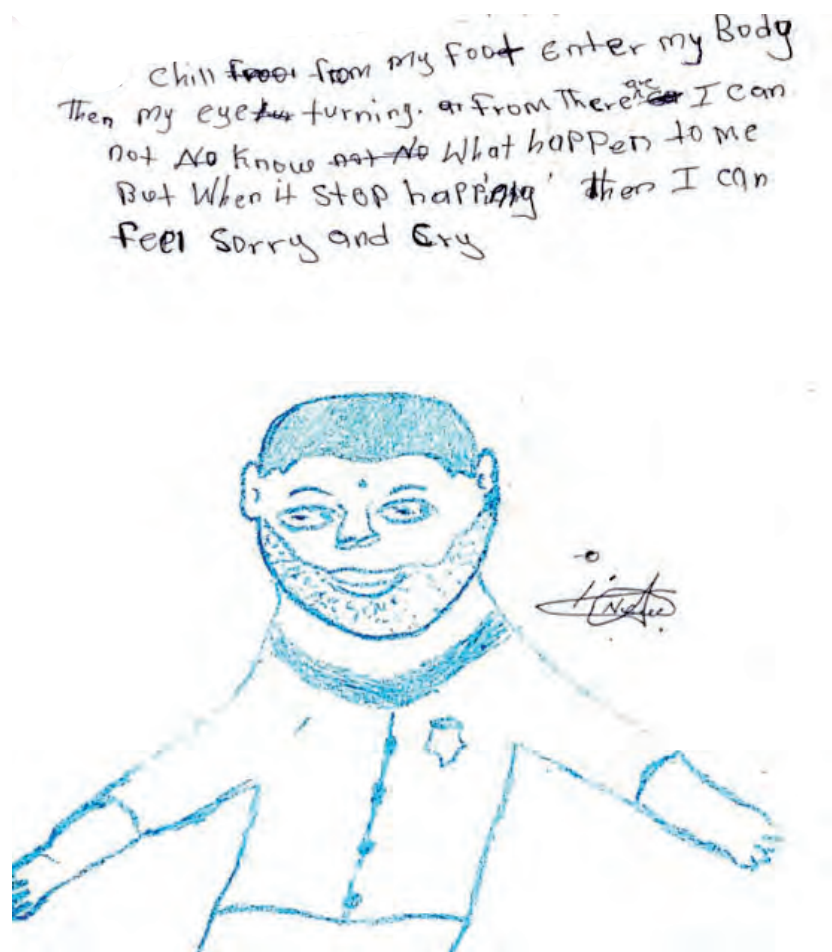


***“God is first, MSF second, and my husband second too”***  
**Mental health conditions and epilepsy in Liberia:**  
**Understanding and healing pathways within a community-based**  
**and patient-centered care approach**

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*“God is everything, He’s the doctor of all doctors. God come first before anything we do under this sun, so I have to put my Papa [God] first” (Joy, patient).*



Drawing by a young patient with epilepsy

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## Executive Summary

Since 2017, MSF OCP has provided free mental health (MH) and epilepsy care in five primary health care clinics (PHCCs) in Montserrado county, Liberia. The clinics have a large cohort of patients and have had a positive impact in treating patients, as well as raising awareness about MH conditions and epilepsy and tackling the high rates of stigma surrounding them. It is known that patients understand their conditions in a variety of ways, and the local socio-cultural environment can have a large influence on health-seeking behaviours. Many people believe that MH conditions and epilepsy are the result of witchcraft and most rely on religious and traditional healers instead of accessing formal healthcare systems. Before coming to the MSF clinics, around 34% of patients in the MSF cohort received treatment from religious and traditional healers only, and an additional 32% from religious and traditional healers as well as other clinical professionals<sup>1</sup>, the former of which can have a positive impact, but can also involve abusive practices such as putting patients in chains. However, a large part of the understanding of the patient histories and healthcare pathways is unknown. The above data, as well as pertinent questions from the field team, and the research conducted by Justine Hallard (Project Coordinator (PC)) on patient-centred care (including how applied social sciences can contribute to a deeper perspective and practical application of a patient-centred care approach)<sup>2</sup>, demonstrated the importance of exploring and understanding how patients seek care; how traditional and religious healers approach care; and how each understands MH conditions/epilepsy and treatments, in order to adopt a more tailored community-based and patient-centred approach which ultimately improves quality of care. Indeed, it is possible to integrate local understandings of these conditions and traditional approaches to treatment, while retaining the complementary role of biomedical approaches. Applied anthropology, in its focus on individual narratives situated in their socio-cultural context, can play a major role in enabling such understandings.

This anthropological study aimed to provide a contextualised understanding of patients' comprehension of MH conditions/epilepsy and their therapeutic pathways. The major areas explored are: Patient, religious/traditional healer and staff experience and comprehension of MH conditions and epilepsy (including stigma towards people with MH conditions and epilepsy and the effect on their healing pathways, as well as family/community roles in decision-making); Medical and spiritual conceptualisations of MH and epilepsy (including the reasons for patients seeing religious and traditional healers); Existing/potential for future collaboration between MSF clinic staff and traditional and religious healers; Patient and caretaker experiences at MSF clinics (surrounding their diagnosis and the staff-patient relationship); and Challenges related to care. Finally, we provide stakeholder recommendations on how to implement better community-based and patient-centred practices that integrate and respect the patient's choices and value-systems within the clinics in Liberia. These findings could also be extrapolated to areas with similar MH care contexts.

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<sup>1</sup> MSF clinics databases, Liberia, November 2020.

<sup>2</sup> Hallard, Justine (2019). For an approach of a patient-centered care in our operations. MSF Souk.

Methods used were in-depth interviews with patients and their caregivers, religious and traditional healers and MSF staff, as well as observations of medical consultations and home visits. The questions posed were based on themes previously discussed and deemed in need of further exploration by field staff. Participants were selected with the help of the clinics' Psychosocial workers (PSWs) and was based on a mix of random and purposive sampling. All interviews were audio-recorded and transcribed in full, and a thematic data analysis triangulating the various methods was conducted manually using Nvivo12.

The findings indicate that the stigmatisation of MH conditions and epilepsy leads to abuse, neglect, school-drop-out/expulsion and exclusion from socio-economic activities, as well as impacts patients' therapeutic pathways. People with both types of condition are often labelled as 'crazy'. Patients and religious and traditional healers hold varying conceptualisations of the causes of MH conditions and epilepsy, but most often believe they are the result of witchcraft. This perceived *spiritual cause* (as well as the belief that biomedicine could not completely 'heal' them) meant that before seeking biomedical treatment, patients and their caregivers sought a *spiritual cure* through traditional and/or religious healers. In general, patients/caregivers and staff held positive views towards religious healers when seeing them only involved prayer and negative views towards traditional healers, whose practices they said did not work and were very expensive. Both groups however often put their patients in chains when patients stayed with them (and this was possibly more common among religious healers). All healers said they were willing to collaborate with MSF to refer patients to the clinics. We also found that while all patients said they had very good experiences at the MSF clinics and that staff were friendly and welcoming, even after coming to the MSF clinics, most still claimed not to be aware of their diagnosis. This could be due to the denial of a highly stigmatised diagnosis, or because diagnoses had not been appropriately communicated by staff.

Various recommendations have been made and are centred on 1). Reinforcing the foundations of the project, and 2). Building on these foundations, especially with a more patient-centred and community-based approach to care. The first part involves building on awareness-raising of MH conditions and epilepsy to tackle stigma with a focus on addressing the fear associated with MH conditions and epilepsy; streamlining the awareness sessions so that staff in all clinics are using the same approach; further developing and promoting counselling activities; and effectively communicating diagnoses in a culturally sensitive manner. The second part involves collaborating with traditional and religious healers (including encouraging them to refer patients to the clinics); improving access to the clinics and treatment (including though providing financial support for transportation and food); supporting patients in their long-term recovery; and improving understanding between national and international staff.

Finally, we argue that an anthropological approach is important for similar future research because in having real conversations with various population groups, research is deeply situated in the socio-cultural context, with participant narratives valued as primary data. This means that initially unapparent but important nuances become evident and so findings and recommendations are more appropriate for the context.

## Abbreviations

CFUH – Cultivation for User’s Hope  
gCHV – General Community Health Volunteer  
HIV – Human Immunodeficiency Virus  
ICM – Intercultural Mediator  
LRD – Liberian Dollars  
MH – Mental Health  
MHC – Mental Health Clinician  
mhGAP – Mental Health Gap Action Programme  
MHU – Mental Health Unit  
MoH – Ministry of Health  
MSF – Médecins sans Frontières (Doctors without Borders)  
NGO – Non-Governmental Organisation  
PHCC – Primary Health Care Centres  
PIH – Partners in Health  
PSW – Psychosocial worker  
PTSD – Post-Traumatic Stress Condition  
RW – Rosie Wilson  
TCC – Technical Coordination Committee  
TB – Tuberculosis  
WHO – World Health Organisation  
WHO mhGAP – WHO Mental Health Gap Action Programme

## 1. Introduction

*In our culture there's a lot of mixed perceptions when it comes to mental health or epilepsy... so the fact that MSF have this project has a great impact... patients come in and we're talking to them, they're expressing how they feel about their condition, the stigma... discrimination... we provide that subtle orientation, helping, so they are able to talk more about all the mental illness and all their experiences (Adam, MHC).*

### 1.1 The Republic of Liberia

#### Geographic region

Liberia is situated on the West coast of Africa, bordered by Guinea in the North, Cote d'Ivoire in the East, Sierra Leone in the West, and the Atlantic Ocean in the South. The country has a population of around 5 million. Liberia is divided into 15 political sub-divisions (counties) and five regions. It is estimated that almost half of all Liberians live within Greater Monrovia (County Development Committee, 2008).



#### Demographics

Liberia is a low-income country and around 64% of the population live below the poverty line, 1.3 million of whom live in extreme poverty (WFP, 2018). The South-Eastern region is the poorest and the gap between the rich and the poor continues to widen (County Development Committee, 2008). More than two-fifths of the population of Liberia is under age 15; only about 5% is older than 60. The country's birth and death rates are among the highest in the world. Life expectancy is about 60 years for females and 57 for males. The Kpelle are the largest ethnic group in Liberia (24% of the population). The Bassa make up 13%, Grebo 10%, and Gio and Mano each 8%. Other population groups include Kru, Loma, Kissi Mandingo and Vai. English is the official language but more than 24 other languages are spoken, including Kpelle, Bassa, Grebo, Gio, Kru, Mano, Loma, Mandingo and Vai. About 86% of Liberians are Christian, 12% Muslim, just under 2% hold traditional beliefs and the remaining are members of other religious groups or are nonreligious (Muslim organizations however dispute the official statistics, stating that Muslims constitute up to 20% of the population (United States Department of State, 2019)). Most Christians are Kpelle or Bassa and most Muslims Mandingo or Vai. Some Liberians who identify primarily as Christian or Muslim also incorporate traditional beliefs into their personal theologies (Encyclopaedia Britannica, 2021).

#### Montserrado County

Montserrado County, where this research took place is in North-West Liberia. Montserrado, and particularly Greater Monrovia (the capital), is considered highly diverse and representative of the population of Liberia as a whole. Kpelle and Bassa - speaking people are in the majority, making up 52% and 21% of the County's population respectively (County Development Committee, 2008).



### **Religious and spiritual beliefs**

A development in the Christian community since the civil war has been the upsurge in churches (especially Pentecostal) emphasizing healing, miracles, and prosperity, and practices akin to those used by traditional<sup>3</sup> and religious<sup>4</sup> healers. However, orthodox Pentecostal Christians are generally critical of this trend because they suspect that many of the healing or prosperity-oriented Pentecostal ministries are fake (Olukoju, 2006).

Traditional religionists, such as those in the Sande (female) and Poro (male) societies believe in the existence of a variety of benevolent and evil spirits (djinna) including ancestral, animistic and water and bush spirits. Ancestral spirits are believed to protect and play mediatory roles in the affairs of their offspring and bush and water spirits are believed to possess humans and be capable of transferring specialized knowledge or power to them. These spirits represent the ultimate sources of power, and humans have to arrange how to communicate with or appease them. It is argued that conformity within society is achieved largely through social pressure, especially the fear of being accused of witchcraft. This has led to the emergence of specialized priests, diviners, physicians, and fortune-tellers who claim to communicate with the spirits. (Olukoju, 2006) and who are used to treat or heal various conditions.

Traditional medicine is defined by the World Health Organization (WHO) as “...the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness” (2021). However, traditional medicine is subject to change and some healers combine biomedicine with their healing methods.

Liberia has official legislative/regulatory texts governing the practice of traditional medicine; however, it seems that these are not put into practice and the country does not have licensing or approval procedures for traditional health practitioners or treatment<sup>5</sup>.

### **Political context**

The roots of Liberia’s civil war go as far back as its founding in 1847 by freed American slaves. New settlers subsequently ran the new country like a colony, establishing a feudal structure. In the name of a Christianizing and civilizing mission, the indigenous population were subjected to forced labor, disenfranchisement, and exclusion from the economy, which led to their impoverishment and cultural alienation (Refugee Review Tribunal Australia, 2009).

The 14-year civil war began in 1989, when Charles Taylor returned to Liberia from Ivory Coast with a force of 100 rebels (the National Patriotic Front of Liberia) seeking to oust the repressive regime of the then-president, Samuel Doe (who himself assassinated the previous Americo-Liberian president William Tolbert). A rival warlord, Prince Yormie Johnson executed Doe in

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<sup>3</sup> A traditional healer is understood as a typically unlicensed (officially) but perhaps highly trained/initiated person who practices healing using traditional practices and rituals, herbal remedies and/or the power of suggestion.

<sup>4</sup> A religious healer is understood as somebody practicing one of the well-known and prolific religions (such as Christianity or Islam), and uses prayer and gestures believed to elicit divine intervention in spiritual and physical healing.

<sup>5</sup> Analysis of questionnaire on traditional medicine. Geneva, World Health Organization, 1992 (unpublished document WHO DOC. 5183A/REV. DOC. 6136A).



1990, however, this failed to bring about stable government; Johnson and Taylor turned on each other, plunging Liberia into seven years of civil war. Taylor held elections in 1997, taking 75% of the vote from an electorate desperate for an end to the violence. One of Taylor's campaign slogans ran: "He killed my Ma, he killed my Pa, but I will vote for him." (The Guardian, 2003). Conflict ensued between Taylor and the opposition (Liberians United for Reconciliation and Democracy (LURD)), leading to a second civil war. In 2003, following widespread international condemnation, Taylor went into exile in Nigeria (McKenna, 2021), leaving Liberia the world's poorest nation with next to no health care system, and Monrovia without electricity or running water (Burtscher, 2005). Over the 14 years of war, 200,000-300,000 people died; the use of child soldiers was common and rates of sexual and gender-based violence extremely high. The latter, as well as substance use disorders and armed robbery remain high today.

## **1.2 Mental health and epilepsy<sup>6</sup>**

Internationally, prevalence of severe mental health conditions is around 3%, and rates of moderate conditions between 10 and 20% (MoH Liberia, 2016). Epilepsy is the most common chronic brain condition which affects over 50 million people worldwide, nearly 80% of whom live in low- and middle-income countries (WHO, 2019).

### **Africa**

Due to the dearth of research into MH conditions in Africa it is difficult to know the prevalence on the continent. For example, even though MH is one of the journal's stated key topics, The Lancet Global Health only published 39 articles that alluded to MH conditions in Africa (Sankoh, Sevalie, & Weston, 2018). Regarding epilepsy, there is a high prevalence in Africa (10 million people are affected directly, representing approximately 20% of people with epilepsy worldwide) (Mugumbate & Zimba, 2018). Rates of epilepsy may be higher in middle-low-income countries and tropical regions due to higher rates of premature birth; malnutrition; infectious causes (such as HIV, Zika and TB); and parasites such as malaria and Toxocariasis. Socioeconomic deprivation, stroke, alcohol use, traditional scarification, genetic factors and traumatic brain injury could also cause epilepsy (Levira et al., 2017).

Despite this, the continent of Africa has only 1.4 MH workers per 100000 people, compared with a global average of nine per 100000, and so the proportion of Africans who receive treatment for these conditions is extremely low. In Sierra Leone for example, the treatment gap (the proportion of those in need who go untreated) for formal MH services has been estimated at 99% (Sankoh et al., 2018).

### **Liberia**

Around 9% of Liberians are reported to suffer from MH conditions, epilepsy or addiction, and 3% from a "severe form" of these conditions (MoH Liberia, 2016). However, due to underreporting this number is likely higher. In a recent literature review (Epilepsy Working Group, 2020), no epilepsy research focusing exclusively on Liberia was found except for two

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<sup>6</sup> Epilepsy is included in MH programmes in Liberia (and other low and middle-income countries) as per the WHO mhGAP intervention guideline.

short reports from the 1980s and 90s. However, it is evident from the MSF clinic's database in Liberia that there is a high prevalence; 63% of active adult patients out of 1240 suffer from epilepsy<sup>1</sup>. There are also very few qualitative studies on MH and epilepsy in Liberia; one published by a psychiatrist working in Liberia in 1970 found that people with symptoms of psychosis were believed to have been bewitched by the water spirit 'Mammy Water' (Wintrob, 1970). More recently, Abramowitz's studies on open mole<sup>7</sup> and its somatization (the patterning of psychological and social conditions into a language of distress, mainly physical symptoms and signs) have informed much of the discussion and debate around MH in Liberia. It is widely known however that people in Liberia with MH conditions and epilepsy can also be highly stigmatised, leading to abuse and causing patients to be excluded from education and social and professional life.

