. The *baidyas* perform some rituals such as '*haat boshano*' to find out causes of the illness among the service seekers. They usually give *jhar-fuk* in which they recite verses which are then blown on the breath in the direction of the service seeker, and amulet to counter or remove sorcery and spirit possession. Apart from performing rituals, giving amulets and sacred water/oil/sugar, the religious specialists also often provide religious guidance and advice on varied aspects of managing everyday life including eating patterns, hygiene and interacting with others. In addition, a few male respondents joined *tabligi* (a group dedicated for Islamic mission) and went for '*chilla*' i.e. a religious practice of meditating and praying in solitude for 40 days, which appears to be a coping strategy and an endeavor to get healed.

Most of the respondents (18 out of 30) consulted a 'Rohingya *daktor* (doctor)' or '*Burmaiya daktor*' who run pharmacies and prescribe medicines without having formal training or a licence or permission from the authorities. The majority of those who accessed the services of the 'Rohingya doctors' reported that they received treatment for chest burn, pounding heart, gastric problems, and pains in the neck or shoulder. They found the treatment effective and expressed interest in continuing to access it if they could afford it. The financial cost of accessing services from traditional, religious and untrained medical service providers ranges from 50 to 10,000 taka based on our data. The cost of seeking informal care was found to be a burden since lack of income has been mentioned as a major stress factor.

Our findings also suggest there is no linear pathway from traditional healers or informal practitioners to a formal mental health care system. In the case of the previously mentioned Rohingya woman who was a widow with seven children, she was first taken to MSF hospital by her neighbours after she fainted. After she was released from the hospital, she received treatment from a *baidya* as her neighbours thought she was possessed by *jinn*. Later, her neighbours raised money to take her to a 'Rohingya *daktor*' who gave her a saline injection and some medicines. When we interviewed her, she was accessing mental health services from a formal health care facility and also from *baidya* and *hujur*. She thought the Rohingya doctor's treatment was very helpful, but she could not afford to continue further.

Only 9 (2 male and 7 female) respondents were using humanitarian MHPSS exclusively at the time when they were interviewed, which underscores the importance of community-level service providers. Mental health professionals thought that seeking treatment from traditional and religious healers did not conflict with formal care practices. They refrained from discouraging their patients to access community-based services because such practices might make people feel stronger inside. However, the formal care providers did not reflect and seek to understand whether and why these services could make people feel stronger, i.e. the meaning and impact of such healing practices in the community.

With regard to the Rohingya doctors' treatment practices, overprescribing certain medicines and use of psychotropic injections, locally known as '*dabai mara*', are regarded as harmful by

the service providers. Moreover, according to a community volunteer, the availability of such services makes it harder to motivate people to continue with formal treatment procedures which require multiple visits to health facilities over a longer period.

### Formal Care: Support and Services

The types of formal services people have accessed are specialized care (psychiatric care, psychotherapy and counselling); psychosocial support services in safe spaces or *shanti-khana*; and group sessions on psychosocial education and managing distress provided by the community outreach volunteers at the community level. Almost all respondents (29 out of 30) accessed multiple health facilities (between 2 and 3 facilities) run by humanitarian agencies at different times or simultaneously to find appropriate treatment, or to be referred by service providers of different sectors. Only one male respondent accessed psychiatric care facilities at the government district hospital through the referral system established among the camp authority, humanitarian and government health facilities. The majority of respondents stated that the medicines prescribed by the doctors help them to feel calm and 'at peace' and sleep well. In most cases, service seekers described their experience at the facilities and interactions with providers as straightforward and helpful. It is important to mention that when asked about the problems or obstacles faced at the facilities, the Rohingyas often responded with a feeling of gratitude for the relief and support they were receiving rather than indicating any gap right away. For instance, one-woman respondent (30 years old) stated, 'We are receiving a lot of help and cooperation. I am getting free medicines. From where I would get money if we needed to pay for the treatment?' As we noted that expressing gratitude was also considered appropriate by some participants, we often needed to rephrase our questions and probe more to find out about the gaps.

Some reported their relationship with the family members changed positively since they started 'going to the doctor'. Both men and women found the assistance provided by the volunteers was helpful in receiving services from health professionals. The volunteers' visits to the service users' homes to explain the treatment process, prescribe directions and remind about the next appointment are valued.

