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Mental health problems in Juba, South Sudan: local perceptions, attitudes and patient care

A socio-anthropological study

South Sudan Program
Under the project, 'Touching Minds, Raising Dignity;
to stop the stigma towards people with mental health problems'.

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Background

Mental health programming is important in post-conflict settings such as South Sudan. Handicap International is currently implementing a project entitled "Touching Mind, Raising Dignity; to stop the stigma toward people with mental health problems" which aims to improve the social and community involvement of people living with mental health problems.

Methods

This qualitative research study was conducted to understand local concepts linked to mental health problems and health-seeking in order to develop effective mental health interventions in the context of Juba, South Sudan.

The study was conducted in four locations in Juba among community members, people with mental health problems, their caregivers and service providers. Focus group discussions & in-depth interviews were conducted with a total of 130 study participants. The interviews were conducted in English or by translating from Juba Arabic. The data was analysed using thematic analysis.

Findings

Local illness concepts

Respondents used two wide categories when discussing people with mental health problems: mad (*majnun*) and sad and tired (*mariid*= sick). Substance abuse related madness and *maratsarra* (epilepsy) were genuine community concerns.Mild signs and symptoms were not recognized as mental health problems, the causes of mental health problems were viewed as numerous and complex, and mental health problems were believed to be common in South Sudan.

Community attitudes and stigma toward people with mental health problems

Stigmatizing attitudes towards *majnun* (mad people) and those who have *maratsarra* was common. Stigma is driven by fears and beliefs associated with mental health problems, manifesting in distancing, isolation of people with mental health problems. Stigma leads to increased psychological distress.

Experiences with mental health

Common challenges for caregivers and people with mental health problems included lack of knowledge about where to seek care, lack of social contacts and lack of skills to deal with those with mental health problems. People with mental problems often have to put their educational and employment plans on hold. Experiences of stigma among those with mental health problems and their caregivers included verbal abuse and gossiping. Stigma coping mechanisms included ignoring negative and stigmatizing comments and avoiding situations where stigma may occur.

Health seeking behaviours

There are a number of different sources of care for people with mental health problems in They can seek care at one source or several sources in various order, often depending on the perceived cause, other contextual factors and family preferences and habits. Mental health services in Juba remain poor. JTH is the only psychiatric hospital in Juba. Aggressive or violent people with mental problems can be referred to Juba Central Prison, which does not have many mental health services available. Community-based care is challenging due to the limited capacities and resources of community members. Reasons for delay in care seeking among those with mental health problems are linked to the severity of signs and symptoms.

Discussion

The findings of this study can be used in mental health programming in Juba. They can be utilized to maintain understanding between health professionals and the local community and when developing specific communication messages or behavior change strategies. The findings can also be used specifically for the prevention and early detection of mental health problems.

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Abbreviations

CPA	Comprehensive peace agreement	**PHC**	Primary health care
FGD	Focus group discussion	**PHCC**	Primary health care centre
HI	Handicap International	**PHCU**	Primary health care unit
IC	Informed consent	**PTSD**	Posttraumatic stress disorder
ICRC	International Committee of the Red Cross	**RAP**	Rapid Assessment Procedures
IDI	In-depth interview	**SSP**	South Sudanese Pounds
JTH	Juba Teaching Hospital		
NGO	Non-governmental organization		

1. Introduction

Handicap International (HI) is implementing a mental health and psychosocial support program entitled "Touching Mind, Raising Dignity" in four conflict ridden countries including in South Sudan. The aim of this program is to improve the social and community involvement of people living with mental health problems in an effort to help them regain their mental capacity and to live with dignity. The program interventions aim to prevent psychiatric collapse, support existing family coping mechanisms, strengthen community based mental health services, and advocate for the rights of people with mental health problems. The community based work includes awareness raising through workshops, identification of people with mental health problems through home visits, provision of services like psychoeducation, counselling, including them in peer support groups and referring (if needed) to JTH and other eligible centres and follow up as needed. HI conducts regular therapy sessions and various other activities in Juba central prison and JTH for people with mental health problems.