Despite the burden of these conditions in Liberia, less than 1% of Liberians have access to clinical MH services (Abramowitz, 2017); the Ebola outbreak in 2014-2015 - which was the largest in history and caused the deaths of almost 5000 Liberians - significantly weakened a health system that was already extremely fragile after the civil war; 8% of Liberia's doctors, nurses, and midwives were lost to the virus (Adepoju, Ilori, Olowookere, & Idowu, 2016). MSF also observed that currently in Liberia, hospitals and PHCCs are running out of basic medical supplies, and staff at government facilities are often absent due to unpaid salaries. These factors may contribute to the fact that many people in both rural and urban areas rely on religious and traditional healers instead of accessing formal healthcare systems; around 34% of patients in the MSF cohort received previous treatment from religious and traditional healers only, and 32% from both religious and traditional healers as well as other clinical professionals<sup>1</sup>.

Liberian authorities consider MH as a major public health problem; the Mental Health Policy and Strategic Plan for Liberia 2016- 2021 completed by the MoH in collaboration with WHO and other agencies is well-organized and supported by law. However, due to lack of government resources directed to the initiative, in the year that this plan ends, many major objectives have not been covered.

## 2. Study rationale

### 2.1 For a patient-centred, community-based<sup>8</sup> approach

In September 2017 MSF-France opened a MH project in Liberia, in partnership with the MoH and the E.S. Grant psychiatric hospital, integrating MH clinics into five PHCCs in Monrovia (Pipeline, Claratown and West Point<sup>9</sup>), and close rural areas (Bromley and Bensonville), in

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<sup>7</sup> Open Mole refers to a local complaint of a soft spot in the centre of the skull where the fontanelle is, accompanied by a range of symptoms including headache, dizziness, social withdrawal, insomnia, nightmares, loss of appetite, and suicidal thoughts. People sometimes describe experiencing this during or following stressful periods, shock, bereavement, or chronic adversity.

<sup>8</sup> By a patient-centred we mean that "...an individual's specific health needs and desired health outcomes are the driving force behind all health care decisions and quality measurements. Patients are partners with their health care providers, and providers treat patients not only from a clinical perspective, but also from an emotional, mental, spiritual, social, and financial perspective (NEJM Catalyst, 2017)". By community-based we refer to "...an approach that moves beyond a focus on increasing access to services and information and a pure focus on efficacy; to involving communities in giving direction to health initiatives and thus reflecting the everyday lives of community members (Rigg, Engelman, & Ramirez, 2018)".

<sup>9</sup> West Point clinic opened in 2019.

Montserrat County. The general objective was to implement the WHO mhGAP (Mental Health Gap action programme) intervention guideline (WHO, 2010), using a task shifting approach in which nurses and clinical officers receive a six-month training course from the Carter Center Foundation. Following this they can practice as consultants and diagnose patients with mental, neurological or substance disorders using a simplified diagnostics tool classifying conditions under nine different categories (depression; psychosis, epilepsy/seizure; developmental disorders; behaviour disorders; dementia; alcohol use disorders; drug use disorders; self-harm/suicide), and provide treatment (medication or counseling). The program incorporates a decentralised approach with the involvement of families, community health workers and Psychosocial workers, who are active in patient detection and follow-up. This approach strengthens the referral system, enhances MoH ownership of MH and epilepsy care (7 out of 9 MH clinicians, the 4 mhGAP nurses and the 18 General Community Health Volunteers (gCHVs) are MoH staff) and overall, aims to improve the lives of people suffering from MH conditions and epilepsy in the catchment areas.



MSF MH clinic run by Bromley PHCC

The five clinics serve hundreds of communities in their catchment area, for example just one rural clinic – Bensonville – serves 79 communities within a radius of 20 km. While the large cohort of active patients (1513 in November 2020<sup>1</sup>) in the project suggests a degree of success in enrolling patients in the programme, a large part of the understanding of patient history and health pathways is unknown. It is important to fill this knowledge and understanding gap as patients and their caregivers understand their MH conditions and epilepsy in a variety of ways, and the local socio-cultural environment can have a large influence on health-seeking behaviours. Misunderstanding this context can lead to miscommunication, alienate patients from their own care and even cause inconsistencies and medical errors (Barnett, 2019).

## 2.2 Study conceptualisation

Discussion among project and clinic staff about various themes often identified among patients took place before commencement of the study. It was believed it was important to explore practices of traditional and religious healers and the frequency of the belief in witchcraft, as well as the impact that this could have on patient care. Additionally, many (including national)

staff could not understand why patients were seeking care from religious and traditional healers at the same time as receiving clinic treatment.

A number of non-MSF partners were involved in the study conceptualisation, including the MoH Mental Health Unit (MHU), the patients' association Cultivation for User's Hope (CFUH), Partners In Health (PIH) (who are conducting a similar MH programme in Maryland, and have been collaborating with traditional and religious healers), the Carter Centre Foundation and the Mother Patern College of Health Sciences (the director of whom is co-chair of the MH Technical Coordination Committee (TCC<sup>10</sup>)) in discussion with the PC. All were favourable to the implementation of the study, mentioning the need to have more anthropological studies in the field of MH in general, and the MHU recognised there was a lack of collaboration with the MoH Community Health Department. This is important considering that it is through the community that first-level communication and awareness is conducted before patients enter MH PHCCs. We were also informed by CFUH that patient contact with traditional and religious healers can cause a deterioration of the patient's condition, and that this requires further exploration.

### **2.3 Anthropological analysis**

In all human societies, beliefs and practices relating to illness are a central characteristic of the culture, and thus how people react to disease, death or other misfortune, and how they seek care cannot be understood without an understanding of their wider socio-cultural context. Indeed, the Lancet Commission on Global Mental Health and Sustainable Development reported that for MH conditions, there is both a "universal human and unique contextual experience", stressing that integrating understandings of local explanatory models and traditional approaches to treatment of MH conditions is possible, while retaining the complementary role of biomedical approaches to treatment (Patel et al., 2018). Applied anthropology, in its focus on individual narratives situated in their socio-cultural context, can play a major role in enabling such understandings.

Recommendations based on the findings are made on how to implement better community-based and patient-centred practices that integrate and respect the patient's choices and value-systems within the MSF MH clinics in Liberia. As the study focuses on the five specific clinics, and because most of the participants are users of the clinics, it is envisaged that the findings and resulting recommendations will be extremely relevant to this specific context. The findings however could also be extrapolated to areas with similar MH care contexts.

### **Aim**

To gain a contextualised understanding of patients' comprehension of MH conditions/epilepsy and their therapeutic pathways, including their use of traditional and religious healing pathways and MSF services.

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<sup>10</sup> The TCC is headed by the MoH and includes the Carter Centre, the Mother Patern College of Health Sciences, PIH and CFUH.

## Objectives

1. To gain a consolidated understanding of comprehension of MH conditions and epilepsy within the cultural and social context through discussion with various stakeholders including patients<sup>11</sup>, their caregiver(s)<sup>12</sup>, clinic staff and religious and traditional healers
2. To understand patients' healing pathways through traditional and religious healers, as well as MSF
3. To analyse whether the perceptions of staff impacts MSF's care approach
4. To propose recommendations based on the study findings in order for MSF to better consider patient experience and choices and integrate a more community-based and patient-centred approach, thus improving health conditions and quality of life.

The key subjects addressed in this study and the layout of the results are as follows:

- Various population groups' experience and comprehension of MH conditions and epilepsy within the cultural and social context
  - Stigma towards people with MH conditions and epilepsy and the effect on their healing pathways
  - Family/community role
- Medical and spiritual conceptualisations of MH and epilepsy
  - Reasons for patients seeing religious and traditional healers
- Existing/potential for future collaboration between MSF clinic staff and traditional and religious healers
- Experience at MSF clinics
  - Diagnosis
  - Staff-patient relationship
- Challenges related to care
- Stakeholder recommendations

## 3. Methods

### 3.1 Recruitment

#### *Patients and caregivers*

With prior verbal consent from patients and caregivers, all patients fitting the study's inclusion criteria at each clinic were selected by the PSWs, and their information (which only included first names and details relating to the inclusion criteria) were provided. A mix of random and purposive sampling was then used to select patients. A random selection was made of one patient from each diagnosis group from each clinic's provided list of patients where there was more than one patient with a certain diagnosis using Excel's Index function (meaning that around three patients and their caregivers were selected from each clinic). If there was only

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<sup>11</sup> The participant cohort includes a variety of MH conditions to reflect the various conditions presented in the patient cohort.

<sup>12</sup> The caregiver is defined as the person who is registered as such in the patient file. This is normally a family member such as parent or sibling, but could also be a neighbour or friend and is the person normally making healthcare decisions with/for the patient and accompanying them to appointments at the clinic and/or healer.



one patient from a particular diagnosis group who fit the inclusion criteria (as was often the case with anxiety), that patient was selected.

Caregivers were included as they can have a large influence on when and how patients receive care. We aimed to include caregivers of the patients interviewed, where they had been, or still were, extensively involved in their care. Patients and caregivers were interviewed separately to reduce the risk of bias, except when the patient preferred that the caregiver stayed with them. Patients and caregivers were invited to participate through a telephone call or home visit by the PSW of their clinic.

#### *Religious and traditional healers*

Access to traditional and religious healers was sought through the PSWs as they know their communities and the traditional and religious healers within them very well, through a phone call or home visit.

#### *Staff*

RW (anthropologist) visited each PSW at each of the five clinics, inviting them and one of their clinicians to participate in an in-depth interview and/or observation of a consultation. The longest-serving clinician (due to having the most experience at the clinic) at each clinic was invited to participate.

### **3.2 Study tools**

#### *In-depth semi-structured interviews*

In-depth semi-structured interviews allow for a contextualised, in-depth exploration and understanding of a topic. The one-to-one discussion also allows for a degree of privacy and the possibility for participants to feel comfortable speaking about sensitive issues (such as MH). Interviews followed a topic guide that included key questions to ask but also offered space for spontaneous follow-up questions. A Liberian intercultural mediator (ICM) who was fluent in English, Kpelle and Mano helped build relationships and trust with participants and provided translation between RW and the participants. Additionally, the clinic's PSW was on site for each interview in case the patient became distressed.

Interviews took place at an outside location where possible (due to COVID-19 and necessary physical distancing) most convenient and comfortable for the participant (for patients and traditional and religious healers, their home or the clinic, and for medical staff, their office).

#### *Participant Observation*

Participant Observations can enable an extra layer of understanding of context, behaviours, experiences, and social norms that may be less likely to be described in interviews (Opel et al. 2013). So as not to further impose on the consultation and reduce the number of people in the room, only the RW and PSW/clinician was present, and the observation was not recorded; instead, notes were taken.

### **3.3 Study population**

- Patients with a past history of, or who were currently receiving MH and epilepsy care from traditional and/or religious healers

- Patients' caregivers
- MSF/MoH healthcare staff: MH clinicians and PSWs, the MH supervisor, psychiatrist, and neurologist working in the 5 PHCCs (Pipeline, Claratown, West Point, Bromley and Bensonville)
- Traditional and religious healers (herbalists/"country doctors", priests, pastors, etc.).

#### *Inclusion criteria*

For all groups, individuals were included if they were: Residents of Montserrado county; Aged over 18; Spoke English, Liberian English, Kpelle, or Mano; Had the capacity to understand the study and consent and provided signed consent. For patients and caregivers, an additional inclusion criterion was: Patients already in the active MSF patient cohort, as well as their caregivers. For MoH/MSF healthcare staff, and traditional and religious healers, an additional inclusion criterion was: Supporting people with MH conditions/epilepsy.

### **3.4 Data Analysis**

Each interview was audio recorded and transcribed into English in their entirety usually immediately after they had been conducted. Observation notes were typed. All interview transcripts and notes were then imported into a qualitative data organisation tool (Nvivo12). The transcripts were read several times, then organized and coded using a coding framework. As the study began with some key questions regarding conceptualisations of MH/epilepsy and the use of traditional and religious healers, the coding framework was formulated both deductively (through pre-established concepts guiding the research questions), and inductively (based on salient and recurrent themes identified in the data). All transcripts were then re-read, and any relevant missed text added to codes and new codes added if necessary. A thematic analysis was then conducted by RW alongside discussions with other members of the MH team to identify and analyse patterns (themes) from the data (Braun and Clarke, 2014). This report assimilates data from all the interviews and observations.

### **3.5 Ethics Approval**

Ethics approval was obtained from Liberia MoH (Ref: NERB-031-20) and MSF (Ref: 2105). Before interviews and observations, all participants read (or had read to them), an information sheet and if they understood and were willing to participate, signed or thumb printed a consent form. Pseudonyms (normally chosen by the participant) were used for all participants.

## **4. Results and Discussion**

The study was conducted between November 2020 and April 2021. In-depth interviews and participant observations continued until thematic saturation was reached within each participant group. In total 44 interviews (with 16 patients, 7 caregivers, 13 healthcare staff and 8 traditional and religious healers<sup>13</sup>), 12 observations of medical consultations and seven home visits were conducted. RW also attended five awareness-raising visits (4 in schools and 1 at a

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<sup>13</sup> Throughout the report, the term 'healers' is used to refer to both religious and traditional healers, unless otherwise clarified.



health centre). All activities were conducted in and around the three urban and two rural MSF MH clinics in Montserrado.

Interview participants were between the age of 19 and 75. Twenty-three were male and 21 female. For patients specifically, the age range was between 19 and 67 and included 8 females and 8 males. Five patients had been diagnosed with epilepsy, 5 with psychosis, and 5 with depression/anxiety/open mole (2 with anxiety condition, 2 with depression, 1 with anxiety, depression and open mole), and 1 with Multiple Unexplained Psychosomatic Symptoms (MUPS)). Twenty-five interviews were conducted in standard English, 15 in Liberian English and four in a mix of Liberian English and Kpelle or Vai. Thirteen patients had a bachelor's degree, 13 had been to school only and 4 had no education. Fifteen patients and caregivers were employed and 8 were unemployed. For healers, 2 had a bachelor's degree, 2 had been to school and 4 had no education. Clinic staff had been working in the clinics for between 1.5 and 3.5 years (since the project's implementation).

Observations of medical consultations and home visits were conducted with 8 patients diagnosed with epilepsy, 5 with psychosis, 2 with both epilepsy and psychosis, 2 with open mole and 2 with developmental disorder. Eleven patients were female and 8 male.

#### 4.1 Experiences of Mental Health conditions and epilepsy

*My passion actually started for mental health when I was little... my grand aunty had a mental health problem and she was being beaten, she was insulted, they said it was witchcraft... I would go to her house... eat the food, and my parents will be angry; why I have to eat food from a mad woman?... Sometimes I was beaten (Nathaniel, MHC).*

**A variety of local terms are used to describe MH conditions and epilepsy in Liberia. In general, they were often referred to as “crazy sickness”. This was most common for psychosis but also sometimes to refer to epilepsy and open mole.**

The below terms were also used by patients, religious and traditional healers, and sometimes by healthcare staff.

##### Epilepsy

*It just like death, to die and resurrect seven times a day (Kruahtaye, patient with epilepsy)*

To describe epilepsy, people used terms such as “falling”, “jerking”, “summersault”, “seesaw” “foaming from the mouth”, “spitting” and “spell”. Additionally, Sophie, whose son had epilepsy said he was “crazy” and Geevon said about her brother with epilepsy;

*He went off, all the people that were selling their gas there were saying “the man is a crazy man”... they can be there looking... he went inside and started crying... the stigma... people judging... He’s crazy.*

Participants mostly therefore referred to symptoms of tonic-clonic (convulsive) seizures. According to the medical staff, it is hard for people to differentiate tonic-clonic seizure symptoms from other seizure types such as absence and psychogenic seizures (believing epilepsy is solely convulsions). Indeed, it is even difficult for doctors and clinicians to conduct complex diagnoses without equipment like an electroencephalogram (EEG).

Four patients said that there is a correlation with the new moon as well as the moon “falling” (setting) and the person “falling (having seizures); “When the new mood stands my eyes will swing, I will feel weak and drop and that whole week I will not be able to do anything for myself” (Lovetee). Research on the moon’s cycle has yielded mixed results, and most focus on the effect of the full moon, rather than the new moon (Baxendale & Fisher, 2008).

### Psychosis

People with psychosis were often described as “crazy people”, having “crazy sickness”, “people in chains”, “mad”, “talking plenty” or “seeing things”, “misbehaving”, “losing mind” “confused”, “on the street”, “behaving strange”, “mad” or being violent. Peter, who had been diagnosed by the clinic as having psychosis, when asked what his condition was, said “traumatised... meaning someone who is occupied with lots of things in their mind, they can’t get over it”.