All women respondents accessed psychosocial support in women-friendly or safe spaces. Most reported finding individual or group sessions, where they focused on managing everyday chores and disturbing emotions, to be helpful. Women reported attending with neighbours and relatives, which made such spaces more accessible and friendly. Attending group sessions was also recognised as beneficial in enhancing social support systems and knowledge about important aspects of camp life. Displacement causes disruption in the social fabric, but several cases show that new forms of social ties and mutual support that have developed over time are helpful. One of the woman participants (45 years old), who had been abandoned by her husband and sons, was largely being taken care of by her neighbors. Her next-door neighbors were a young couple who did not know her before displacement. They stated, "She only has a brother who lives in a faraway camp, and he asked us to take care of her. We take care of her like our own aunt because there's no one else around who can support her. She is alone." They fed her on difficult days, knew which health center she went to and also knew about her medication.

Compared with women, the availability of safe spaces for men was found to be limited. Considering that men have better access to public spaces (mosques, local bazaar, etc.), community-level psychosocial interventions have been more focused on addressing women's needs. However, our data suggests that access to such public spaces is challenging for men who have mental health conditions, as it potentially exposes them to verbal and physical abuse.

### 2.3 Accessibility to Mental Health Services

The analysis of people's accounts reveals the following as the major barriers in accessing services:

#### Financial Barriers and Poor Health Conditions

As psychiatric care is available only at limited health facilities, which were far from the camp where the respondents resided, the major barrier to accessing such services was arranging for transport costs. In cases where the health centres were close by, the main challenge reported remained physically getting to the centers, as some service seekers suffered from physical problems. Besides, lack of strength or energy, lack of motivation and fear were reported as challenging to overcome for many. A woman respondent (25 years old) stated, "I feel scared to go on the road and ride a 'car' (*tuktuk*). I do not want to go to hospital for that. At the hospital I feel scared and feverish too." A majority of the service seekers identified long waiting times in the queue to see the doctor as a challenge. One male participant (35 years old) stated, "They (service providers) say that I will get cured if I take medicines regularly. But I find it painful to sit and wait for so long to see the doctor at the hospital. I start getting pain in my back. It is because the military (in Myanmar) broke my legs and back while I was in jail." He also felt restless, nervous and weak while waiting at the health centre. Some reported even after waiting for hours, the people at the center would not listen to their request to see the doctors sooner.

#### Lack of Support

For most service seekers, the support of caregiver/s was mentioned as vital in accessing formal service for multiple reasons, such as having difficulties in remembering the locations, not being able to take care of the money to pay for the transport, and to keep doctors' prescriptions safe. Moreover, in cases where the service seekers are on medication, as most medicines are not handed over to them for safety reasons, being accompanied by an adult caregiver or support person is crucial. One female service seeker (45 years old) stated that once when she went to the hospital accompanied by her 10-year-old son, the doctor sent her away without giving her medicine saying "Why have you come with this small boy? Can't you bring anyone else in your family?" She felt humiliated and never went to that hospital again. Although she had three adult sons, a daughter and daughters-in-laws, she said none were willing to take her to the health facility. Her case shows that the lack of necessary support from the family acts as a barrier in accessing services. Also, the experiences at the health centers matters. Few participants, particularly those with lower levels of support from family members, expressed worries about being scolded by the service providers for not keeping their papers

(prescriptions) organised, not bringing anyone with them or being early or late to an appointment.

According to service providers, the stigma associated with accessing mental health service, which in local language is framed as “going to the ‘*phaul khana*’ (mad house)”, negatively impacts people’s lives and influences their decision to access formal care. However, most service seekers did not consider this stigma as a barrier in seeking mental health support. In most cases, the people around them knew about their illness, and accessing formal treatment did not make any difference in social interactions and relations. One male participant (48 years old) stated that community people encouraged him to seek services. However, there is stigma associated with having mental illness, which makes people feel isolated and humiliated, and bars them from enjoying a good social life. For instance, some reported that it was difficult to arrange marriages for their children. A young woman (20 years old) stated that because of her illness some neighbours considered her ‘unclean’, and she felt angry and isolated because of that.

## 2.4 Gender Dynamics In Accessing Formal Care

Women often face difficulties in accessing services because of their household and care responsibilities. To continue to access services, it was important that women were ‘not being late’ to return and still having meals prepared on time. They reported facing more disregard of their mental health condition and non-recognition of their sufferings from family members than men reported.

While in the case of all but one married male respondent, the wives were their main caregivers and involved in accessing and managing formal treatment practices, women usually accessed services with sons, brothers, sisters-in-law, nephews, neighbours or volunteers. A female respondent stated, “The doctor told me to bring my husband to the hospital a few times, but he (husband) refused.” However, husbands’ decisions matter in shaping access to care. One female respondent missed her doctor’s appointment on the day we interviewed her, as her husband forbade her from going with the community volunteer, despite the volunteer being a woman. Not having any adult male family members or ‘not having a son’ adversely influenced women’s access.