This document describes a socio anthropological research study that was conducted in Juba, South Sudan to assist HI in adjusting and adapting current project interventions to make them more culturally competent and meaningful in the context of South Sudan.

2. Background and significance of the study

Mental health is considered a key public health problem for conflict-affected populations such as South Sudan (IASC 2007; Mollica et al 2004; Turnip et al 2010). People experiencing poor mental health suffer substantial distress and may be more vulnerable to violence, suicidality, poor physical health, and harmful health practices such as substance abuse. Mental health problems can also hinder individuals' desires and attitudes regarding reconciliation in post conflict societies, their ability to address social and economic needs, as well as their ability to function as a member of society (Pham et al 2004; Vinck et al 2007).

Post-traumatic stress disorder (PTSD) and distress are common among populations that have experienced war (De Jong et al 2007 Dejong et al 2003; De Jonget al 2001). There has been an increasing focus on PTSD in conflict settings worldwide (Johnson & Thompson 2008; Murphy 2007; Marshal et al 2005; Mollica et al 1999). A number of studies conducted among children affected by armed conflict and displacement indicate an increased risk for mental health problems (Barenbaum et al 2004; Lustig et al 2004, Stichic 2001).

However, only a few studies have been conducted in recent years on mental health problems in South Sudan. Studies among refugees during the conflict have shown that PTSD and depression are common (Karunkara et al 2004; Neuner et al 2004). A cross-sectional survey conducted after the conflict in Juba (2009) indicatedthe prevalence of PTSD at 36% and depression close to 50% (Roberts et al 2009).

Poverty and other socioeconomic factors such as urbanization, migration and social inequality have been identified as important stressors for mental health problems worldwide (Fekadu et al 2014; Okasha 2002). A recent study in South Sudan noted that exposure to traumatic events and socioeconomic disadvantages are important risk factors for the comorbidity of PTSD and depression (Ayazi et al 2012). These social determinants of mental health contribute to a cycle where people with mental health problems have limited access to treatment and therefore become increasingly marginalized.

Mental problems can be considered a silent epidemic in most parts of Africa because of lack of political commitment, structural and systemic barriers such as inadequate health care infrastructure, insufficient number of mental health specialists and lack of access to all levels of care. In addition, mental health remains a difficult public health problem due to inadequate funds and lack of mental health policies (Collins et al 2011; Becker & Kleinman 2013).

Stigma and discrimination also hinder the development of mental health services and can lead to the unwillingness of patients to access mental health facilities as well as to the unwillingness of health personnel to diagnose patients using psychiatric diagnoses (Collins et al 2011; Patel et al 2007; Hyman, Chisholm, Kessler, Patel & Whiteford, 2006; Patel, 1996). A cross sectional survey conducted in Juba, South Sudan identified a high level of

stigma toward people with mental problems, highlighting the importance of addressing stigma when building up mental health services (Ayazi et al 2014). Reduced community stigma toward people with mental problems can both prevent mental illness and improve access to quality mental health services.

Access to adequate mental health services remains limited in South Sudan. Recent assessments indicate limited infrastructure and human resources directed toward care for those with mental health problems (Green 2012; IMC 2013; Sing & Singh 2014; Healthnet TPO/ Dutch Consortium for Rehabilitation, 2015). In addition, South Sudan does not have a mental health act (IMC 2013).

It is well documented that beliefs about aetiology influence presentation, management and treatment outcomes of illness. For example, beliefs in supernatural causes of mental health problems are widespread in Africa (Chukwu & Onyeneho 2015; Kabir et al 2004; Gureje et al 2000; Rosen 2006). Previous studies also highlight that African explanatory models are often multi-dimensional and linked to the collectivist orientation of cultures. They commonly have a spiritual explanation that has a significant impact on human affairs (Monteiro & Wall, 2011; Amuyunzu-Nyamongo, 2013; Akyeampong & Kleinman, 2015; Monteiro & Balogun, 2014). Local perceptions can also provide valuable information regarding mental illness coping mechanisms in post-conflict settings (Familiar et al 2013).