### Liberian “open mole”

*Since '97... [one patient] was not working because he had open mole... He saw a lot of things, he witnessed a lot of killing; the rebels killed his father...they were running from the war... the rebels killed his sister right in front of him... so all of those things are on his mind... He felt guilty because he was there and he couldn't help... so he developed this strong headache that he called open mole... he started his treatment...and now this guy is well... he's one of the best carpenters (Bridget, PSW).*

The term open mole was used according to the estimation of one staff member by around four in 100 patients to describe their own condition. The symptoms were extremely varied, unsystematic, changeable, culturally sanctioned physical expressions, behaviours and understandings.

**Symptoms of open mole included: headaches, the impression of a hole or soft spot in the centre of the skull (similar to the soft areas in an infant’s unformed skull or the sunken fontanel associated with infant dehydration), a crawling sensation on the head, “worryness/hard thinking” (related to loss, an abusive partner or financial concerns), palpitations, difficulties sleeping, feelings of hopelessness, suicidal thoughts, lack of appetite, weight-loss, sitting by themselves, unable to take care of themselves, a burning sensation in the body, constipation, neck pain, fainting, “falling”, weak veins, short temper, crying, “jerking”, trembling, paralysis, shortness of breath and/or simply open mole.**

Additionally, one staff member believed open mole was caused by home delivery (the mother being told to push too much, which was believed to put pressure on the fontanelle) and

dehydration. John (a patient with anxiety) said open mole meant someone was “crazy”. Similarly, Joy (a patient with open mole) said; “I used to be like crazy person, sometimes I will go off totally, I will not be myself”.

Sometimes the symptoms were more complex;

*I feel like snake entering my body, so when I went to the church the man of God saw it too... and said you are suffering from a serpent that can embarrass you at night... Whenever it's entering in me it uses my legs... then I will start behaving like serpent... I will feel like my eyes is stressing and I will see my body soft like I don't have bones... how serpent can... People said the open mole that was on me, it was something spiritual... Before I want to go out, I'll get scared and I had to come back because I feel like if I go among public, I will just drop... it used to... make me shame... It was something like somebody that's developing spells (Jay, open mole).*

The term was used simultaneously used as a symptom and the name of a condition in itself (including among some staff);

*Lisa (MHC): They say “Oh come feel my mole, my mole is down”... the frontal mole is open all the way to the way to the occipital, the back... it will take them years [to close].*  
*RW: And what do they mean by mole?*  
*Lisa: Er, I don't know how to say. The mole is when sometimes it's sunken in; they say “its soft, my mole is soft”.*

Open mole symptoms emphasized the somatic, as alluded to by Elizabeth (MHC); “[Open mole patients] will have a lot of worry, but they are not worried about what is causing the headache, they are worrying about the headache”. In this way, patient narratives often also de-emphasized their personal history;

*Generally, they all term everything as open mole because for example when a patient has bipolar, people think he has open mole; when the patient has epilepsy or depression whatever, people say he has open mole... Most times because of stigma people refuse to accept that they have mental health problems... because in Liberia people feel when you have mental health problem you are always dirty (Nathaniel, MHC).*

Discussing only the secondary physical complaints accompanying the psychological conditions may thus provide a legitimated “sick role”, which releases patients from stigma, and affords them care (Kleinman, 1997). This may have been particularly important in Liberia, where until recently there has been virtually no psychotherapists or neurologists available, and since traditional and religious healers and non-psychiatric medical doctors have handled the majority of MH conditions, most care for these problems has been under the guise for other (non-MH or epileptic) conditions.

Open mole has some similarities with somatized MH illnesses widely known among West African populations, including Brain Fag (Prince, 1960) and Nigerian ode ori, innu and were

ironu (Patel, 1995). Similarly, in a study in Taiwan conducted by Kleinman (1977) 22 of 25 patients later diagnosed with a depressive syndrome initially presented at the clinic with solely somatic symptoms such as pressure on the chest or heart (seemingly similar to the pressure on the head with open mole), and many rejected the idea that they experienced a MH condition. According to Burtcher (2009), the pattern of "speaking with the body" is probably much more common globally than expressing distress and anxiety in purely abstract, psychological terms.

Despite this, in Liberia since the 1950s, various visiting psychiatrists and psychologists have denied the existence of open mole;

*There was always a problem, there was always some pushing and pulling with this issue of open mole. [The psychiatrist] always told people "you don't have open mole". Telling people abruptly in their face that "indeed what you say you lie, it doesn't exist, your mole doesn't open"- traditionally or culturally - for us in Liberia is rough because these people know what they experience, they know what they feel... When she said "everyone who come to say 'I have open mole', diagnose them automatically as depression". Most of the staff said "no, because people own interpretation of open mole is not just about depression, could be anxiety it could even be epilepsy... so yes, we have international staff that have conflict with this open mole issue (Nathaniel, MHC).*

This notion had clearly been transmitted to some of the clinic staff who - as biomedically trained NGO workers - most often diagnosed open mole as depression, anxiety or trauma - despite the variety of conditions patients described - some even admonishing patients for using the term;

*There's an everyday word "I've got open mole"... Open mole is a way for our patients to describe what they're going through. Some take a severe headache to be open mole, they say "Oh my head is hurting, it feels like it wants to burst, I think about open mole"... We relate that to physical, social and family problems... If the person describes hopelessness, worry. We say "all the things you are describing, it's what we call depression... there is a word, we call it depression" (Adam, PSW).*

*We say "there's nothing called open mole, its either a thing called anxiety, depression, PTSD, anxiety disorder bla bla bla, trauma... If you leave Liberia, you will not hear anybody else talking about open mole.... What's happening to you is not open mole, it's depression, it's anxiety disorder"... When you explain to them, they might not believe you because all their lives they have known it as open mole, but as they start to take their medication, and they start to improve... then they will start to know that what you told them is true (Bridget, PSW).*

In discussing previous treatment of open mole at the JFK hospital and now at the MSF clinic, Jay was confused about at which clinic who said what, but it was clear that her clinicians were critical of the use of the term Open mole, and now she also said she changed the terminology she used (although she still told me her diagnosis was open mole);

Jay: She said it was depression that can cause the thing we called open-mole, there's nothing they call open-mole, in standard English it's called depression. We are the ones who called it open mole but it's depression... [Another clinician] said... "there's no way that your mole can open... so in biology or in science field there's nothing they call open mole".

RW: And how did you feel when he said this?

Jay: I felt bad but then later when he started to explain things to me, I came to myself... We the Africans we just called it open mole, but when I just say the scientific way then it can be depression and anxiety.

**Some visiting psychiatrists and psychologists have denied the existence of open mole. This had clearly been transmitted to some of the clinic staff who admonished patients for using the term.**

This is despite growing up with the concept of open mole. For example, the ICM explained how her mother used to put cooling paste on her head for open mole and said: "before I knew any medical -" cutting off to say: "it's caused by high concentration and stress and pain on the head". In this way, staff often overlay their early accounts of open mole with a testament to their greater insight and knowledge resulting from their biomedical training. Somatised symptoms are therefore reproduced as Western rather than local constructions, and patronisingly, patients with open mole in Liberia are seen as uneducated, and are thought to *believe* that they have open mole, but that they do not know that what they describe is actually something else; a different diagnosis (depression/anxiety). Often patients had never previously heard of this new diagnosis. According to Abramowitz (2017), rather than acknowledging open mole as an indigenous illness; an *actual* complaint with an ontologically valid status, such discourse reduces the condition to an idiom of complaint, which negates the embodied experience of patients.

## Stigma

Clinic staff were open about their own previous conceptualisations of MH conditions and epilepsy;

*Actually, I was a bit afraid... I had a lot of misinformation about them; [that] some of them are being punished by some people or because of their behaviour, and probably in the past life, what they did in the past is haunting them now, and sometimes we used to see them, make fun of them... you see them coming, you take something to protect yourself from them or you run away... People with epilepsy, we also have a lot of myths about them... you don't eat together, you don't walk together, you don't even have to care for them like you care for other people, yeah, they are a kind of different set of people among us... you think if you go to help you could catch it from them... People stop them from doing certain things they are supposed to do.... The stigma is from within the community, family members, relatives, neighbours (Elizabeth, MHC).*

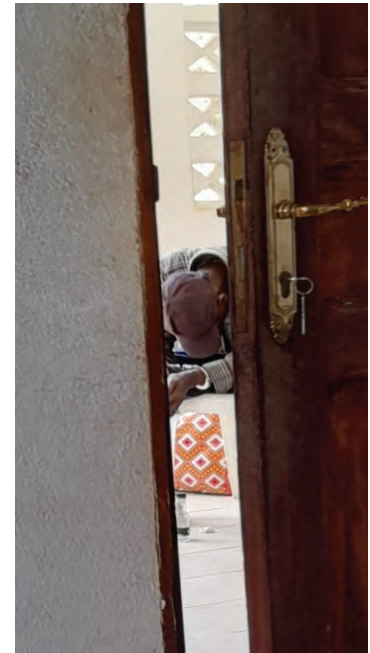
*I used to think it was only people in the dumpsite, picking and eating from the garbage that had MH conditions... then I realised it is not only people who are walking naked in the street... Some patients themselves say they're useless and they want to end their life (Frank, MHC).*



As Mark spoke to me about the stigma he faced due to his depression, he wrote the word that most people said when speaking about MH conditions; “CRAZY”, in capital letters on his notepad, retracing the lettering every time we returned to the topic, and explaining how this led him to deny his diagnosis;

*I used to say to myself “I’m not crazy man” ... to accept that you have this adjective attached to you, that was a serious problem... I refused to take [the medication]... because I felt that I was not a crazy man... People in the community... will say “this crazy one - you will listen to him?” They will say “move from here, you not sound, you crazy man”.*

Bridget (PSW) explained that when patients with epilepsy are describing their symptoms, such as “falling” they do not say that saliva can come out of their mouth, because there is the perception that this really means the person has epilepsy, and they do not want to acknowledge this. It was most common for people with psychosis and epilepsy to face stigma. For example, during an observation at one of the clinics, staff were tending to a patient with psychosis who had become violent. The ordeal was quite



Patient with psychosis in handcuffs

public and dramatic, with the patient, handcuffed, left to sit in the waiting room with the other patients once he had received the tranquiliser, while the policeman who had brought him in kept watch. A mother who was waiting with her 9-year-old son who had autism, observing what was happening asked the PSW worriedly if the clinic was a place for “crazy people”, and asked if her son would receive “crazy-people medication”. On the other hand, when Magda, who had with open mole was asked if she faced any stigma, she responded; “No, because it’s not a bad sickness like epilepsy... thank God it’s not any bad sickness”.

Stigma was not only directed at patients but also their caregivers;

**Almost all patients and caregivers said that they faced stigma from their community or family due to the illness. Severe consequences of this stigma were dropping out/being expelled from school, abandonment and various types of abuse.**

*Some people in the church and community used to tell me “here, her son is crazy, she says her son was coming to go America but he’s now crazy” ... I never argue with them even when sometimes I’m passing and they’re saying “her son crazy, her son crazy” (Ruth, mother of patient with psychosis).*

Healthcare staff said that some patients asked them not to visit their homes, and some would go to a clinic outside of their catchment area as they did not want people from their community seeing them going to the MH department, and others would not go to the clinic at all but preferred to speak to their clinician or

PSW over the phone or ask a relative to pick up their medication for them;

*In [rural clinic] there was not enough drugs for a patient, so we asked them to go to [urban clinic] to get it and she said yes, that she lived near [there]. However, she said she normally goes to [the rural clinic] as she doesn’t want to be seen near where she*

*lives. It was even her son who was the patient [who had epilepsy], not her. It's hard to believe a 3-year-old can be stigmatised (Sam, medical specialist).*

Similarly, Daniel (MHC) stated that people fear going to E.S. Grant (psychiatric) Hospital as “they see it as a prison where you can be punished or treated anyhow”. The stigma also meant that often people would not tell anyone outside of their family about their condition. Severe consequences of this stigma (especially for epilepsy) included being expelled from or leaving school (this was especially the case for girls), thus affecting future job prospects;

*I used to feel bad, I never used to go around people again, I used to sit on my own.... People will be laughing at me so I told my mother “is good that I drop from school... many days I dropped on the ground no one to pick up my copybooks, all will be lost... you can give me business to sell” and my mother said “No because if I give you business, you will not sell because you will go and drop in the street and people will take all of the market [goods]” (Lovetee, patient with epilepsy).*

Other severe consequences included having to move house (as was the case for Jezarrah, a patient with epilepsy). Additionally, Precious (another patient with epilepsy) was abandoned by her father once her symptoms started, and Lisa, MHC explained the abuse patients can face within their family or community;

*When the child is falling... you say “go and draw the water, go and clean”, so they make them work. They overuse their children... because they feel they are not normal so they ill-treat them.*

Through working with patients with MH conditions and epilepsy, this stigma even affected some staff;

*People sometimes make fun saying “You are a doctor for the crazy people”, like, you yourself are not well. The caretaker here asked me a question... in a low tone. “were you mad before? You took treatment yourself and now you are treating them?” (Joseph, MHC).*

The awareness-raising organised by the clinics may be having a positive impact on reducing the stigma; on a visit to a church to meet with a religious healer, one adolescent patient with epilepsy who was currently staying there had a seizure and the other people in the vicinity sat with her and did not move away. Staff were also keen to show the community that epilepsy was not contagious;

*We went to training, and [then] we were walking in Claratown... one of the patients who came from the clinic was walking behind us and she dropped. And she started foaming, people ran... I said “we have to perform what we just learned”... The entire Claratown came to where we were, and everyone made a circle around us, to see what we were doing, because they know that when a person falls, nobody should touch them... But it was different, we were there touching her... So from there we even had people coming to the clinic (Bridget, PSW).*



In summary, the commonly used term “crazy” to describe MH conditions and epilepsy was deeply stigmatising and resulted in some patients initially denying that they were unwell and not taking medication. Additionally, while some (especially male) patients said they are not “moved” by the stigma, it often affected how they sought care, for example, by preferring to go to the clinic rather than having staff visit them or even visiting clinics far away so that they did not risk running into anyone they knew (this is even despite the clinics being incorporated into the PHCCs), which must have been inconvenient for them. It also may have affected the possibilities for informal networks of support; some would not talk to their friends about their condition.

### **The role of caregivers and the community**

*Clinics could be the last point of care; the family and community are spoken to first for help and may provide financial support (Sekou, PSW).*

**The patients’ family, especially parents and siblings played a large support role and often made key decisions regarding their healthcare.**

*[My sister] is a nurse, and she’s number one... she finds my drugs... Everybody is taking care of me especially the doctor, my sister and one of my brothers (Kruahtaye, patient with epilepsy).*

*We ensure the caregiver comes along. We say “you are the main doctor, because we are not in your home... so you need to play this role”... We see their caregiver to educate, how to encourage psychosocial support, patient self-care (Adam, PSW).*

While husbands, fathers and brothers were some of the male caregivers mentioned, the main caregiver in this study and cited by patients whose caregivers were not interviewed, tended to be female family-members (five of the seven caregivers interviewed were women). These were mothers, mothers-in-law, grandmothers, aunts and sisters;

*They called me... [because] nobody was taking care of him.... I am the only woman, I got five brothers... When I went, I saw my brother’s condition... very poor... I ran down I bought some drugs, fluids, I went I treated him, I told him “lets go back [home]” (Geevon, sister of patient with epilepsy).*

Caregivers often expressed the difficulties inherent in their role; such as stigma, the time, effort and money needed to find a cure, and sometimes the inability to work due to needing to be at home to look after their dependant (who themselves often could not work and support the household). This meant that they suffered further financial hardship and isolation, and some caregivers themselves expressed feelings of hopelessness.

While sometimes being a source of stigma, members of the local community could also provide valuable support such as helping to take patients to the hospital (sometimes the community even provided financial support for treatment) and provided encouragement, advice, and

counselling;

*I got friends, some guys they can come to me and we lecture together and sometimes they can say “My man like once you are committed and you can pray, things will work out for you” (Moses, patient with psychosis).*

Advice provided included where to get treatment, such as from a clinic or healer, sometimes with this advice seeming to engender an element of pressure;

*Somebody came to me; “try and look for a herbalist, try and go to church, this thing has still long on you, you getting old in it”. You know every time they ring the song in my ear, “look for money, go to Guinea, look for money, go to Ivory Coast”, every day (Michael, patient with psychosis).*

*People will have to listen to people “Yes, you have to do this, do that”... because there are patients who are not able to make decisions for themselves... so whatever anyone tells them that’s what they will do. So, they say “let’s take the person to this place, let’s take the person to the traditional healer”, and in those confused states the relatives of the patients will carry the patient there, but when there is no solution or no improvement, they will have to come back to us (Elizabeth, MHC).*

In summary, illness affecting an individual has repercussions on the family, and so it takes on a collective dimension, meaning that disease is lived through therapeutic itineraries largely driven by relatives and the wider community (Legrip-Randriambelo, 2020).