Service providers mentioned certain cultural practices and religious norms, dictating strict adherence to women’s *pardah*, i.e. veiling and linking it with family honor and religiousness, restricted Rohingya women’s mobility and access to services. Community volunteers also suggested that women’s participation in community-level interventions are also controlled by religious leaders and political actors such as members of armed groups. Service providers who supported women facing gender-based violence observed that often women do not seek support because of the societal norms dictating a certain level of tolerance. Women also fear the consequences of speaking up from their family members and societally.

While ‘conservativeness’ within the community was identified as a barrier for women by the service providers, we found mixed opinions regarding women’s participation in varied interventions. One psychosocial support officer at *shanti-khana* stated, “The girls come on their own these days (without requiring much community outreach activities). The Rohingya



girls who have never interacted with outsiders in the past now know how to introduce themselves to a stranger like you. Our service seekers have gained a lot of self-confidence and esteem. The negative attitude in the community about girls going out to undertake training or education has been changing”.

Men find it difficult to access and continue taking formal care because of their livelihood activities. According to one service provider, “Men are difficult to reach. They go to different places for work and other purposes. Therefore, we face problems in engaging with men while conducting community-level sessions to provide psychosocial education and identify those who need help to bring them to formal care. Also, men are less likely to seek help.” According to the service providers, the wide scale mental health challenges faced by men are often revealed through violence or substance abuse.

## 2.5 Existing Gaps and Challenges in Service Delivery

Most of the specialised service providers with whom we conducted interviews work in organisations that link mental health support with other support such as primary health care, skill training, gender-based violence and other protection issues, education, maternal health and child nutrition. Service providers at all layers of the pyramid thought that significant improvement has been achieved in establishing a more comprehensive support system since the initial phase of providing humanitarian assistance. In discussing the evolving nature of their interventions and strategies, a psychologist working at a UNHCR partner organization stated, “As the Rohingyas are adjusting to the situation, their needs are changing. We are also adjusting the services we deliver and our approach to align with changes. We have introduced sessions on anger management as there is an increasing number of cases of domestic violence and interpersonal conflicts. We are also introducing group sessions for Rohingya children.”

According to service providers, these interventions have received positive feedback from the community level group sessions. However, it is important to note that at the time of the fieldwork, there was limited knowledge about the effectiveness of mental health interventions, as no impact assessment or systematic evaluation study was available. Moreover, the processes of designing interventions were not based on any research examining or assessing the need and largely followed a top-down approach. According to service providers, strategies and pathways of delivering and receiving services were effective, though not adequate. Apart from funding and resource constraints, the following gaps and challenges in providing services were highlighted by the service providers.

### Language and Cultural Barrier

Although the language barrier has also largely been overcome through working with Rohingya volunteers as interpreters, a few providers raised concerns over the impact of this practice on treatment outcomes and the maintenance of client confidentiality. Moreover, while most service providers have gradually improved their understanding of Rohingya terms regarding distress and mental disorders, it was acknowledged that emotions are difficult to translate from one language and culture to another. The importance of adapting psychological assessment



tools and treatment processes to local terminology and culturally specific concept of illnesses has been underscored by service providing agencies (UNHCR 2019). According to the service providers, although workshop and training materials have been adapted to Rohingya language and needs in most cases, a gap has remained in assessing mental health conditions, as culturally appropriate scales are not available.

### Barriers Related to Perception and Mistrust Towards Formal Care

People's attitudes and perceptions can also constitute barriers to care, leading to the underutilisation of services. Some participants reported that the formal care providers did not acknowledge or give adequate attention to their real problems and difficult life circumstances, which made them feel frustrated and question the relevance of their care practices to their needs. For instance, a male participant (30 years old) stated, "The doctor tells me 'not to worry' and 'not to feel tension'. How can I not worry? I have no work here and I don't have my father and brothers with me (nearby)". Then he described the physical problems for which he said that the doctors did not give any medication. He thought that was not helpful and stated, "He (the doctor) does not understand my problem".

Mental health professionals also highlighted that people suffering from mental health conditions often came to facilities with somatic complaints and wanted to get injections or medicines. Meanwhile, therapy or counselling sessions, according to one service provider, were considered as '*bayobio*' (insubstantial) by many mental health service seekers. More males (N=8) reported frustration with the services than females (N=2).