Health-seeking behavior is pluralistic in many African countries and the use of informal health providers is common (Bo et al 2014). Previous assessments in South Sudan have identified the use of traditional healers and witches to cure mental illness along with the use of biomedical service providers (IMC 2013; Dutch 2015).

3. Purpose of the study

Understanding local concepts linked to mental problems and health-seeking behavior is essential for the development of effective public mental health interventions (Ventevogel et al 2013; De Jong 2002). This will allow healthcare workers, detention workers, community based workers and HI staff members to better support people with mental health problems by developing informed interventions and strategies that are meaningful for people with mental health problems and the surrounding communities.

The study will also allow for the development of evidence-based approaches to combat stigma and discrimination toward people with mental health problems in the context of South Sudan.

The findings of this study will be used to develop context specific operational recommendations for HI programming and advocacy that aims to improve mental health care in South Sudan.

4. Objectives

- Understand perceptions toward mental health among families, various community members, leaders, service providers and local authorities
- Identify mental health myths and beliefs rooted in society and among service providers
- Analyse the understanding of traditions, practices and skills among community members related to mental health
- Describe the dynamic of the interaction between those with mental health problems and their families, the community, service providers and local authorities
- Understand and analyse the referral pathway for people with mental health problems.

5. Study setting

South Sudan

South Sudan became an independent state in 2011, preceded by the Comprehensive Peace Agreement (CPA) in 2005 that ended nearly 20 years of conflict between the government of Sudan and the rebel movements in the South. As the result of the conflict, over 1.9 million people were killed, over four million persons were internally displaced, and up to one million people became refugees mainly in camps and cities in Kenya, Uganda, Central Africa Republic, Ethiopia, Egypt and other neighbouring countries (Roberts et al 2009). Despite the CPA, conflicts in South Sudan continue to take place. The Sudan People's Liberation Movement, the ruling political party that originally led the way for independence, is now divided and fighting for power. One major conflict in 2013 lead to thousands of deaths and displacements (LeRiche & Arnold, 2012). In February 2016, the U.N. displacement site in Malakal was attacked, killing 25 people and wounding over 120 more. Other regions of the country that had previously been relatively safe from clashes have experienced assaults during the past months.

The conflict has greatly impacted the economy of South Sudan. Its currency has weakened, inflation has spiralled and oil revenues have dropped due to decreased production and falling world prices. The cost of goods and services has increased tremendously. Food prices are at record highs, which is increasing poverty. Based on security reports, crime has also increased with looting and armed robberies more common. Even the government has been affected by the economic situation, resulting in unpaid government salaries. In addition, health facility staff reports increasing lack of critical supplies and Maintaining security, political stability and economic growth remains vital for the government of South Sudan.

Juba

The study was conducted in Juba, the capital of and largest city in South Sudan. It also serves as a capital of Central Equatorial State, which is currently one of ten states in the country[1]. In 2011, the population of Juba was estimated at approximately 370,000. Due to conflict and population movements, it is not known how many people currently live in the city. However, Juba has steadily grown since the adoption of the CPA with large numbers of returning refugees settling in the city.

Juba is a river port and the southern limit for river traffic on the White Nile. It is also a commercial centre for agricultural products produced in the surrounding area and a highway hub with roads radiating into Uganda, Kenya and the Demographic Republic of Congo. The city has a university, banks and it hosts foreign embassies. It also has governmental and private primary and secondary schools, as well as health facilities, pharmacies and small shops and restaurants. Juba is home to a teaching hospital with a psychiatric ward and Juba central prison with a psychiatric wing, which are the only governmental entities in South Sudan providing institutional services for people with mental health problems.