#### **4.2 Medical and Spiritual conceptualisations of MH conditions and epilepsy**

*Some people say ‘Yes, I know [about the diagnosis], but I also believe in spell (Sekou, PSW).*

In every society, religious, spiritual and cultural values have a significant impact on conceptualisations of health and illness, as well as patient’s healthcare pathways. Local cultural systems provide both the theoretical framework of myth and the established script for ritual behaviour that transform an individual's affliction into a sanctioned symbolic form for the group (Kleinman, 1997). Understanding cultural perceptions of health and illness, as well as these pathways thus requires understanding the spiritual and religious dimensions related to it.

Some patients held biomedical understandings of disease. For example, Jezarrah believed his epilepsy was caused by an anaesthetic he had been given for an operation, Moses believed his psychosis was caused by stress, and John - while at first believed, like his family, that his anxiety was caused by witchcraft - after discussing with clinic staff and conducting his own research, was now sure of the cause being past events and stress;

*Sometimes war zones, sometimes loneliness all these leads to anxiety condition... a genetic confutation... stress, depression... During the war... I was 6 years old.... someone shoot, they kill the person in front of me, so that memory can strongly lead to anxiety condition, and... people saying negative things like your parents saying “you*

*will not make it in life”... so I learned from it that this anxiety was a medicine thing, it was not a witchcraft thing. It was a natural something that happened. So I... started to do research and discovered that it was exactly condition that was happening to me.*

Additionally, some healers used medical terms to describe various conditions and their causes, such as epilepsy, elephantiasis, infertility, stomach ulcers, typhoid, malaria, meningitis, snake bites and drug use. However, people usually believed that various symptoms were not “caused by an illness” (Lisa, MHC).

**Seven healers and most patients said witchcraft was responsible for MH conditions and epilepsy, and healers often listed “African Sign” (a curse conjured using witchcraft) as a condition they treat, denoting that they saw it being not only the cause of certain diseases or injuries, but also a disease in itself. This belief was held alongside the belief in a Christian or Muslim God.**

It was usually believed that the bewitching was caused by a jealous family member or friend due to having more material possessions, a good job, intelligence (procured through ‘magical’ means), being stronger in the spiritual realm, or -especially for men - by a woman whom he had wronged or cheated on. The bewitcher was believed by Luke (PSW) to “want to play witch against God”, and the curse was achieved by visiting a medicine man and/or putting ‘poison’ in the victim’s food, or ‘throwing’ ‘African sign’ (spiritual or demonic forces), in the form of a shadow which would cause misfortune. Patients and their family members tended to agree that they had been bewitched;

*Hallie (father of patient with epilepsy): [The Pastor] told me that it’s you they were after [rather than my son], which of course what he said is true, because somebody tried to poison me traditionally.... and the man told me that... since they didn’t get you, it’s the reason they got your son... Somebody brought a poison at my door step... so the thing on [my son], I could consider to be the [poison] on the porch.... that medicine [poison] is always made out of that palm tree.... They bring that thing between Sierra Leone and Liberia.*

*RW: Who was trying to do this?*

*Hallie: My best friend... when he lost his job, they replace me with him and he and myself was working together, so he tried to shift blame on me... nobody told me that, but I used my own judgement. Because my son is in the medical field.*

Hallie believed there was a difference between natural epilepsy and epilepsy caused by poison – which he thought his son had due to the severity of his condition;

*I felt discouraged, because... somebody say the natural epilepsy can finish, but this one, when somebody poison you... it’s hard, so when they say your child’s got epilepsy you wonder... This case, I can’t get over it... [Other] people with that sickness, [there is someone else with it], the boy can play football... but my son has [seizures] every day, so I wonder, is this sickness really natural? Or is it poison?... he was not born with*

*epilepsy. I went through the medication, the vaccines, everything... then all of a sudden, he's convulsing, so is that natural? I don't know. I did not expect it to go that far.*

Similarly, Ruth and her son Peter, who had psychosis, believed the condition was related to him failing to obtain a US visa – which he had been trying to get for the past 10 years – supposedly because of bewitching by his ex-girlfriend; “When we went for the interview... there where the madness started from”. As an aside, two other patients also related their illness to a visa application (and consequently access to a supposed better life) being turned down. One patient with epilepsy had tried to get a visa to the US but was refused because he was considered ‘ill’ – supposedly contagious. The patient believed that the failure to get the visa was the cause of his epilepsy, not the other way around.

Additionally, one Pastor told a patient that he had been bewitched by a traditional healer he had previously seen because he did not pay him. Another believed that Precious’s epilepsy was caused by her name and advised her to change it. Nancy was even told to leave her house because someone had bewitched it as they wanted her land, which was the cause of her psychosis. She recalled that a man in her community had had a conflict with her husband, but because he could not hurt the husband, he had told her “[I have] something in my hand and if you play with me, I will destroy your life”.

Patients also believed in biomedical and spiritual causes of their illness at the same time. For example, Jay believed her open mole was caused by a lack of sleep due to studying too much and worry related to not knowing what her illness was, and at the same time, that a “nightman” (djinn) and her grandmother had bewitched her;

*[She] put a snake in my head... because she's my step grandmother, yes, she don't want to see me improving in life, she don't want to see me going back to school, she don't want to see anything good coming from out of me and since I want to be a Christian [rather than Muslim] she will give me hard time... She will just wake up midnight, I'll be laying down and she will be standing over me... and the moment I start to sleep I will feel something entering my body from my head... and it will just be there until in the morning... then when I wake up, I see [my grandmother] standing over me she will be just be acting like she coming to pray.*

Similarly, Peter who was diagnosed with psychosis believed his illness was caused by a combination of witchcraft and smoking marijuana.

**The diverse definitions between diseases with biological causes, and those with spiritual causes leads Liberians to make distinctions between biomedical and spiritual treatment. At the same time, spiritual and biomedical treatments in general do not appear in opposition, but neither do they fully integrate. These sometimes dissonant articulations can lead to a weaving between treatment models that transcend religious affiliations and biomedical models.**

MH conditions and epilepsy especially were synonymous with spiritual conditions.

*They say mental health is not a common hospital sickness like malaria, diabetes developmental delay, autism... because they believed that either it was caused by ancestral spirits, or it's a witchcraft behaviour or it's the person's own wickedness that make other people to [bewitch] them (Wilton, patient with psychosis).*

This was particularly the case with epilepsy;

*Some of them say... someone has bewitched them, because of what they see... Some of them complained of seeing fire before their seizure, some of seeing a djinna, that is a devil in front of them, seeing water, a lot of things... they think because I saw these things it's a witch (Paul, PSW).*

Kruahtaye believed his epilepsy was a divine punishment;

*I'm just a sinner, nothing... sin number one sexual immorality, because when I left my children's mother after other women, that was the time I got sick... and besides that, lying is sin, stealing... [People] have said to me "ooh, you are responsible. You are the cause of your illness". I say "well, my agreement is that if I was not lying down with her, yes, I was not going to be sick".*

As the illness was caused by immorality, it needed to be cured through asserting moral capacities. In this way, the role of the patient - such as their faith in God and their adherence to any restrictions the healer might put in place during their treatment (such as no sexual discourse) - was also important in their healing.

In summary, the plurality of meanings given to MH conditions and epilepsy by healers, patients and caregivers (explored in section 4.1) generates diverse definitions between "foreign diseases" with biological causes, and "African sicknesses" caused by witchcraft. Following this logic, Liberians make a distinction between foreign, white or kwe<sup>14</sup> medicine/treatment (biomedicine), and spiritual/religious treatment (traditional medicine). At the same time however, the approach to illness and healing is complementary and syncretic; religious/traditional care and biomedical treatments in general do not appear in opposition, but rather in an "oppositional mimetic" (Obadia, 2007). They do not always exclude each other (although this is sometimes the case), but neither do they fully integrate. These dynamic, and nevertheless sometimes dissonant, articulations can lead to a weaving between models for patients, which transcend their religious affiliations and biomedical models (Legrip-Randriambelo, 2020). Some of the ways this is achieved is explored in the following section.

### **Reasons for people going to traditional and religious healers**

*The healer can heal (Paul, PSW)*

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<sup>14</sup> This is an originally Kpelle term meaning 'civilized' and now is often used to refer to biomedicine.





There were five main reasons people went to traditional and religious healers;

### 1. Spiritual treatment for a spiritual illness

*If it's a spiritual thing and you take a tablet, it won't work (Esther, religious healer).*

Ruth's first point of call when her son experienced symptoms of psychosis was her pastor; "I called my pastor because of his behaviour... we run after him then take him straight to the church". It was logical that one would first receive spiritual treatment for the djinna or demon, and on the other hand (sometimes at the same time), biomedicine to treat the physical expression of a condition;

*We believe that what occurs in the physical originates in the spiritual. Demons are real and they are spirits, and to operate on the spiritual, they need a physical entity – the body. Any sickness could be caused by this, including malaria and epilepsy. We should always medicate every sickness, but I don't believe that every sickness is medical. Some believe in hospitals, some in prayer... If they are already on medication, we don't deprive them, if it cures, thank God. We keep applying the spiritual part as it brings out the solution... Once a family brought someone, we prayed and I referred them to the hospital as what we observed was also medical, not only spiritual (Ramsay, religious healer).*

### 2. The search for a cure

The belief in a spiritual cause also allows for the belief in and hope of a spiritual *cure*. Indeed, people were looking for more than treatment from religious and spiritual healers; but for healing;

*Hallie: You go to the church for healing... You want to be well.*

*RW: Okay, and the medication is not healing?*

*Hallie: No, that's not the point actually... you want the medication to be backed up because you have the tablet and you praying to God, then it is in force, so the healing maybe in that direction may come sooner or later... [My son] himself wants to be cured, but the time is not yet here.*

*Mark: People have gotten healed, from the traditional healers... [and] from the faith base...[My] last episode we went [to a healer] because...they had the belief that this man could do it once and for all... [and] I have one of my wife's first cousins... who had epilepsy and went to the faith base and he was prayed for and he's completely*

*healed. He didn't take any medication... This is what the herbalist adds the clinic can't provide, they claim that they know how to deal with the witchcraft, then the religious institutions, they claim that they can deliver<sup>15</sup> the demons from the person...*

*RW: Even if the person is feeling better from having medication?*

*Mark: No, they don't, they know that they can feel better today and get worse tomorrow... I had twelve different relapses.... People are looking for a situation where they don't have to be taking tablets all the time, they don't have to suffer from this thing anymore, they want a quick result... Taking medication is like slavery.*

People knew that medication would not necessarily cure them, and that they may have to take it for the rest of their life. Medication therefore was used as a 'back-up' to prayer or traditional healing. Indeed, there are many diseases that biomedicine is not able to "cure". Patient non-compliance and dissatisfaction with care is argued to be in part a function of the absence of healing in modern health care (Kleinman, 1997). For example, through a biomedical approach, while 65% to 70% of people with epilepsy achieve long-term seizure freedom with the first or second antiseizure drug prescribed (Ventola, 2014), symptoms can still 'only' be managed but not 'cured';

*They will try to go to the traditional healer first. If the traditional healer does not help them, they will come to the clinic... From the clinic, you have some people and the child is still falling, so they will stop the medication and go after the traditional healer, because they think that when they come to the clinic the child will stop falling and never fall again, and that's not the case... they feel discouraged (Bridget, PSW).*

On the other hand, deliverance "is permanent" (Jay, patient with open mole), and, as evidenced above, some patients knew of someone with the same condition who had been 'cured' by healers. Healers also said that their patients could be cured; Ramsay (a religious healer) stated; "We have got solutions for them. They were solved, healed and set free... by prayer". Additionally, Bendu (a traditional healer) said she does not need to refer anyone to the clinic as she herself can heal anything. Similarly, Thomas (a religious healer) stated that "By God's grace, nobody ever comes and goes with the problem... if it's not helping, this guy [pointing to a man sitting nearby] would be in chains". When healers did say they could not cure everything, the reason was said that it was because it was a medical and not spiritual illness.

Indeed, the need to make curable, ailments described as incurable by a medical expert encourages patients and their families to explore and experiment with pluralistic therapies (Legrip-Randriambelo, 2020). Healers' hybridity allows them to be mobilised dynamically, allowing for complementary approaches. This may be especially important for MH conditions, where symptoms and social representations can evolve over time.

### **3. Holistic, patient-centred care**

*They have a good response to having a solution. It's difficult if they don't know [the solution] as they become nervous...it builds spiritual capacity, ability and mind, to get*

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<sup>15</sup> Practices and rituals to cleanse people of traditional or Christian demons and evil spirits.



*stronger and better. With counselling, once they understand they can individually take a stand... We don't just pray, we talk to them (Ramsay, spiritual healer).*

Traditional and religious healers usually take a holistic approach that includes not only the patient but also their socio-cultural environment, as opposed to biomedicine, which is prepared on a mass scale and so does not meet the needs of each patient. In this way, traditional and religious healing is a collective effort within various therapeutic cultures that define the interfaces between health and disease (Alice Desclaux, Diarra, & Musso, 2020). It was found in Sierra Leone that people viewed traditional healers as being accessible, welcoming, understanding and treating them well (Burtscher, 2020). In our study healers provided diagnosis, first aid, sometimes financial support for treatment, and counselling; listening to patients and practicing a “narrative medicine”, based on patient discourse. In this way, patients were considered key players in the healing process and not as passive receptacles of a medical science which asserts itself as unique and legitimate (Fancello, 2020). The traditional healer also always prescribes medication or performs some healing acts, and they may spend a significant amount of time with the patient. Indeed, Mathew, a religious healer said “People can come at any time at any hour”. Another 2016 study in Liberia found that traditional healers were much more caring than nurses and doctors (Modarres & Berg, 2016). This could still be the case today;

*Sometimes some of us [staff] don't know how to talk to them... sometimes we come from different different backgrounds. Sometimes my approach I may not mean any harm, but... my harsh way of talking... Some maybe when you come and you are not in a good mood when you come in you say “Hey, sit down! move from here! Don't enter here! Where are those masks?!” ... Sometimes they will see a traditional healer before coming to us. And sometimes the traditional healer pays more attention to them (Lisa, MHC).*

Experiences at hospitals also tended to be negative, as they were expensive and sometimes involved poor treatment, misdiagnosis and misinformation;

*My Mum took me to the clinic. To Elwa, JFK, but they couldn't see anything, what they saw was typhoid.... but then later when a traditional woman entered... I was crying from my head. She says, “what happening to you?”, I say I just feeling something walking in my head, so that how she told me that “this is not something that you be in hospital its traditional something”. “You go to herbalist they will put medicine on your head, that is open mole”. So that was how they discharge me, and my parents brought me home and they started to do the herbalist something (Jay, patient with open mole).*

*Some don't want to stay 3 or 4 days at hospital so prefer the church. People give up and say "let me pray to die then go" (Mathew, Pastor).*

**People view healers as being accessible, welcoming and understanding. They spend time with the patient, always providing some kind of healing practice and counselling; listening to patients and practicing a "narrative medicine". In this way patients are considered key players in the healing process rather than passive receptacles of a medical science.**

Wilton said; "The hospital told me 'you need to live on medication the rest of your life because bipolar is the worst kind of mental illness'". On the other hand, the setting of religious and spiritual healers may also be more pleasant and private than a hospital; Bendu (traditional healer) showed us to a small, quiet clearing in the forest with bamboo beds where she treats her patients. In comparison, many biomedical settings are busy and stressful places, with shortcomings in material and human resources and where - as evidence above - staff can sometimes be impolite or rushed.

#### **4. No other option**

Herman et al., (2018) in their study among traditional healers and MH patients in Monrovia, found that participants preferred biomedicine to traditional medicine. Despite this, an earlier study in Nimba county, Liberia found that patients (with various conditions) only used the formal health sector three times per year, compared to 10 times from the informal sector, possibly due to lack of availability and cost of the former (Kruk, Rockers, Varpilah, & MacAuley, 2011). A similar phenomenon could have been at play for some participants in this study; to their knowledge, they had no other healthcare option or did not know what the illness was;

*I was suffering too much... I wanted to go in the interior so they can tell me what happening to me... to the medicine man, because at the time we didn't know any hospital to go to (Nancy, patient with psychosis).*

Indeed, previous to MSF and other NGOs providing MH services, there was only one psychiatrist in the entire country; while there was a limited number of MH clinicians, there would have always another healer to consult.

#### **5. Denial related to stigma**

Another reason for people going to healers was due to denial due to the stigma related to MH conditions;

*It's because of our society... our culture, anything that has to do with MH/epilepsy they say is not medical – its attributed to war – like you got medicine to help you fight and this goes against the medicine lore – so they go to a healer because it's One; a healer/demon issue or two; Stigma – when you tell people to go to the clinic they say "but I'm not crazy!". They think it's because of the demon or a family member did something because of jealousy, so they go to the herbalist or Pastor for deliverance (Frank, MHC).*

Below traditional and religious healing is analysed in detail, including their similarities and differences.