To sum up, people's narratives showed that frustrations arise due to the discrepancies between how they define their illness, how they perceive their treatment needs and the services they received at mental health facilities. For instance, a 31-year-old male respondent who was seeking treatment at a psychiatric facility stated that he suffered when his 'head gets worse' and 'madness arises' in him, and he thought that in order to get healed he needed to have an x-ray of his belly performed, since his illness started when he was hit in his belly by his brothers in a fight. He further stated, "If at the hospital they do not take an x-ray next time to examine my problem, I will stop going to the hospital." Apart from a perceived lack of diagnosis through x-rays or other medical tests, some thought that they were not given adequate or appropriate medicine because hospitals do not keep stocks of the medicines, and even if they had it in stock, they give it out sparingly. One 70-year-old man stated, "They don't give injections, only give small tablets like quinine which don't work".

According to the service providers, 'misperceptions' and mistrust arise due to certain psychological conditions and because of the Rohingyas' 'lack of education' and 'lack of understanding' of formal mental health care practices. It is common to explain refugees' mistrust and underutilisation of humanitarian health care system as due to a lack of knowledge and reason and tackle it through education campaigns and marginalisation of traditional healing methods, while not paying attention to historical, political and cultural factors (Steinke and Hovelmann 2020, Miller and Rasco 2004). For instance, Miller and Rasco (2004) argue that one of the reasons for under-utilization and non-adherence to formal mental health care among the refugees is because of the difference between the western biomedical model and the cultural understandings of the refugee groups. In the Rohingya context, although the cultural differences in explaining and experiencing illness was recognised by the service

providers, none of them mentioned the necessity of learning about those differences and bridging the gap between cultural and biomedical interpretation when discussing mistrust, somatization, perceptual barriers and underutilization. Overemphasis of the Rohingyas' 'lack of knowledge' by the service providers showed the lack of attention and the gap in constructing a culturally sensitive health system, which according to Ong (2003) requires not only considering cultural differences but also revising medical knowledge.

### Structural Barriers

Provisions for psychiatric and hospital care were considered inadequate by the service providers. According to service providers, shortages of psychiatric drugs and specialised practitioners to supervise other psychological and health professionals in prescribing drugs were identified as gaps in the existing care system. Moreover, although it was recognized that supports provided in other sectors in the humanitarian context can contribute to improving people's mental health, it was reported to be difficult to coordinate responses and deliver services in a complementary way across sectors, largely because of the time and work pressures.

## 2. 6 Marginalization, Inequality and Mental Health

Both refugees and service providers reported that people with mental health conditions experience exclusion, discrimination, stigma and violence, resulting in not only emotional distress, but also deprivation of dignity and human rights. Women reported experiencing marginalisation and stigma in the form of being ignored, living in fear of being abandoned (2 cases) and abandonment (2 cases). One female respondent (36 years old) spoke about feeling humiliated: "People tell him (husband) that if you go to the CIC (camp-in charge) office taking this mad woman with you, you will easily get permission to marry another woman." What was hurting her the most was that her husband was regularly beating her up and keeping her chained, but her children never protected her as if she "never carried them in the womb and raised them". Male respondents faced exclusion from livelihood opportunities available at the camp as the *majhis* (community leaders) reportedly never listed their names for jobs, saying that they are not fit for work.

A total of 10 respondents (5 male and 5 female) had experienced violence after displacement. This finding highlights the need to address safety and security concerns of those with mental health conditions. Most males were teased and verbally abused by community members for being '*phaul*' i.e. 'mad'. Three women reported experiencing domestic violence repeatedly. Two women who were beaten up by community leaders (*majhi* and a religious teacher) referred to feeling powerless, and saw being a woman and being poor as the reasons why they faced abuse and injustice. Poorer individuals had limited knowledge about the political organization and administrative system in the camp setting, and had limited access to resources, authority and justice. Our findings suggested that limited access to authority to seek justice and protection affects people's mental health and vulnerability.

## 2.7 Key Findings

People's narratives reflect multiple barriers to accessing services and seeking help for their mental health difficulties, including physical and cost-related barriers, cultural barriers, informational barriers and poor health conditions. Some also believed that their difficulties should be treated with medication or diagnostic tests, creating a gap between their perception of what is needed and what is available at the service (e.g., counselling-based psychological support). In dealing with barriers, family composition and kinship ties, economic condition, family members' educational level or having employment at any humanitarian agency are factors that have a significant impact on care seeking. The important role played by the family and other community members in caregiving needs further recognition and emphasis while designing psychosocial education and awareness raising programmes to enhance their motivation and support.

Gender roles and norms shape mental health vulnerability and accessibility in multiple ways. Women often reported facing difficulties in accessing services because of their household and care responsibilities. Women also face more disregard for their mental health condition, and non-recognition of their suffering by other family members than men do. While men mostly receive support from immediate family with regard to accessing services, in a number of cases, women's access also depends on extended families, neighbors and volunteers. Although drug abuse and violence (at both community and domestic levels) are linked to men's mental health needs and explained as negative coping mechanisms, health care agencies put less attention on addressing men's mental health vulnerability, with men having poor access to psychosocial support services.

Local understanding of mental illness is deeply rooted in religious and cultural beliefs and practices. The existing mental health delivery system shows an enormous gap in integrating knowledge about culturally specific ways of experiencing and responding to mental distress among the refugee population groups. Such knowledge and endeavours are important for identifying and developing community strengths and resources (Miller and Rasco 2004). Besides, cultural ways in narrating and addressing mental health problems among the Rohingyas pose challenges for service providers in engaging with their clients more effectively. This highlights the need to strengthen knowledge about ethno-psychological conceptualizations among the providers as well as including local knowledge and resources within the formal care system.

The Rohingyas have maintained their reliance on traditional and untrained medical service providers whose services they sought prior to displacement. Despite the widespread practice of seeking treatment from 'Rohingya doctors', the risks associated with such treatment practices and how they influence people's engagement with formal care are not adequately discussed at the level of humanitarian agencies. Inequality and violence increase mental health vulnerability, and these also affect treatment outcomes. There is differentiation among the Rohingyas based on their economic condition and their relative power. Lack of livelihoods and income are both stress factors, and limit poorer group's ability to draw on social support, networks and knowledge to gain access to formal interventions.

The community volunteers are a valuable source of knowledge about local beliefs, practices and social norms, and they also transmit feedback from service seekers. Their services are

particularly crucial for women, as some women cannot access or continue to receive support if the volunteers do not take them to the facilities. Their ability to enhance people's access and engagement with formal care derives from their knowledge and experience of working at the intersection between the Rohingya worldview and biomedical models of psychology. There is limited systematic evaluations of the mental health services that are being provided by agencies. Also, there has been limited research to assess the prevalence of mental illness and to explore mental health vulnerabilities and needs in the community.

### **3. Mental Health Service Access in Displacement: The Case of South Sudanese Refugees in Uganda**

#### **3.1 Drivers of Mental Health Problems**

Almost all refugees linked their mental health problems to their experiences during the civil war in South Sudan, though two refugees also mentioned struggling earlier in life, prior to being displaced. Triggers of mental health problems described by refugees included personally experiencing and witnessing violence and the torture and the killing of neighbours and family members. One male respondent told researchers -'the doctor said I have some mental problems which developed at the time when the rebels killed my parents. I saw it and it tortured me.'

As well as bereavement, family separation and distress about the war, refugees point to challenges around poverty, poor living conditions, and lack of livelihood opportunities as a source of distress during everyday life in displacement. There are also fewer opportunities available to either engage in agriculture to feed families or to earn money in comparison to Sudan. Not being able to communicate with relatives who they

left in Sudan and worrying about them were mentioned as major stress factors. 'The reason why I said the life in Uganda is not good is just because it is fine you will get the food and you feed on, but the stress is still there. You can't forget because you think about Sudan ...about your relatives- brothers etc. because you're at the camp without families and that will make you not have rest in your heart' said a 35-year-old woman diagnosed with stress, who had been in the camp for four years. Continuous fighting within communities was also identified as a major risk to the mental health of the refugees by the service providers.

#### **3.2 Treatment Seeking Behaviour and Practices**

##### **Traditional Treatment**

Eight of the 22 respondents had been diagnosed by a health worker or doctor as having a mental health problem or disorder. One male respondent described having been told he had a problem with his head that required treatment. Two older male respondents had been to a traditional healer when they first felt unwell due to concerns that their feelings were a sign of possession by evil spirits. One had been a businessman prior to 2017, but then lost all his money during the war; the other, a single parent, had begun to struggle when his mother

became too frail to help him with caring for his children. One received some herbs from the traditional healer to treat his condition. All the other respondents stated that they had never seen a traditional healer about their mental health, with one of them referring to such healers as 'witch doctors'.

Despite only two respondents referring to visiting traditional healers, however, the words in Juba Arabic, Bari and Dinka used by refugees to describe psychological suffering are much more nuanced than the diagnoses of 'mental disorders' supplied by treatment providers. There were several different words used by refugees to describe their condition in their own language: these included words that denote stress or worry such as 'irifu' and 'amayi', terms such as 'jin' that point to spirit possession and evil, and more neutral terms for mental health problems such as 'yeyesi'.