### *Traditional Healers*



Advertisement for a traditional healer on one of the main roads (Sinkor) in Monrovia

*Traditional healers see themselves as between the spiritual and physical world.... The first thing people think about is the spiritual aspect and think the clinic can't deal with that (Sekou, PSW).*

Fifteen of the 23 patients and caregivers said they had been to see a traditional healer in the past and all said that they were no longer seeing one. In addition to the 15, Marta, the mother of a patient with epilepsy said she did not see any traditional healers because; “I don’t believe in all that thing, only God... through God, God can make the doctor to give medicine, it helps, that’s all”. Afterwards, the PSW said that the caregiver and her daughter had been to see many traditional healers, and that she may have said she did not due to being embarrassed about it.

Most patients had seen between four and six different traditional healers, with some saying they saw more than they could remember. Two patients/caregivers had been to see a healer in Guinea; Jay (who had open mole) was sent there because her grandmother – who was a healer – lived there, and Hallie (whose son had epilepsy) had heard that traditional healers are cheaper outside of Liberia (although he was surprised at being asked for \$700<sup>16</sup> when he got there). Patients could stay with traditional healers for up to three years, or the patient would regularly go to them/the healer would visit their home. The religion of the traditional healer was not important; for example, a Christian patient could see a Muslim healer.

The decision to see them was normally made by the patients’ family members, mostly their mother, followed by their brother, sister, wife, husband, father, cousin, a friend, themselves, and even in one case, a church member.

### *Reasons for seeing a traditional healer*

In addition to the reasons presented in the previous section, patients and caregivers said they decided to see specifically traditional healers because they faced pressure from others;

<sup>16</sup> All values are given in US dollars except when stated that the value is in Liberian dollars (LRD).

*We were looking for a solution... When I went to the medicine man... I wanted it quick to get healed, but [my son] used to say “Mama I want no medicine, God will heal me” ... All of us we were confused, so all of us used to take him. Somebody come and say “oh Ruth I know somebody, let’s go try, its nothing but trying” (Ruth, mother of patient with psychosis).*

*They asked me to carry a red chicken, and a black chicken that they was going to perform a ritual that the person who bewitch me could die, so my wife was sitting like this, my cousin was sitting like this, and poor me was in the middle [laughing]... because I want to be healed, I never said no to them, I was always saying yes, only to get healed. That was my only thinking... I really didn’t believe [the healer]... [My family] were feeling frustrated because I’ve been sick for almost 30 years... so they said “Well Wilton we will give up on you, this is your last option, you refuse to go there we will give up on you” ... So we went (Wilton, patient with psychosis).*

*I got fear in me, I don’t want to see traditional person, they convince my mother... they brough him to the house... I disagreed with that, but they force it... I felt that it was not a normal thing that they were doing, it was trick (Moses, patient with psychosis).*

### Traditional healers’ understanding of illness

Two patients said the traditional healer did not tell them what their condition was, or the cause, however most told patients (especially with epilepsy and psychosis) that their illness was caused by witchcraft, ‘African sign’ or various djinna<sup>17</sup>. One healer believed the causes to be dust, nightmares, sorrow, if a husband forces his wife to have sex, (adding that it is not good to have sex where the sun rises, as the two Djinna (Rakibu and Ratibu) study there and could take your life). Hallie said that his traditional healer told him his son had epilepsy;

*He said “this looks like epilepsy” because traditionally we all know it... so he said... this lady could cure epilepsy... After he vomited all those frog eggs... they try to say it was epilepsy.... It's not something you can hide, the sickness, it’s something physical... you will see them drop...so when the epilepsy is on the child you can know.*

Patients with open mole were told they had open mole by the healer, who usually said the cause was stress. Magda was told that it was caused by her weave and sharing wigs and combs. Ousmane (traditional healer) believed that open mole was caused by having too many children; “plenty talking the whole day”; “plenty thinking and grey hair, worriness”; holding a heavy load on the head; the sun; and liquor. Moses (patient with psychosis) was also told that his illness was caused by seeing other traditional healers.

### Practices

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<sup>17</sup> Fatoumata (the mother of a patient with open mole) said the healer had told her about A Muslim Djinna which was good, and an African Djinna that disabled her daughter.





Veranda where Ousmane conducts his rituals and the small room where he makes medication and has boards on which are written Quranic verses.

*Case Study: Ousmane, from Sierra Leone is an initiate of the Poro (male secret society). This involves participating in various (secret) rituals, scarring, and making a celibacy oath. He leads us to his office; a veranda at the back of the house covered with bamboo matting, a pile of dry vegetation in the middle. There are some dried vines/leaves tied to the fence which he uses these to communicate with the djinna. We are asked to take off our shoes, and he walks around the veranda chanting before inviting us to sit. He explains his work; when a patient arrives at the front of the house, he calls to his wife to ask the person's name. On top of the pile of vegetation is a bound stack of reeds, which he holds up and lets go of. If they fall, the patient cannot be cured and is sent home. Ousmane chants (by memory) some verses from the Quran that he has pulled from under the vegetation pile and makes marks on the paper beneath where he has written 'Allah' in Arabic, based on what has "come to him". At the bottom of the page, he circles some of the marks and says from this he knows whether the patient will get better and how the day will be.*

*Under the vegetation some vines are bound in a circle that he says he can turn into a snake. He also withdraws a candle and razorblade, saying that when the patient comes for protection against African sign, he puts the candle on the stomach and uses the razor to cut the patient. There is also a scathe with a tiny plastic hand attached to it. He explains that when someone wants to kill a person, he mashes some leaves and puts them in the patient's eyes, rubs it on their brow and the back of the neck, then they can see the 'criminal' 'inside' the mirror. They then place the knife for example on the 'criminal's' eye in the mirror, which will subsequently be damaged. He can also ask the patient to bring a rooster, cloth, a single-barrel gun with four bullets and a hair pin, which he puts together and when lightning strikes, the 'criminal' will be struck down.*

*He says the Quran states that if he kills seven people in a year, he will also get "crazy".*

*For people with epilepsy and psychosis, Ousmane puts leaves in the eyes and nose of the patient, as well as a talisman (containing verses from the Quran) around their stomach. Then the patient lays on the matt and sleeps as he recites Quranic verse. He chews some leaf and spits it on them and in their eyes and mouth. To check if they are well, he asks them to cook for him. If they cook well, they are better, and if not, they have to continue until it is satisfactory, which "proves they are well".*

Many healers, like Bendu (traditional healer) said that the treatment was communicated to them by God; "What God told me [about the leaves] you will not know where to go. God has given me the wisdom". The most common practices used were making mixtures out of leaves (the names of which were not disclosed) or bitter-root, red (palm) oil, chalk and/or pepper for the

client to rub on their body, drink, put in the nose, eyes, mouth, on the head or in the anus; spiritual baths with leaves; fasting (to expel the devil); sacrifices of cattle, sheep, goats or chickens (often to be used to 'kill' the person who bewitched the patient); scarring (according to one patient this placed him in spiritual darkness so his enemies could not see him); laying under a heated cloth; and wearing particular white clothing. Some also had complex rituals involving a number of these practices, as illustrated in the case study. Nancy said the healer took periwinkles (known as kiss meat) out of her arms, and Ruth said they sucked needles out of her son's body; both of which were said to be the cause of the psychosis.

Open mole was treated by the traditional healer shaving or makes a parting on the head and putting a paste made from mashed leaves, spices and chalk along the fontanelle. Ousmane also said he weaves a talisman into the hair.

Wilton (a patient with psychosis) said he had been in chains for two-three months at a traditional healer and Moses explained;

*I was in chains... for over I think one week, and sleeping outside... They said they wanted to train me that I could pay attention to what they are giving me because I was hostile... It was making me hurt, it's too painful, they will take you, lock your hands, lock your feet and shove you down under plum tree, you sleep there, you know, it was too painful; these hands were swollen, so painful.*

#### Payment

*The first treatment attempt we went to it really bankrupt my Dad (Mark, patient with depression).*

Magda (a patient with open mole) said the traditional healer she saw was free, but all others said they were very expensive; between \$10 and \$700 (one however had to pay \$1000 for staying with the healer for a year), with most being asked to pay around \$300;

*It's plenty [laughs], it's really plenty. My first time... I went there with \$17000 LRD... no result. We went back for the second time \$140000 LRD, still no result. We went right around Kakata... \$9000 LRD - we left there nothing. The man who came here to work on [my wife]: \$3750... [plus] alcohol and cigarettes... a big rooster, nothing<sup>18</sup> (Saah, husband of a patient with psychosis).*

It was common for traditional healers to ask caregivers for various materials such as goats, sheep, chickens, rice, buckets, candles, water, oil, salt, mattresses, bedsheets and pots. They also often had to pay for transportation to get to the healer. One caregiver even had to pay when they wanted to take their relative home early.

Traditional healers stated monetary price was similar (although slightly less) than that stated by patients; ranging from between 0 and \$300. Ousmane said he charged according to the sickness, for example if someone was "jerking", he would charge \$250, whereas for fortune-

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<sup>18</sup> The total amount this patient paid was about \$150.

telling he charges \$20. He explained that if he charges wrongly, he could get ill, and justified the cost by saying said that at the clinic you also have to pay and because he needed to buy food (a sheep) and other materials for the patient (however, later in the interview he said that the patient had to buy the materials before they came). This was frustrating for staff because the treatment at the clinic is free;

*Yesterday there was a patient who spent \$300 on alternative treatment. They had been hospitalised due to cluster seizures. BJH [hospital] asked if they could afford a CT [computerized tomography] scan and they said no... (Sam, medical specialist).*

### Impact

*I don't believe in the African medicine anymore because the mind is calming down, only by study done and pills prescribed, and we pray (Kruahtaye, patient with epilepsy).*

In contrast to religious healers, all patients who saw a traditional healer said that it had not worked for them (Ruth, said it had even made her son's psychosis worse), or if it did work, it only did so in the short term;

*He told me to sniff the flavour leaves... I started coming through... to the extent that I wasn't running in the bush anymore, then all those voices that used to flog my head demanding me to do things subsided... the period of time I stayed with the traditional healers... one month or so, you know my whole mind was settling (Wilton, patient with psychosis).*

Some were now skeptical or believed the healers to be crooks;

*They lie, they take heavy money from me when they do nothing (Saah, husband of patient with psychosis).*

*Scammers, just to get money... the man will say that the spirit is incarnating and telling him what to do, which off course is a lie... I didn't go back there because I know what he was after and what he was doing is a complete mockery... when you fall prey to them, they will just extort money from you and at the end of the day nothing you will get from it (John, patient with anxiety).*

John said he would tell people not to see traditional healers but to go to the clinic instead. A number of patients also did not like the idea of the healer 'killing' the person who they believed bewitched the patient;

*I can't do sacrifice... somebody saying "give me chicken", I don't like it because in the Bible some people say when you do it either it's yourself you giving or you killing somebody (Joy, patient with open mole).*

Many patients went to hospitals and clinics after seeing healers because the traditional healing was not working;



*My brother and I have gone to so many traditional healers and it didn't help me, so he said let us go to the clinic so the clinic can try (Islah, patient with epilepsy).*

### **Religious Healers**

*[Laughs]... You know God is the boss (Moses, patient with psychosis)*



Church of a healer in a rural area, with his patients sitting under a tree.

Patients often saw both traditional and religious healers at the same time,

*[My father] believes in the traditional thing, and my mother don't believe in it. My mother going in the Christianity side... So his side is for me to go to traditional healers to help me and my mother want for prayer to help me (Moses, patient with psychosis).*

However most visited traditional healers first, and when they did not deliver a cure, they then went to religious healers. Fourteen of the 23 patients and caregivers (61%) said they had and/or were currently seeing a religious healer. Most had been to between two and five churches (some many more), in search of a cure. In contrast to traditional healers, the religion of religious healers matched their own religion, except for one patient (Jay) who was brought up Muslim and said she would 'sneak' to a Christian church for healing without her family's knowledge. According to Jay, this was because she was able to read the bible and not the Quran, because she had an affinity to Jesus, and because she had had a previous bad experience with a Muslim healer. The decision for the patient to see a religious healer was usually made by the patients' family members; normally mothers, fathers, brothers, husbands, and wives.

**Many Christian patients went to Pentecostal churches, known for their teaching of divine healing.**

### **Reasons for seeing a religious healer**

*The pastor used to tell me to have faith, "God has healed you, you will never die... you will never die, you will live and give testimony", and it happened (Joy, patient with open mole).*

In addition to the reasons discussed in the previous section, the main reason people went to see specifically religious healers was because faith in God was a key part in their healing; in order to encourage her to take the medication, the gCHV told Nancy (a patient with psychosis) "you can't pray without faith", using prayer as a metaphor for the medication. Indeed, most (13 - 77%) patients and caregivers believed that the treatment worked because God had provided the

medication and the healthcare staff, and worked through them. This meant that faith in God was a priority. Nancy's husband, when asked if anyone helped him to take care of Nancy, responded; "No, nobody. God". Similarly, Ruth, the mother of patient with psychosis said;

*Through this medicine God helps, God is first... [My son] was on the street, but God take him from there. All the country medicine, church people I passed through, the medicine, but God is first, God will intervene in that medicine... God is first and [the clinic] solved the problem... the medicine, he is taking it for his mind. At the same time, we praying God can deliver him.*

*I always attend service to involve God... God intervene through the medication that's why am healthy now. We believe that in Africa we don't have physical enemy but we have spiritual enemy. So we believe that if God isn't involve in it, the spiritual enemy they will still come back and infect that particular medication that you are taking.*

At the same time, Jezarrah held the seemingly contrasting view that people should not go to see traditional or spiritual healers for conditions like his (epilepsy) and should only focus on medication; "You just need medication and not like country doctor or going to any spiritual man". In this way, there could be a difference in perception between spiritual healers you go to or stay with, to treat a particular condition, and going to the standard weekly church service.

Jay (a patient with open mole) went to church;

*...to set myself free. I know for the medication... they will not fight spiritual battle for me, they will only do a science something, the clinic will not do spiritual battle. So I go to the church for spiritual battles then I go to the hospital for medication to get rest in mind, sleep and get free from anxiety.*

The need for medication *and* prayer also worked the other way around; Geevon (the sister of a patient with epilepsy) said that one could not only pray without medication, that both were needed for healing;

*He is taking the medicine, at the same time backing it with prayer... It's foolishness to say "I have faith, I'm going to church, [so] I will go lay down on the road and a car will not kill me". [So it's] not because you going to church you will say I will leave the medicine... if you only go to church, you don't take the medicine, it will not work... God give the knowledge to the doctors to provide the medicine, so the medicine and the spiritual one they work together.*

#### Religious healers' understanding of illness

According to patient narratives, fewer religious healers than traditional healers claimed to know the cause of the patient's illness, but like traditional healers, those that did said it was caused by witchcraft/djinna.

## Practices



A church service in a rural area

*You will have to give your own prayer request... The man deals with a huge number of people. I wish you could visit there one day to say the crowd for yourself, so to see that man is not an easy thing... If he tells us to buy the mantle, to buy the anointing oil, or do this and take like the water, you take it.... I'll go and sleep there and spend the whole day when we have the service, then I come back in the night (Hallie, father of patient with epilepsy).*

People who stayed at churches did so for between a week and three years. The main forms of treatment offered were praying (including over holy water or oil); having 'holy baths' in holy water or oil; drinking holy water, oil, or Vimto (which represents the blood of Christ); having the oil rubbed on their body; fasting; deliverance; counselling; and Bible study.



The Bible and "healing" water

Some pastors, like traditional healers, also provided 'herbal medicines' made of leaves, to put in baths and food; made sacrifices with chickens and/or sheep (according to one patient, the blood of which was then placed on his head); and conducted various rituals: Thomas said he takes people into the bush (called The Mountain) where they dress in white, fast for 21 days, clean themselves and pray, including for an end to war. Mark (a patient with depression) said when he was at his church;

*We slept there and then at midnight... because they believed that witchcraft fly*



Chain used by religious healer for patients with epilepsy and psychosis

*at night... they will be singing... all of you have to pray... I'll lay down there and then... they will put candles around me... They say candle bath, candle cycle... then they say "we now dealing with the demons"... I was [with one healer] for over two years... I was a skeleton... I fasted, and then... they say you should eat dry garri with coconut, cassava so you see how painful that is... I was in chains; they give me something they called devil incense... They lay you down, because it's so painful I'll be fighting, everyone will come and hold me... and then they will put that thing in your nose, that thing go straight into your head... it burns more than even pepper when they put that thing to your head.*

Geevon also said her brother (who had epilepsy) was not given any food while he was staying at the church, and there were reports of some patients not being given water. Ruth, (the mother of a patient with psychosis) was displeased at the use of 'herbs' by the church, saying "it looks like he was doing medicine but he was using God's name", as this particular Pastor was not also using prayer.