Many more refugees reported going to their church for counselling, prayers and other support with their mental health than to formal treatment providers, echoing findings by Adaku et al (2016) and Storer (2017) on the important role played by South Sudanese church leaders and elders in administering social and emotional support in Arua. This type of support was spoken about positively because of its accessibility and availability - but it also offers cultural propriety and familiarity. Many refugees said that if they had a friend in a similar situation, they would help refer him or her to the church leaders because they had helped them with prayers, encouragement and other emotional support. This was also noted by respondents to reflect what would happen back in South Sudan if someone showed signs of mental health problems.

#### Formal Care: Support and Services

Counselling was the most widely reported treatment refugees had received. Advice received by refugees from mental health professionals on how to cope with their mental health condition included to avoid drinking alcohol, engaging in negative talk, being in isolation or in groups which would remind one of the past. One refugee was advised to share happy moments with loved ones. One 24-year-old man said that the health worker he saw encouraged him 'to avoid stress and stay with my friends, avoid drinking alcohol and smoking cigarettes and avoid negative talks.' These recommendations are however limited in assisting people in overcoming the trauma they have experienced, given that they do not necessarily account for the ongoing reasons that people may still be feeling depressed or hopeless in the present. Only one refugee reported receiving mental health medication.

One woman aged 29 whose husband had died of AIDS and left her living with the virus and having to care for their children alone was given encouragement by a doctor she saw at the clinic. He told her that her poor mental health, whilst distressing, would not be able to kill her, and she had taken solace in his assurance to keep going. 'If I die now who will take care of my children? He started encouraging me that if I am taking medication and taking care of my children nothing can happen to me. That's the thing that made me be strong today.' This emphasizes the way that feeling cared for and supported helped respondents to cope. The quotation also illustrates the power of the idea that one should 'keep going' for the sake of one's children as a motivator for continuing with life as it is. However, 'coping' through a focus on the present can also be a distraction from the unavailability of opportunities to actually address and reconcile trauma.

A particularly interesting finding is that all except one refugee received counselling through their church, rather than a formal provider. Many refugees also mentioned going to neighbours or other community members for support with their mental health. It should be noted that 'counselling' is often used as a general term to refer to advice and support rather than psychotherapy specifically. However, the emphasis placed by respondents on churches, neighbours and community members as their primary source of advice and help with coping rather than formal treatment providers reflects findings elsewhere in the literature as to the significant role of community-based networks of mutual support. This is often overlooked within the design of mental health services. Two male respondents said that they had stopped using formal mental health services and now only sought support from the community. One mentioned waiting for medication for two months but not receiving it, and so gave up and stopped going to the health centre; the other had left because their doctor changed, and they got a new provider who they felt did not understand their problem.

### 3.3 Accessibility of Services

Refugees reported a number of challenges in accessing treatment. These included the distance from the camp to the health care providers, a lack of money to either pay for transportation to a health centre or to buy medication if it was prescribed, and unavailability of medication. 'There is need to improve on the services and I would recommend that drugs for our mental health conditions be available at all times and doctors should come visit us,' explained a 35-year-old man who suffered trauma during the fighting in South Sudan and had been in the camp for five years. Another man, aged 32, who had formerly been a businessman but had become incapacitated and unable to work due to his condition stated-'It's not easy to get transport when I don't have money and some drugs that are necessary may not be at the health centre which I need to buy' he explained.

Furthermore, people expressed communication challenges between themselves and doctors, and poor quality of services, including unhelpful doctors who do not understand the nature of their problem or provide appropriate care. A 29-year-old woman who used to be a businesswoman and farmer but has been alone in the camp for three years and relies on food aid, told researchers: 'Sometimes you will go to the hospital and you will not find the doctor and you might go there from morning up to evening and that really makes me feel bad and sometimes you will be staying without food but if the doctor is there you will get the medicine.'

### 3.4 Gender Dynamics in Accessing Care

Most respondents (N=15 ) felt there were differences in the problems of women and men. Some felt that women had an easier time in the camps. Mentioned frequently (more than three times) was the idea that women are given more support than men by agencies (e.g. sugar, sanitary items) and this makes life easier for them. Another respondent said that women are helped quickly when they become pregnant. However, some respondents, particularly women themselves, felt that women take things more seriously than men, and 'overthink' (in the words of some participants) and worry more. In terms of care and support received within the family, one respondent felt that men do not understand women's mental health problems.



However, there are also indications within the data from both service providers and from refugees that men are seriously struggling, yet the outward symptoms of their condition may actually further marginalise them from support. Four respondents mentioned that men become violent when they are mentally ill. This symptom of poor mental health is not interpreted as a symptom of vulnerability and men's need for support, reinforcing fears of women being at higher risk instead. In contrast, one respondent mentioned that men are calmer than women when distressed, which may also feed into assumptions that men are coping better and are less in need of support.

Connected to this was the suggestion by some respondents that men's coping mechanisms are destructive; for example, as one woman noted, 'women take food and feed their children while men end up selling the items and drink alcohol.' This may be a coping mechanism - but may lead agencies to be averse to helping. Indeed, refugees noted that gender dynamics have been substantially altered by displacement; women have become the breadwinners of families where their husbands have died, and men struggle with their role in the family because of the lack of work opportunities and dependence on UNHCR, whose policies have also played a part in shifting household responsibilities. Women are also given food allowances rather than male heads of households – as one refugee woman whose husband had died observed, 'women get more things than men (in the camps) because women take care of the children'.

### **3.5 Existing Gaps and Challenges in Service Delivery**

There was no specific organisation that took on mental health service provision for implementation among the refugees. Only six out of fifteen service providers had some specific component of their services targeting mental health cases while the rest were adjusting to offering psychosocial support because of the need and seeing that some of their activities were affected due to trauma among the refugees. Some of the service providers primarily targeted children where there were cases of mental health involving their parents. Such cases were referred to other health partner organisations while they took care of the children. Organisations also deal with GBV issues among the refugee communities, conduct sensitisation among the communities about mental health and provide psychosocial support and basic counselling. They have links with churches and use 'role model families' to guide the communities in counselling services. Role model families are selected by organisations from among families with children and with positive standing in the community; the adults of the family act as peer mentors to help struggling families to cope.

Amidst the service delivery to the mental health patients, the service providers perceive that a common challenge and obstacle to accessing mental health services are the cultural differences between South Sudanese refugees and those working from a MHPSS perspective. Service providers felt that some refugees believe mental health is a curse hence can't be treated, while others believe it is demonic attack for which they need spiritual interventions or the use of herbs from witch doctors. These beliefs are perceived to make refugees less likely to attend mental health services. As one service provider stated 'Due to traditional beliefs many of the refugees first rush to these people (healers) for help. Once they fail then they come to the facilities as a last resort. By then the patient's condition may have worsened.'

Limited funding to deliver adequate services and limited availability of both specialised and non-specialised care providers were also identified as major challenges. Service providers noted that delays in supply of drugs for mental health treatment to health centres - as UNHCR policy is that “no refugee is to buy drugs” – have made it very difficult to support patients. This lack of medication availability and understaffing by specialised service providers are recognised by service providers as factors that make refugee patients give up and depart from care facilities without being attended to – a perverse outcome of a policy intended to protect refugees from drug abuse.

Service providers also experience difficulties in maintaining contact with refugees once they are diagnosed with mental health conditions. Some tend to ignore directives for treatment, while others move away from the refugee camps due to stigma and delivering services to them becomes a challenge. Accessing the clients is hard, not only because of transport challenges, but because of the mobility of refugees, who move around to pursue livelihood opportunities. According to one service provider ‘...they move a lot, there are moments you make a follow up on the patients by the time you get to their homes you find they are in Sudan or have moved to some other camps.’

### 3.6 Key Findings

Refugees’ preference for turning to others in their community for assistance indicates that support for and investment in community-based mental health initiatives may be an effective way to overcome practical obstacles to treatment-seeking and adherence such as communication barriers and distance from service providers.

Service providers may however currently misunderstand the drivers of this preference. It is important to note that only two refugees mentioned attending traditional healers, with the majority stating that they would not pursue this as an option – though it should be noted that these beliefs are frequently stigmatised and the presence of refugee peer researchers may have prevented disclosure of such practices. However, belief in curses and witchcraft was repeated by providers as being a major obstacle to refugees’ engagement with formal MHPSS services. More research may be necessary to explore whether refugees’ beliefs about the causes of mental health problems affect their engagement in treatment.

However, a much more common theme in both service provider and service seeker interviews, and one that can be more practically addressed, is the enormous limitations to those formal services which are available, with this deterring refugees’ access and consistent use. A more holistic approach by service providers which considers spiritual as well as medical needs would reflect both the ways that refugees think about their mental health difficulties, and the broader networks of support that refugees turn to within their communities, without introducing stigma and judgment around why people think that they become unwell.