To the religious healers these practices had a 'logical' explanation; beating was used to "get the devil out", and patients were put in chains to "calm them down". Mathew explained; "I chain you for 1 week to 2 months so the spirit can talk to you, pray, then the spirit leaves you and you're normal". Thomas said he chains people with psychosis by their foot, to the tree or the wall "because they're not sane and are fighting and there's a demon". One of the MSF clinics' patients – an adolescent girl with epilepsy – was currently staying with him and had previously been "tied" and was "now fine". He did not try to hide this practice and even showed us the chain. While it is likely that such practices are underreported, most of the clinic staff had seen or heard of patients being put in chains and/or beaten, either at the family home or when staying with a religious healer;

*There is a church in Sinkor that... has close to 50 patients all in chains, they are locked up in the room... So this lady claim to be a catholic sister who according to her was instructed by God to treat those people... you take this chamber and defecate in it... sometimes somebody gets aggressive get angry takes this bucket and throws it over other people. There were so many of them there, so many, she could just go to the street and*

**Abusive practices seemed more common among religious than traditional healers. Four patients, all with psychosis reported being put in chains at a church. The fact that a term to refer to people with psychosis was "people in chains"; shows how common chaining people with psychosis is.**



*just collect them and chain them in that room (Nathaniel, MHC).*

Staff addressed this by trying shut down such establishments through reporting them to the MoH and the Ministry of Justice, talking to the family and healers, and where appropriate, educating them on MH conditions and epilepsy, involving social workers and/or referring patients to the clinic or E. S. Grant Hospital. In the meantime, sometimes clinic staff would take the patient's medication to them. According to staff, sometimes if a healer knew that staff were coming, they would take the patient out of the chains or would not be there when the staff arrived. Family members were open to discussion and would sometimes remove the patient following their advice;

*I almost called the police on one of [the religious healers], but then I did it another way... I phoned the families of this mentally ill person and discouraged them from keeping their family there... because it's complete abuse, infringement of rights. But I didn't call the police because the person was close to me, and if I called them the person would - ... we can pursue anyone who does that kind of thing... Three, four families then got their family members from there (Luke, PSW).*

#### Payment

According to the religious healers, God communicated to them what the patient needed to pay or provide; Marta explained; "God could say "buy this" – the oils etc... "When they pay they are in our care". Most healers (such as Ramsay) said they provided services (prayer and counselling) for free or for a low cost. They often saw themselves as volunteers conducting "God's work", meaning that patients gave what they could. While some patients also said that some religious healers provided their services for free, for most there were four types of cost: Firstly, there was the transportation cost which depended on where the church was, but Hallie was paying \$1 per day for this, which he struggled with. Secondly, for the pastor, there could be an outright fee of between 50 and \$150. However, this was rare. Most fell into the third category of asking for payment for, or bringing; Holy water, oil, salt, incense, mosquito coils, matches, a mantle, water, mustard seeds, a sheep (to feed the patient), cement, chairs, cups, a spoon, a pot etc. These cost between just under \$1 and \$5.





Some of the items patients of religious healers may be asked to buy, including Florida 'healing' Water (cologne) and Divine Light Herbal Healing Mixture.

The fourth type of cost asked of patients was 'seed'. Mathew stated that nobody paid for a consultation before they were healed. I asked if they paid afterwards and he responded; "the only thing, when I pray, I tell them you must sow your seed, only God can, I can't charge you. God can stand on the seed and heal you". At this point Luke (PSW) cut in to say "the seed is money". The Pastor explained that the 'seed' is for the Kingdom of God, from the heart (to thank God for the healing). I asked how much the 'seed' is and he said from \$500 LRD to \$20, but that some were unable to pay and so came to fulfil their 'vow' later when they had the money. Similarly, when asked if he charged patients, Terren responded that he did not, however, when asked about 'seed', he stated that it was \$5. Therefore, the cost may not be initially stated or obvious. For Joy (patient with open mole), her 'seed' was leasing some land to her church for free.

### Impact

*The power of the faith is strong (Allie, medical specialist).*

Ten out of 13 patients and caregivers (77%) who went to churches said that the prayer and support of the pastor and other church members had a positive impact;

*I was struck by a voice in my ear... "you will die, you will die" ... I ran to the church there where I was prayed upon and that's how the whole thing subsided... It calm down and you know when you depressed it's better to be around people, when people talk to you, counsel you... but loneliness intensify it... It works (John, patient with anxiety).*

Only two patients (Michael and Moses) – both with psychosis who had experienced abusive practices at the church - said the church was not helping them. Hallie also said the church had not yet cured his son (who had epilepsy), but he continued to go in the hope of healing; "[His]

condition still remains the same... Some go there they get their healing on the spot, but some it takes time, I don't know whether mine will come, I don't know".

### Willingness of staff and healers to collaborate

**All of the healers said that they either currently referred patients to the MSF clinics, or that they would in the future now that they know about them, due to the perceived difference between spiritual and medical illness, meaning that they could not cure the medical part of the illness, and because referral would bring them personal gain.**

Five of the eight healers interviewed said they knew about the MSF MH clinics. Healthcare staff often said that healers would not want to collaborate (such as by referring patients to the clinics) due to financial or egotistical gain;

*[Patients] pay money, rice every month. So they do all they can to discourage the family from taking them to the hospital... We went... to see [one healer] if we could collaborate that he can keep [our] patient, but out of chain and that we provide the medication... He was very very angry with us that we want to steal his patient... he asked that [the family] pay... some impossible things that the*

*family couldn't afford, saying "if you want to take your patient away these are things that you have to pay... why can't we go elsewhere to find our patients?" ... And then this [other] church... where there was many patients in chains... the pastor was welcoming... [then he] observed that most of the patients that were provided medication were getting better and the family were like removing them so he shut his door before us (Nathaniel, MHC).*

*Luke (PSW): [Healers] would say the healing process started from them [laughing], because they want glory.*

*RW: Are traditional and religious healers receptive to working together?*

*Luke: They are not, they are uneasy... they think you are going to tell them what they already know [laughing].*

However, some seemed genuinely willing to refer patients to the clinics;

*Yes [I refer patients], because I do the spiritual aspect, and afterwards if they're not cured I refer them... I am happy when I bring them as when they get better, people will know me, and will tell others so will come to me more (Esther, religious healer).*

*When it's not working, I ask the parent to take them [home], I don't want to waste my time on them (Thomas, religious healer).*

Seven (nearly half) of staff interviewed attested to this willingness to collaborate. A 2018 study in Monrovia, also showed that traditional healers treating MH conditions expressed willingness to collaborate with physicians in order to strengthen their skills. However, it also found that physicians were hesitant to collaborate or share knowledge with them because traditional medicine was believed to be inferior or inadequate (Herman et al., 2018). This however did not seem to be the case among MSF clinic staff; Adam (PSW) outlined the importance of this collaboration;

*No matter what you do, this is what people believe, we can't prevent them from going to herbalists or churches, but at least if we build a relationship with spiritual leaders, it can help us work together... One of the things that helped us, we organized an awareness session... a Pastor was actively attending... He's referring patients to us now... They also encourage them to come to the clinic and take their medication... There's one who brings the patient for the medication and takes them home... Most people who are seeing a traditional healer we try to talk to them to ask how is it going... It was very difficult because people were not ready to accept it, but as time went by, when they started seeing improvement among patients, it was easier.*

While some healers said they referred patients to the clinics, some also wanted clinicians to refer patients to them so they could treat patients that clinics could not, due to their focus on biomedicine rather than spirituality;

*Nasma (religious healer): Some have been ill for 10 years before they come here... then when they came here they got better... The patient says "I'm tired with the hospital, there's no solution so I come here"*  
*Passer-by: Yes. That's what we've been praying for, to work together. After they go to the clinic, after a week they come down with the same situation. Some have no treatment or it's not working, so we are happy if we can collaborate with [the PSW] so he can also refer them. The hospital has no understanding because it's a spiritual problem.*

**Some healers also wanted clinicians to refer patients to them as due to their focus on spirituality rather than biomedicine, they could treat or cure what the clinic could not.**

#### 4.3 Experience at the MSF clinics

*The medicine they was giving me, it was improving my health, it improved life (Peter, patient with psychosis).*

One patient had heard about the clinics on the radio; however, all other patients and caregivers (roughly half and half) had heard about them through community awareness conducted by gCHVs or word-of-mouth (or both). The latter tended to be from family-members, friends, neighbours (including those who knew someone with a similar condition who was being treated at an MSF clinic) and other patients at other clinics. One patient also said they had been told by a member of staff at Redemption Hospital.

#### Diagnosis

One patient (John) was told by clinic staff that he had anxiety disorder, which he then researched and agreed with. Magda and Joy said they were diagnosed with open mole. Additionally, Kruahtaye was already aware (from visiting a non-MSF clinic previously) that he had epilepsy, and Hallie was aware (from a traditional healer) that his son had epilepsy. However, most other patients and caregivers (15) claimed that staff had not told them what their diagnosis was or explained their condition, and were just given medication;

*Fatu (patient with epilepsy): They didn't tell me anything about my sickness, they only give me medication.*

*RW: Do you feel that you understand what your condition is?*

*Fatu: No, I don't, but I really want to know more about my condition.*

Jezarrah who also had epilepsy, said he was not given a diagnosis but was just told his condition was not spiritual;

*Jezarrah: They never stated anything, but they told me that it's a medical physical problem and it can be solved through medication... I was thinking that they was going to describe the kind of sickness I have...*

*RW: Did they give the sickness a name?*

*Jezarrah: No, no, no, they said it's a medical problem... they told me my medication, I should continue taking it... and they always told me that one day my problem will be solved.*

**Most patients and caregivers claimed that staff had not told them what their diagnosis was or explained their condition; that they were just given medication.**

Similarly, Lovetee, who had epilepsy also said she was only told she maybe had a “mental problem” and to “take the medicine... and tell us what happened then we will start from there”, and Kruahtaye’s caregiver did not seem to know much about epilepsy, believing it is caused by clots of blood in the veins and brain.

For patients with epilepsy, it was also common for staff to say they could have malaria (without mentioning epilepsy), and sometimes advised they should be tested for this first;

*One man come here and said “Old Ma it's not spell on the boy”... So I say “what is it?” They say “some kind of sickness... when the malaria too much it will make you jerk”... The sickness I don't know it finish or it hasn't finish, I want you to check him (Sophie, mother of patient with epilepsy).*

*RW: They didn't tell you the reason why you were falling?*

*Precious (patient with epilepsy): No... the doctors said it means I got malaria in me... when I'm taking the medicine and still falling.*

When I asked about patients not knowing their condition, PSWs said the diagnosis had been explained but that especially for epilepsy, patients may be in denial, and that giving a diagnosis like psychosis may be too much for patients;

*We use their understanding... because... sometimes they feel you are putting a heavy condition on them, you are trying to diagnose them, or something very bad (Paul, PSW).*



*When you use the word epilepsy they will be discouraged, so we don't use the word immediately because they will feel bad and be overwhelmed... They see epilepsy as a devastating illness, big illness, so when they explain it to us, we say it's a brain situation and we talk about the common causes they are able to identify, so for example a head injury, then they'll say "oh yes, I had a head injury... since then I've been having seizures" (Adam, PSW).*

**In some cases, the condition may have been explained but not understood. Patients may also sometimes be in denial (especially about the diagnosis of epilepsy) due to the stigma attached to the condition**

Denial seems plausible considering the stigma attached to epilepsy. This could be why Jezarrah did not mention the word at all during our interview, and why also, according to his mother, he did not tell her anything about his diagnosis after his first clinic appointment because he “likes to hide things” from her, but told -possibly reassured- her that it was not ‘spell’. However, not knowing their diagnosis happened across the spectrum of conditions and most patients wanted to know more about their condition. For example, Nancy (patient with psychosis) said; “I really want to know about my problem, more explanation about my illness, what is happening to me, the cause of it and the name”.

In some cases, the condition may have been explained but not effectively enough got the patient or caregiver to understand;

*Peter: My diagnosis was I was not in the right form of mind... they say I have mental problem.*

*RW: Were you able to understand that?*

*Peter: Yeah yeah... someone who is going out of their mind*

*RW: Did the clinic use any other terms like psychosis or...?*

*Peter: Yeah yeah yeah they used all of that... they explain it but I never get it clear.*

Patients had varying reactions to their diagnoses when they got one. John (diagnosed with anxiety) felt relief that it was not witchcraft. However, Magda, who was diagnosed with depression (but explained it as open mole) said she “felt bad because it never used to happen to me before”. When he found out his son had epilepsy, Hallie said he felt discouraged, as epilepsy is “not a sickness for poor man”, because it is time-consuming and expensive to find treatment.



## Staff-patient relationship

*It hits you because you see the load that they are carrying (Adam, PSW).*



Nvivo Wordcloud analysis from interviews with healthcare staff

All clinic staff seemed to enjoy their work and showed a large amount of empathy for their patients;

*You have to put yourself in the patient's shoes, you have to understand they have a lot on their mind... they're going through a lot of psychological problems, even those with epilepsy... most of them are concerned... "when am I going to get well?... am I going to fall?"... We had a patient who said to me, "Even my mum can say I'm stupid" .... so after some time I started praising him... I had the sister explain a few things and so after I said "Ok let me talk to my friend alone" ... So sometimes when you think about your road, of helping patients, you feel proud, you feel good inside, you have that inside joy, but sometimes it becomes difficult that you are aware that you are seeing your brothers and sisters going through these situations (Paul, PSW).*

*Oh I love them so much, I love them. So sometimes when [patients] come [other staff] say “you didn’t come, you missed your day” I jump! I jump outside “no please! Allow this patient to come in! please!” ... because sometimes things are very very tough... and if you say “you’re not supposed to come at this time”, it can pain them, it can hurt them... I really want to help them, so when they come in, I let them take their time so they are not rushed... I feel pity in my heart ... I really got in this field to see how best to help my people. And I’m happy, I’m so happy, when I’m in the field, when I’m seeing patients coming to me... Because we are not 100% free from mental illness, as individuals, we are not free 100% (Lisa, MHC).*

Hallie (the father of a patient with epilepsy) said “when you have a schedule, you don't miss a day. They will be angry with you”, so it is possible that sometimes clinic staff get angry at people for missing appointments or being late.

International staff also said they had a good rapport and communication with patients despite the linguistic and cultural differences. All staff, especially the PSWs seemed empathetic, reassuring, warm, able to joke with the patients when appropriate, encouraging them, thanking

them for taking their medication, and in the patient's first visit, clearly explaining what the next steps would be. It was common for national staff to give patients their personal phone numbers and said patients often called them to see how *they* were. Frank (MHC) enthused; "Anytime, I say if they have a problem, just call me... I'm always happy if I get a call from them that they're improving" and in a counselling session, Ben said to his patient "Any time you have questions you can talk to me... I'm always here, I live in [your community]". Similarly, Bridget (PSW) explained;

*We have patients from far away coming to the clinic... So we encourage them to go to [another one] because it's closer, but they say "no, we want to stay here because we feel safe". So I say to them... everywhere MSF is, the patient is safe, just how you see me, you go there you will see Adam, you will meet Elizabeth... there will be people like us in each clinic... the people are trained to treat you the same way... call me, call me, any negative feedback call me (Bridget, PSW).*

On their side, all patients and caregivers said they felt close to and listened to by the clinic staff, often saying they felt like family;

*We are family, when I come they are laughing, they are even be joking with us; you know not that kind of frowny face like "what you are doing?" they can be smiling (Michael, patient with psychosis).*

*People take me as their brother... we joke, we have best conversation together... I decided to come here is because here is my rightful place, this is the only area I can get healed (Moses, patient with psychosis).*

*I was free when I explained my story to them, they embrace me very well, they talk to me good and then they told me that I shouldn't worry, that God will do his best and then I started my treatment and I find it very good... they are friendly... I was angry... they calm me down and then I came to myself (Jay, patient with open mole).*

Some patients and caregivers compared their treatment with other clinics they had previously attended;

*I stopped my education... That was when my life started going backwards, I started seeing myself to be a failure but when we went to the clinic, the way they discussed with me that's what give me strength today... I know that I still have future... It's not like any other clinic that you enter and the people make you discouraged... they always giving me courage as a little brother... At many clinics... they will not listen to you, they will not see no valuable things in you because they will see you to be like you are not normal, you are not like them but [at MSF urban] clinic the people always giving me courage... they are lovely people (Jezarrah, patient with epilepsy).*

However, in an observation of a check-up at another clinic for a patient with epilepsy, when the patient said she had been experiencing weakness, stomach-ache and loss of appetite, Ellen (MHC) did not provide a possible explanation or reassurance (as discussed in the previous

section), instead only saying that she would send her to another clinic “and they might give you medication”. She asked which month it was, with no explanation why she was doing this. She then ran through the Patient Health Questionnaire (PHQ9) in a very formal detached manner. In another observation of a first consultation, after the patient explained his symptoms and was clearly distressed; holding his head, rubbing his eyes and asking if he could still work, after reading through – again very formally – the questionnaire, this clinician concluded abruptly; “We will diagnose you with depression and acute psychosis”. Again, there was no explanation of, or reassurance about the condition, just “we will discuss everything in counselling” and that he would receive medication. The patient’s brother who had brought him in asked what psychosis is, and the patient nodded. The clinician responded “it’s a mental health illness and we say the symptoms are acute because it’s short”. Then she explained depression, but not psychosis.