Mental health challenges may be triggered by the trauma of conflict and displacement, but they are exacerbated by poor quality of life in humanitarian settings; in less severe cases, better livelihood opportunities can help refugees to rebuild their mental health. This is particularly the case for men, whose status in their families and communities have shifted in ways which are highly deleterious to their self-esteem and can lead to behaviours that not only



worsen their own mental health, but harm their families too, including turning to violence, alcohol and drugs.

Indeed, gender shapes both coping mechanisms and care-seeking behaviour; vulnerability and distress may therefore look different for men and women. Training for service providers must integrate a gender lens, and gender-adapted community outreach and services are needed to destigmatise mental health problems amongst men. With humanitarian assistance focused on addressing household (and largely material) vulnerabilities through women, who are then more likely to interface with agencies, men's mental health and service use remains particularly overlooked.

## 4. Recommendations

### Improving Service Integration and Coordination Between Humanitarian Agencies

Given that refugees engage with a range of humanitarian actors, it is essential to mainstream mental health awareness across all agencies and develop robust referral systems for those who are not aware of or are prevented from directly accessing psychosocial support services. In both Uganda and Bangladesh, the most economically deprived refugees encounter the greatest difficulties in accessing information about services and should thus be a particular target of any strategy; yet clinic-based interventions are limited and inadequate, with the distance and cost of travel to centers impeding the search for support.

A clear and coordinated strategy among agencies providing clinical interventions for distributing such services across camps, and stronger communication networks for delivering information about available specialized care services in the 'field' or at community level, can help to improve coverage. Building a centrally accessible database of mental health cases for easy follow-up and tracking of patients in case they move to other locations or access services from multiple service providers, at the same time equipping the nearby health centres with qualified staff to handle mental health cases and making the relevant drugs easily accessible to the patients, will be of great importance.

To effectively support refugees' mental health, various services and supports need to be complementary and interlinked within a coherent system. Mental health interventions need to go along with protection services and livelihood interventions among many other sectors. To prohibit violations of the human rights of people with mental health conditions, all agencies within and beyond health need coordinated effort, and a system of monitoring must be established at the community level. To improve the overall wellbeing of the population groups and to ensure positive treatment outcomes, the service providers emphasised the need for maintenance of law and order in the camp setting.

To raise community awareness, messages regarding the protection needs of people with mental health conditions could be incorporated by all agencies in their communication campaigns. The existence of 'role model' families in Uganda provides a possible means to do this, as do peer workers in Bangladesh.

## Accounting for Sociocultural Dynamics That Shape Access to Support

Cultural differences in explaining symptoms, experiences of distress and coping mechanisms can alienate clients from service providers, discourage help-seeking, and reinforce stigma. The service providers need to consider the ways culture affects refugees' experiences, how they described symptoms of illnesses and their preferred forms of care. Also, they need to consider the myriad ways the structures in which refugees are embedded shape their treatment-seeking practices and outcomes.

Whilst support mechanisms which account for the roles and responsibilities of different family and community members can improve access, gender dimensions in giving and receiving support need to be considered in interventions that seek to build on these dynamics. In both contexts, women receive less support from their spouses compared to men when they have mental health difficulties, but are the main caregivers when men need formal support. Men have poorer access to psycho-social services as most facilities target women. Besides, their negative coping mechanisms or outward symptoms of their condition further marginalise them from support. Gendered needs, experiences and access barriers must be considered to both develop culturally sensitive care and improve access. This means designing interventions which properly account for and reflect the different experiences of men and women.

## Investing In Community-Based Outreach And Services

Community outreach activities and networks formed among the various service providers within and beyond health, are proving to be effective in linking people to the formal support system. There should be an ongoing effort to promote such mechanisms to further develop the referral system. Community volunteer services provide an important medium for disseminating information regarding mental health and services, raising awareness, identifying people who need mental health support and connecting people to formal care provision. As their current roles are valued and effective, their role and contribution in designing and delivering mental health services must be expanded.

Increasing engagement with community members for collaboration and inclusion of their expertise can promote culturally appropriate and sustainable health systems as well as community empowerment. Given that religion is a significant part of everyday life for refugees and shapes norms about mental health, interventions need to be premised within a better understanding of religious healing practices and existing social networks as sources of individual and communal resilience. In Bangladesh, engaging with religious leaders at mosques can also provide an opportunity to disseminate messages about available care and protecting people with mental health conditions from abuse and discrimination. In Uganda, providing support through churches may more effectively target those who are most vulnerable, promote accessibility of services, and enhance community-based forms of assistance and solidarity.

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