Additionally, while in another clinic one morning, a man with psychosis came in agitated saying that a doctor told him two years ago that he’d be discharged but it’s now been two years and they are still forcing him to take medication. The clinician argued with him, which caused him to become more agitated, and the PSW told him to wait for an appointment, without saying when this might be. Sometimes the communication could also be a bit patronising. For example, in an observation, after Sekou (PSW) explained to the patient about when their next appointment would be, he did not think she was listening, so asked her to repeat what he said to prove that she was. In another, he spoke only to patient’s boyfriend, rather than the patient herself.

Another issue in all clinics was that patients’ sessions were often interrupted by other staff walking in looking for a file or wanting to ask a question. In these ways, staff may sometimes be too focused on the management of care rather than on the individual.

#### 4.4 Challenges related to care

*Most of the time our work is not completed because of the social aspect of it. Patients come, they’re supposed to take medication but they don’t have food or transportation, and at times no family support because the family doesn’t have anything. So at times it’s difficult (Bridget, PSW).*

##### 1. Treatment adherence

###### **Medication**

The most commonly cited challenges related to caring for patients and treatment adherence mentioned by staff and patients were;

- Access to the services due to distance to the clinic and cost of transportation
- Patients not having enough food to take their medication with

**While patients had positive experiences at the clinics, there were a number of challenges; almost half of the patients/caregivers faced difficulties in accessing the clinic (especially in rural areas), due to lack and/or cost of transportation, distance and traffic, time constraints and other priorities such as family, work and study obligations. These issues were said to be alleviated by outreach for both medication and counselling.**

- Missed appointments due to illiteracy (not being able to read the prescription), unstable mind-set, time constraints, work, school or other competing priorities
- Patients presenting late to the clinic (i.e., once their condition was severe)
- Stigma which caused patients to avoid the clinic due to not wanting to be seen there, or for patients with epilepsy, not wanting to take the journey to the clinic due to being afraid of having a seizure on the way
- Being put off by waiting times at the clinic
- Patients not having enough information about their condition and the clinics
- Patients seeing traditional and/or religious healers which interfered with their clinic care (discussed further in section 4.4.2)
- Patients independently stopping or altering their medication or only taking medication while they had symptoms
- Patients not wanting to be on medication for the long-term (due to side effects and because there is no guarantee that the free medication from MSF will always be there anyway)
- Difficulties in treating agitated or violent patients
- Lack of caregiver or government support (for example relying on a caregiver to take them to appointments)
- Caregivers talking for patients in consultations and patients not feeling comfortable discussing intimate problems in front of their caregiver
- Children coming for their medication without a caregiver
- A lack of space in some of the clinics and the time available to spend with patients.

### **Counselling**

*Counselling is needed... Open mole cases, anxiety cases, the PTSD, you need it. Even epilepsy, some people need it... Even at times sometimes we feel depressed, and we do counselling on ourselves (Bridget, PSW).*

Counselling at the clinics usually involves providing practical advice, a lot of reassurance and is very family/community-based; in one session with a patient with open mole who had been worried about paying for her son's graduation and her other children's schooling, Paul (PSW) advised how to pay for the graduation and said he would come to her house tomorrow when the son would be there to discuss it with him. He then taught her how to take deep breaths and stretch to help her relax.

Many staff members mentioned that patients often expect and prefer medication over counselling, especially at the start of their treatment;

*A few of them will make you know that they are about to die if you don't give them medication... even if you try to explain to them that right now they don't need medication... at the end of the day you feel like you're a bad practitioner (Elizabeth, MHC).*

According to Sekou (PSW) this was because "They think the clinic is just for pills, and that it should be the church that does [counselling]. However only one patient, when asked, said they preferred to have only medication. Most greatly valued the counselling, and if they did not

receive it, were keen to start;

*Both [medication and counselling] are important because they playing their own part, the medication give me time to sleep I relax and then the counselling they speak to me on the part of the anxiety like the fear (Jay, patient with open mole).*

## **2. Traditional and religious healers**

*[Laughing] I say “ok, take the tablet, and pray” (Luke, PSW).*

Patients and their caregivers had however previously sought treatment from a variety of places as they looked for a cure before coming to the MSF clinics. These included various hospitals such as JFK, E. S. Grant Hospital and local pharmacies (where medication was said to be very expensive and sometimes there were stock ruptures), as well as various religious and traditional healers, who had an especially strong influence on patient’s care pathways and behaviours, according to clinic staff, due to being more respected than biomedical interventions. Indeed, while some patients may not tell the healthcare staff they see a religious or traditional healer, over 60% in the MSF clinics have seen or are seeing a healer<sup>5</sup>. Visiting the clinic was thus sometimes seen as a last resort when the traditional or religious treatment was not working. Most healthcare staff acknowledged and understood why patients went to see healers, and said that some (especially religious healers) could be helpful in the healing and referral process, especially related to a more holistic conception of care;

*[Epilepsy] is complicated. I think this is part of the reason why most people even go to traditional healers or even think these things are a witch because if I have my child who keeps telling me I see a man in front of me... they believe that it must have been the cause, the person who inflicted the epilepsy on the child, they always see a djinna, or a devil... or they see fire, so this also makes people to think “this is not ordinary” (Paul, PSW).*

*If its prayers, that’s fine, because treatment should be holistic... treatment shouldn’t be just on pills... All should come to the clinic, then we can encourage other support (Sekou, PSW).*

Magda (a patient with open mole) said when she told staff she had seen a healer that they; “never hold it against me, they never got angry with it, they only said okay, let’s try our medicine”. Indeed, Luke (PSW) said he believed traditional treatment for open mole worked; bringing the ‘burning’ down; even if you had a normal headache, and you used a healer, it eases a bit”. Luke also said that religious healers “*have a special gift*”. The belief in the spiritual cause of illness and healing however perplexed some international staff;

*It surprised me that even though they are under anti-epileptic treatment, if they are doing well, they still go [to the healer]... They say “Thanks to God I don’t have more seizures”. Not the medication... They are open, not embarrassed... Personally I have no problem with that... If it helps you just do it. But my question is, how much are they led to believe they’ll be cured? I don’t think they should do both... I don’t trust when*



*someone gives you a substance to take... Yesterday a one-year-old patient had an allergic reaction to herbs a healer gave her (Sam, medical specialist).*

Concerns about the effect on any herbs given, abuse, going to a healer instead of the clinic and not taking medication, were common among all staff;

*From a medical standpoint... sometimes we see [patient's going to healers] as a little bit of conflict because sometimes it's difficult to tell which is causing what.... when they get a reaction from the herb, sometimes they shift the blame on the medication (Adam, PSW).*

Some however were more actively against patients seeing especially traditional healers and laughed about their seemingly 'backward' beliefs. For example, when Elizabeth (MHC) when asked if patients find going to see a religious or traditional healer helpful, she responded laughing "I would say no because they have to come back to us". Elizabeth went on to say that staff were;

*...not really happy that [patients] will always want to go [to the healer] first, even with all the education... [they] still want to go there... [One patient] [laughs] she actually mixed that with spiritual beliefs... Myself I was believing that at first, so some people still do.*

Michael, a patient with psychosis said he had been ashamed to tell clinic staff he had been to a traditional healer and was worried they would be angry with him. Hallie (the father of a patient with epilepsy) also said he had not told staff and they had not asked;

*They know me to be going to the church... nobody will tell you say don't go there, nobody can't judge you, but the country side [traditional healers] - no, they will not allow you to go there. They will advise you that it's not good.*

This could be because of previous experiences with staff of other clinics;

*Jay (patient with open mole): A nurse came to me she saw the medication in my head, she asked me to wash it from there... she said but this thing isn't good. At times it can cause any infection in the body.*

*RW: And how did you feel when she told you to wash it out?*

*Jay: I was feeling bad.*

MSF staff sometimes had similar reactions; Magda (a patient with open mole) and Michael (a patient with psychosis), said they were told that they should not be going to traditional healers. However, some agreed with this advice; "[My mother] felt good about that...because she wanted the right way for me to get better" (Peter, patient with psychosis).

There was a difference in perception however of religious and traditional healers by staff;

*Adam, PSW: For spiritual healers I don't really feel bad because for them they go to church, they pray... because of that we don't discourage them. We believe there is a supreme God who uses that to treat you, so if you're praying to Him that's a good thing.*

*RW: What about traditional healers?*

*Adam: Traditional healers a lot of things happen, because sometimes they don't treat them well. The patient is in chains, confined to one place, sometimes they treat them badly, beat them.*

As religious healers also conducted some of the same practices as traditional healers (using herbs, chaining) criticised by staff, staff may be influenced by their own religious background (all were Christian). In this way, and as was found in Madagascar, the religious conviction of the health professional profoundly influences their opinions on conventional medicine, but do not necessarily influence practice (Legrip-Randriambelo, 2020).

In a slightly contradictory dialogue that could have come about due to the contradictions inherent in medical training and culture that on the one hand gives no space to alternative forms of therapy, but on the other, proposes that patients' beliefs are respected, Bridget (PSW) stated that she encouraged people not to go to see traditional healers, but also that she did not discourage people from going;

*We are encouraging them every day that medication is the right thing, not to go to the traditional healer, even though he has his own power, we are not discouraging you... I am not there to say "Oh the traditional healer is not good"... No! my concern is the patient... so I should start from there, and not discourage them about where they go.*

**Whatever their personal beliefs about religious and traditional healers, healthcare staff had to be strategic about this contentious issue in the patient's pathway;**

***You have to be wise in dealing with them. You have to draw the line, if not you'll lose your patients. We say "you can go to pray, but at the same time you have to take your medication". If you refuse to talk to the most influential person in the family, even if they are a religious or traditional healer, what are you going to do? What they say is final... We explain that taking medication does not make them a deviant. If you tell them not to go to either you are looking for problems (Frank, MHC).***

Most patients seeing religious healers said that they were allowed to receive clinic medication, and said some even encouraged them to go to the clinic. Additionally, five healers interviewed said patients could take medication. In talking about his relapse due to stopping his medication, Mark stated;

*The pastor called me, he said "my man, everyone don't have the same level of anointing and all of that, so you can still take your medication and pray God will still help you.... look at you... would you like to continue every time people holding you, restraining*

*you?” ... I sit down, I thought about it and say “if this is the only way to go then I will continue taking my medication, so from 2009 and up to this, no re-lapse”.*

*I should be an aid to others. The two can coexist. If they are already on medication we don't deprive them, if it cures, thank God. We keep applying the spiritual part as it brings out the solution (Ramsay, religious healer).*

However, some patients reported that while they were seeing a healer for their illness, they were not allowed to take their medication or that they could not because they did not have access to the clinic or food to take their medication with. Additionally, one adolescent patient who was staying with a religious healer (Thomas) was worried about asking him whether she could take her anti-epileptic medication, and therefore did not take it. This was more common among traditional healers; one patient with epilepsy and a father of a patient with epilepsy said that they could not take clinic medication while they were seeing a traditional healer, and three healers, including Ousmane said that people cannot take clinic medicine at the same time as country medicine as “Country medicine and Kwe medicine at the same time can damage you quick”.

*The healer is saying; “don't waste your time, a tablet won't help, I will deliver you” .... most patients have seen some kind of healer or pastor who will tell them the condition is not a hospital sickness so they shouldn't waste their time going to the hospital... One patient... after he was prescribed medication... the Pastor was saying to the father, “What? You can't trust God?!” and told him not to give the tablets (Luke, PSW).*

According to staff, some healers only let the patients take their medication (or medication they themselves procured through pharmacies) or other clinics, on their own terms.

Healers were also often sceptical of the clinics' ability to treat patients (Esther spoke about a patient who, “the more medication they had, the more seizures they had, so they were brought to the church”). Similar findings were made in a study among traditional healers treating MH conditions in South Africa; most were willing to collaborate with physicians but some believed that biomedicine was ineffective in curing patients (Sorsdahl, Stein, & Flisher, 2010).

### **3. Communication between staff**

Another challenge occasionally cited by national staff was related to misunderstanding of the local context by international staff, as well as clashes regarding changing protocols and power dynamics;

*Expats expected clinicians to see 12 patients per day. This caused tension... It wasn't about quality but how many patients you see. The foreign doctors think you are slow, but at the end of the day there's a lot you can learn by going slow (Daniel, MHC).*

This relationship was obviously complex and national staff simultaneously held positive and negative views about international staff;

*Expats they come in and they say “this, you have to do it this way, you have to do it that way” ... If you want us to do something for 3 months while you are here, move along with you! After 3 months you will leave and another expat will come and say “Oh this should not be here, it should be here!” ... So for me personally, I really don’t have any problems with expatriates (Bridget, PSW).*

On their side, some international staff cited communication difficulties;

*Now I feel close to [the clinic staff] but it takes time to build that relationship. Sometimes I was wondering if they were happy to see me, they were very cold, saying “I don’t understand her” because of the language and accent. I didn’t feel welcome... From their perspective it’s difficult to adapt to someone each month (Allie, medical specialist).*

## **5. Study limitations**

Throughout the study, efforts were made to maintain self-reflexivity and an acknowledgment of the subjective nature of data collection and analysis, by being aware of any assumptions being made about what participants say so as not to impose pre-defined theories onto their narratives. As in all studies, bias cannot be completely avoided. However, efforts were made to reduce bias by for example asking open-ended, non-leading questions. Additionally, it is acknowledged that RW is non-Liberian and is more familiar with a Western healthcare setting than a Liberian setting, especially with regards to religious and traditional healers. The ICM assisted in bridging these gaps.

It is crucial to consider that RW influenced the research setting with her presence (McCambridge, Witton, & Elbourne, 2014). In addition, most study participants were already associated with MSF. Similarly, staff narratives took place in the context of speaking to another MSF staff member, which almost certainly influenced their responses. For example, when asked if they ever went to see a religious or traditional healer, all immediately and firmly responded in the negative;

*That is not part of my mind! I never thought of that [laughing]. Even my children I never took them to a traditional healer. What I do believe is, when you pray, things can happen (Luke PSW).*

Despite this, and later saying in relation to the Pentecostal church; “I don’t believe much in healing”, a few weeks after our interview, Luke had a health issue. He said that he had been to hospital for antibiotics and pain-killers but despite being eligible for MSF medical insurance, then paid \$130 to see a traditional healer due to believing it to be more effective. Additionally, at the end of an interview with a religious healer, Luke told the healer; “some people we send to you and you help them”. When asked afterwards if he does this, he laughed a lot and said “Quite impossible!”, that the patient decides themselves if they want to go. It was therefore unclear which statement (to the healer or to RW), was true.

Additionally, the fact that five out of the eight healers interviewed said they knew about the MSF MH clinics cannot be taken as a representation of healers in Monrovia; the healers had often already met the PSW who recruited them through awareness sessions. They may have thus also been more aware of MH conditions and epilepsy than those who had not previously been in contact with the PSWs. Additionally, healers' willingness for later collaboration must be taken in the context of being interviewed by MSF staff. Indeed, after two healers said that they already referred people to the clinic, RW was told by the PSWs that this was not the case.

These issues were minimised through careful explanation of RW's role as the PI and their neutrality, and strict assurance of anonymity and confidentiality. The team also ensured they showed impartial interest in the different healing options available.

RW also relied on the translation and transcription skills of the ICM for some of the interviews, and considering the inevitable translator bias and misinterpretations, loss and distortion of information could not be fully avoided. To reduce the bias as much as possible, training and regular feedback was provided for the ICM.

Finally, due to the limited amount of time to conduct this research, some interesting themes could not be further explored in its full depth.

## **6. Operational Recommendations**

*I hope you are going to stay here for a longer time. [If not], even more than two, three hundred persons will still be on the street, because they can't afford the medicine, so I pray you people stay long with us, don't leave, we love you, we need you, we feel happy with you (Michael, patient with psychosis).*

This research aimed to shed light on therapeutic practices ignored by health protocols more often anchored in public health systems, and from which a part of the population who either do not consult these places or leave them for lack of individualized care are excluded.

### **6.1 Reinforcing the foundations of the project**

#### **The paradigm of the fear and the fight against stigmatisation**

It was evident that people affected by MH conditions and epilepsy (not only patients) feel a great deal of fear related to the conditions (of death, contagiousness, reactions from others), and are subject to high levels of stigma.

Specifically, from society these fears are related to;

- Fears of "crazy" people, associated with violence
- Fears of "catching" epilepsy

According to patients and caregivers, these fears are related to;

- Patients harming themselves or others
- Caregivers not being able to find a "cure"
- Not understanding what is happening to the patient
- Being "imprisoned" in the psychiatric hospital



- Being excluded from society and the economy
- Disappointing family and the community if they do not accept treatment from traditional and/or religious healers, even if it is abusive
- Mixing traditional treatment and biomedicine

According to medical staff, fears related to;

- Medical staff in Liberia being afraid of touching patients with epilepsy or advising them to see a healer as they believe MH has a spiritual cause (Fear of the demon).

The fact that mental illness is seen in opposition with physical illness, and because mental illnesses are usually less well known than many other diseases, probably generates more fears and myths due to its “invisible aspect”. Thus, the coupling of fear and ignorance is the engine of stigma in a society heavily determining people’s behaviour.

Stigmatisation against people living with a MH or epilepsy condition is leading to:

- Abuse and exploitation
- School dropout
- Denial of the condition leading to late presentation at healthcare centres
- Suicide

#### Recommendations at national level:

- Reinforcing medical curriculum on MH and epilepsy in medical schools as there is a lack of knowledge of these conditions among medical staff themselves. MH partners and patients to intervene for debate, awareness etc.
- Advocacy for a national awareness campaign with MoH and other partners, including testimonies of patients: debates in communities, on-air campaigns etc.
- Collaborative work on patients’ rights with the Carter Center, CFUH, WHO Quality Rights training etc.
- Implement clear protocols in case of detection of stigma related issues mentioned above.

#### Recommendations at project/patient level:

- Work better on anti-stigma awareness messages; find effective methods and channels to discuss stigma by including key stakeholders (including caregivers and other family members) at community level. Upon detecting serious harm caused by stigma, provide counselling where possible and address the issue with group awareness sessions, continuing to involve gCHVs and PSWs.
- Work on the de-stigmatisation of words like Epilepsy and encourage staff not to use terms such as “crazy”, even if the patient does, or adjectives qualifying a patient by their disease, such as: “she is psychotic or epileptic”. Instead encourage the use of “she has a MH condition or epilepsy”.
- If a patient is uncomfortable coming to clinic, if, feasible (i.e. depending on how busy staff/clinics are) offer an alternative solution like home visits, or vice versa. Additionally, during intake ask for consent before home visits in order for patients to have an informed choice.

- Contribute to making E.S Grant Hospital less stigmatising by helping to make the place more friendly, colourful; a safe place where patients can reconnect with themselves. Support patients through group therapy, art-therapy, counselling, training etc.
- Work on the self-stigma of patients: value them in counselling and encourage them to express their fears through peer support groups for patients and caregivers (CFUH and the Liberia Association of Psychosocial Services (LAPS) have proposed this to MSF).
- Counselling could be provided which specifically addresses fear surrounding MH conditions and epilepsy.

### Streamlining awareness sessions

It has been observed that each outreach team has a different approach and messages, also using different wording.

### Recommendations

- The team should use the same vocabulary as patients where possible, but must omit some words that contribute to stigmatisation (such as “crazy”).
- The report also shows how much mothers are the caregiver but also often the decision maker in terms of therapeutic pathway (even if other family members will validate the final decision like the father). Specific women’s awareness groups through women’s associations could be organised. However, women are too often in charge of taking care of patients. To support in this burden, once a patient is identified, the father and other family members have to be included in the care through family counselling and awareness.
- In general, all types of awareness activities and care advice could involve a component acknowledging the toll the care can take on the caregiver (using sensitive language so as not to make the patient feel blamed), and the need for family and community members to share the responsibility.
- Patient and caregiver education about epilepsy and various MH conditions could be implemented in the waiting rooms with a pre-designed flipchart.

### Developing counselling activities

If this objective is already inherent to the project as a qualitative improvement of care, the study showed that more patients than the team believe, are willing to follow counselling sessions, and show satisfaction once they start their sessions;

### Recommendations

- More workshops to be organised with teams to see how counselling can be better proposed to patients and assess the efficacy of previous workshops.
- MSF has to be coherent with its will to develop counselling, and as PSWs also expressed the lack of time for counselling, more counsellors’ positions should be opened.
- The national team clearly expressed their will to be certified as Counsellors through the Master’s in Counselling for PSWs, recently launched at the Mother Patern College of Health Science.
- More training by the MSF clinical psychologist was also requested, which both Medical and Psychosocial teams attend.

- With appropriate training of staff, group therapy could be introduced, which could help open up discussion and help fight stigma and shame around MH conditions and epilepsy.
- Where appropriate, counselling sessions can also address the effects of stigmatisation and provide education/reassurance about MH conditions/epilepsy.
- Caregivers themselves often expressed feelings of hopelessness related to their role, and so could also benefit more from counselling where appropriate.

### Communicating diagnoses

*When I read about it... that is the time I realised that it was an anxiety, it was not witchcraft... It brought a relief to me... because I was totally confused... since I've done the assessment and I've discovered that it's the sickness that is happening to me... that how I started taking the [medication] (John, patient with anxiety).*

Many patients and caregivers are not aware of their diagnosis, only being told to take their medication and wanting to know more. However, healthcare staff affirmed explaining the diagnosis to the patient and said they either did not understand or were in denial.

In both scenarios, the fact that patients do not know their diagnosis is problematic regarding:

- Patient's rights to knowing their diagnosis and being having agency in their healthcare
- Fighting stigmatisation and informing the wider family/community about MH and epilepsy
- The possibility to research their condition further.

### Recommendations:

- Patient education strategy to be implemented with the support of the HQ Referent, with a Patient Education Manager who could come for 6-12 months to elaborate the strategy with the team on how to communicate diagnoses and empower patients.
- Identify a team member to be in charge of patient education. The position should be medical; the mhGAP nurses would be ideal as already discussed in the field.
- Differentiate between the diagnoses of anxiety and depression (often they are lumped together as a diagnosis, giving the impression they are homogeneous).
- Many patients believed that their medication must be taken with food, which meant that some were unnecessarily not taking medication. However not all medication required food to be taken at the same time; therefore, further training of clinicians may be necessary on this subject and this be communicated to the patient if appropriate to their specific medication to avoid them missing treatment. Also some supply of biscuits could be envisaged for patients in need to take food with their treatment.

### *The case of open mole*

Open mole is specific to Liberia. It shows that MH conditions can be expressed and categorised differently from one culture to another, but also that expressing MH conditions through the expression of physical complaints makes it easier for patients to look for medical care, which helps them to present at clinics earlier, and also for the team to earlier detect MH conditions.

### Recommendations:

- Respecting the categorisation of open mole.
- Recording open mole as a second diagnosis in the database will contribute to a better knowledge of what open mole is in Liberia. Specific research on this topic could even been conducted at a later stage.
- A workshop with the field team and the MH referent from HQ could be organised to decide how to consider the topic of open mole within the project, and then brief international staff on the topic.

## **6.2 Building on the foundations, promoting patient-centred care**

*You need values. Religion in our culture is a value. If you tell someone “you need to do away with your values”, you are telling them to do away with their treatment (Frank, MHC).*

All interviews showed the team’s willingness for a more holistic approach to patient care. This could improve the general acceptance of care, as well as their condition, as it respects individuality, choices and at the same time, the socio-cultural context.

### **Collaborating with traditional and religious healers**

*Sometimes even if you speak to the religious healers make them to understand that medication helps, when they tell the patient’s relatives “you have to take this medicine”, they will prefer to listen to them then to listen to us... they have so much respect and influence (Nathaniel, MHC).*

Benjamin Ballah, from CFUH explained that “the medical model has sought to distance itself”, despite both the medical and traditional aspect originating in herbal remedies. Indeed, examples of synergy with between biomedicine and traditional medicine are rare (it was attempted by MSF in Mauritania but after a while the collaboration between the institutions concerned waned (Alice Desclaux et al., 2020)). However, there is evidence that traditional healers have greater influence in treating illnesses where behaviour change is required than medical staff (Colvin et al., 2003), and people’s trust in religious and traditional healers is high.

In their MH program in Maryland, Partners in Health (PIH) have already been collaborating with traditional and religious healers for two years. The PC was invited in February, during the study, to visit PIH and had a very good impression of such collaboration, especially with religious healers. According to PIH, collaborating with healers contribute to:

- Providing awareness and gaining trust in communities (since healers are themselves already trusted)
- Properly training these actors to involve them in the therapeutic pathway to “diagnose” patients
- Referring patient as soon as possible
- Train them as caregivers if the patient is staying with them
- Distinguishing positive and negative practices (and reporting negative ones, including SGBV, which may be common in such settings)
- Training healers in counselling as they play a supportive role
- Patients feeling more supported in their own

- Including patients' faith in their recovery, as was important among participants.

#### Recommendations at national level:

- Government authorities could be encouraged to assert more control over the practices of religious and traditional healers (such as though authorizing certain healers as is done in other countries).

#### Recommendations at patient/project level:

- It therefore makes sense that MSF collaborate with traditional and religious healers and see them as key stakeholders who can support the patient treatment pathway, playing an advisory role, explaining when and for what they should go to the clinics and play a role in referrals (as has already successfully being done in some clinics). Raising awareness about the importance of early detection of MH/epilepsy conditions, and earlier referrals to the clinics could arise through such collaboration.
- By organizing workshops, MSF could foster a discussion comparing traditional perceptions and ideas around witchcraft with biomedical perspectives related to MH/epilepsy conditions. It could also give traditional healers the opportunity to explain to staff why people consult them, and why and how they treat them. This could help healthcare providers gain a more concrete understanding of health seeking behavior.
- PIH could be invited to facilitate these workshops and share direct experience with MSF team and healers.
- In encouraging traditional healers to collaborate, clinic staff should also accept and not be harsh or devalue their work. Professional tensions can be resolved and mutual respect, appreciation, and trust among traditional healers, MSF staff, and other organisations working on MH in Liberia generated through inter-professional education and clinical mentorship of healers. Similar collaboration has been implemented throughout the world including Malaysia, South Africa, China, and India (Herman et al., 2018), leading to improved care and reduced stigma of mental health conditions.
- MSF should consider providing incentives (as PIH does), as making referrals could mean a loss of income. These could be in the form of small ad-hoc financial incentives and the training mentioned above. However, the frames of this collaboration will have to be sharply defined in order to minimise risk of abuse of the incentive system and the potential that such a collaboration will strengthen healers' popularity in the community. Abusive practices identified through this collaboration will be reported to authorities and the collaboration with healers engaging in such practices stopped.
- Clinic staff could also emphasise that clinic services are free, thus they are not trying to 'take away' healers' patients.
- Traditional healers expressed a willingness to collaborate and improve their skills as health care providers, and the pluralistic nature of Liberian culture is prepared to build collaboration between these practices. The next step is formalizing this process and generating a cooperative environment between traditional and biomedical practitioners.

\*More information about the activities of PIH have been written up in an internal report.

Especially spiritual components of health-seeking behaviour should be understood – ignoring



this aspect could result in increased risk for patients as they and various cultural dimension of the relationship to disease, the body, medication, and the complex nature of the therapeutic relationship as access to care (living conditions, financial means, social status) become homogenised, and large parts of their history and conceptualisations are ignored (Fancello, 2020). On a more general level, superimposing Western cultural categories on other cultures, assumes that Western categories are culture-free<sup>2</sup>.

### Improving access to the clinics and treatment

Transportation to get to the clinics was often mentioned as a barrier to care by staff and patients, as well as being able to afford food to take with the medication. PIH, in its TB program explained how successful this support was in terms of patient adherence to treatment. Additionally, some patients are asked at MoH facilities to buy medication.

### Recommendations:

- MSF could provide financial support for food and transportation for those most in need (identified by the PSWs). More home-based care and mobile clinics are also under discussion.
- Both PSWs and patients requested being prescribed two months-worth of medication to avoid coming to the clinics so often. However, it should be explained that this is not possible due to storage conditions.
- Help patients with other medical conditions, especially for neurological conditions and children with developmental conditions; parents could be supported to take care of these children and social nets or cash transfer programmes (perhaps through WFP or food security organisations) could be looked into and patients supported with finding out if they are eligible for such schemes. These topics are under discussion at field level.

### The process of Recovery

*Once we show up and give our own recovery story, because that's our most powerful tools in this recovery moment... they be like "are you kidding me? you mean you were like my child?" ... If I was not with this particular group put together by Carter Center... then I'll not know the way out, or maybe I could have been worse again (Benjamin Ballah).*

The concept of "Recovery" as described in MH literature integrates the following notion of patient-centered care as a central component:

*From the perspective of the individual with mental illness, recovery means gaining and retaining hope, understanding of one's abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self. It is important to remember that recovery is not synonymous with cure. Recovery refers to both internal conditions experienced by persons who describe themselves as being in recovery – hope, healing, empowerment and connection – and external conditions that facilitate recovery – implementation of human rights, a positive culture of healing, and recovery-oriented services (WHO, 2012).*

Thus, recovery focuses on the uniqueness of each patient, supports genuine choices in treatment, facilitates the person's rights, enables dignity and respect through active partnership

and communication, and supports them to define for themselves what their own recovery looks like<sup>2</sup>.

If the project is patient-centered, (but still has further to go i.e. the recommendations given here), the process unfortunately stops at the end of the treatment, without considering how to support the patient's reintegration into society and in general, life as a person, and not especially as a patient. The patients' association, Cultivation For Users' Hope (CFUH) is playing a very active role in this sense. CFUH aims to empower people with MH conditions in order to prevent relapse, including by establishing 'cells' in various community, visiting members, providing peer mentoring and empowerment training, and telling staff's own recovery pathways. CFUH also aims to provide small start-up grants working with other local organisations (such as Liberia Pure, which trains bee-keepers), to develop their skills and hobbies, and thus providing future education and employment opportunities. Indeed, Geevon, the sister of a patient with epilepsy said;

*When the person getting well what the next thing? you have to find something for the person to do, the person can even have little fun... be in the community... When he's busy... he will not be sitting down and asking "why is it that am sitting down like this and my friends...?" [Now] the man depressed... he alone.*

#### Recommendations

- Train staff in the recovery approach, such as through workshops with CFUH.
- Encourage patients and caregivers with peer mentoring and empower and follow them in their recovery. CFUH and LAPS have started this and should be supported with it.
- Awareness and service promotion messages disseminated in the communities should include recovery as well as treatment information.
- Referral pathways with CFUH should be strengthened.

#### Understanding between national and international staff

While relations between national and international staff are overall good, both sides explained phases of misunderstanding, with international staff telling national staff what to do without knowing the Liberian context. Frustrations can arise - especially within short term missions - from both sides and jeopardize the quality of work.

#### Recommendations

- Reconsider short term missions for this project, with a preference for those over 6 months so that strategies can be effectively implemented and monitored.
- A cultural briefing could be written by the national team and explained on arrival to international staff. Topics included could be stigma related to MH and epilepsy, the therapeutic pathway of the patient (traditional/spiritual healers), open mole, the role of the family and community, Liberian vocabulary used to talk about epilepsy and MH, and spiritual beliefs surrounding MH and epilepsy.
- To avoid international staff wanting to change everything on arrival despite what is being said by the national team, the Standard Operational Procedures (SOP) have to be finalized as soon as possible.

## Other

MoH staff complained about a lack of incentives, and project members about being understaffed. If MSF wants to apply all the recommendations for better patient-centred care, action need to be taken to valorise and give necessary resources to the team.

### 6.3 TCC Partners' recommendations

The report was shared with TCC partners (MHU, Mother Patern College of Health Sciences, CFUH, Carter Center, PIH), and with the TCC sub-committee dedicated to Training and Research by the MHU. Partners were invited to provide feedback on the report, especially on the results and operational recommendations within two weeks. Unfortunately, only one partner, the Mother Patern College of Health Science, responded, despite a gentle reminder email being sent after ten days and an extra week added. The feedback therefore is not representative of all the partners working on MH in Liberia and so has not been incorporated into the report. A presentation of the study at TCC level, organised by the MHU Director and TCC co-chair, followed by a debate has been scheduled for the 17<sup>th</sup> June.

## 7. Conclusions

The aim of this anthropological study was to gain a contextualised understanding of patients' comprehension of MH conditions and epilepsy and their therapeutic pathways, including their use of traditional and religious healing pathways and MSF services. An anthropological approach is important for such research because in having real conversations with various population groups (as opposed to questionnaires/surveys), research is more deeply situated in the socio-cultural context, with participant narratives valued as primary data. This means that initially unapparent but important nuances become evident and so findings and recommendations are more appropriate for the context.

Our findings indicate that MH conditions and epilepsy are highly stigmatised, which leads to abuse, neglect, school-drop-out/expulsion, exclusion from socio-economic activities as well as impacts patients' therapeutic pathways. Patients and religious and traditional healers hold varying conceptualisations of the causes of MH conditions and epilepsy, but most often believe they are the result of witchcraft. This perceived *spiritual cause* meant that people sought a *spiritual cure*, through traditional and/or religious healers. In general, patients and staff held positive views towards religious healers when seeing them only involved prayer and negative views towards traditional healers, whose practices they said did not work and were very expensive. Both groups however often put their patients in chains when patients stayed with them. All healers said they were willing to collaborate with MSF to refer patients to the clinics. Another main finding was that even after patients came to the MSF clinics, most still claimed not to be aware of their diagnosis, indicating that it may not always be appropriately communicated to them. Various recommendations have been made, including building on awareness-raising of MH conditions and epilepsy to tackle stigma, better communicating diagnoses, collaborating with traditional and religious healers, and supporting patients in their long-term recovery process. In summary, all recommendations include the need to maintain

and strengthen collaboration with other partners (such as the MoH, PIH, CFUH, Carter Center) in incorporating a fully patient-centred and community-based approach.

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