Public services are still being developed and major areas of the city are without paved roads, electricity and sewage systems. Public transportation is limited and, due to the recent oil crisis, lack of fuel is limiting the use of vehicles even further. Housing is predominantly traditional including mud brick houses with grass-thatched roofs (tukuls). However, modern cement buildings have slowly become slightly more common since independence. The overall atmosphere in Juba is traditional and rural. Increasing incidents of crime and resulting sense of insecurity among population areproblems in Juba along with other issues such as increasing homelessness, orphanage and street children.

The study was conducted in three town blocks and one payam in Juba; Juba Town-block, Kator-block, Munuki-block and Rajaf-payam, which are HI project intervention areas covering a population of approximately 250,000. All study areas are typical Juba neighbourhoods that include a mix of people with different ethnic backgrounds.

[1] In October 2015 South Sudanese president SalvaKiir announced establishment of additional 18 states.

Most people are either Christians or animalists. Rajaf-payam differs slightly from the other neighbourhoods as it's more rural, located outside of the city along the East bank of the Nile. All these areas had experienced an increase in the population since the CPA and independence of South Sudan.

Health systems

Health systems in South Sudan consist of: 1) governmental health system, 2) private health system, 3) non-governmental organizations (NGOs) health system, and 4) traditional health system.

South Sudan's governmental health care structure consists of different levels of health facilities that correspond with the government structure. On a national level, there are teaching hospitals that provide secondary and tertiary health care. Currently the structure of the country includes ten states that are further divided into 79 counties with state and county hospitals. Each county is divided into payams and bomas, which are the lowest administrative authority and where primary healthcare services are delivered through health units and primary healthcare centres (HSDP, 2012).

In addition, health services are provided by a number of non-governmental organizations and faith-based organizations (FBOs) as well as by private hospitals and clinics.

Mental health services

Government mental health services in Juba are limited to specialized services provided in psychiatric unit of the Juba Teaching Hospital (JTH), which has both inpatient and outpatient sections. At the time of the study, the department had 12 beds, one psychiatrist, 1 Medical Officer, 1 Clinical Officer and some nine psychologists, around 12 trainee psychologists and seven nurses. The nurses in the unit were not specialized or trained in mental health problems as they rotate from one ward to another in the hospital. Medications were not widely available during the time of the study and accordingly most patients were required to purchase them from a private pharmacy. At the time of the study there were six people admitted in the inpatient ward.

People with severe mental health problems are referred to Juba central prison if they are considered a danger to themselves and/or others. Admission to the prison requires a court order requested by the relatives of the concerned person along with a police report and a statement from the JTH psychiatrist. At the time of the study, there were 16 women and approximately 70 men in Juba prison due to mental problems. Men with mental health problems are housed in a separate area, however, it is open and accessible to all inmates. Women are housed in the same area with all other female inmates. Prison services include a small health clinic that can assist with minor health problems and regular visits by a physiatrist who can prescribe medications and write release statements for those who have recovered and are ready to return home. At the time of the study, the psychiatrist had not visited the prison for several weeks. The prison does not provide medications. If medication is required it is purchased by relatives from a private pharmacy. Social workers in the prison liaise between the inmates with mental health problems and their relatives to prepare for their release or to inform them about medications and other needs such as food, illness, death etc. During the time of the study, the majority of people with mental health problems in prison had no contact with their relatives. Accordingly, they may have inadequate food, clothing and medications. Some of them remained in prison because they had no one to claim responsibility for them; a requirement for release.

Handicap International is addressing these gaps through coordination with the International Committee of the Red Cross (ICRC) and other agencies. HI has created a therapy & training centre where inmates having mental health problems are taking part in different therapeutic activities like recreation, communication, art therapy activities and counselling and social skills. HI is also looking at improving the awareness among staff and prisoners, skills of clinical staff on mental health issues and working to improve the living situation of people with MH problems.

Community level mental health services are limited to a few primary healthcare facilities that have received training on how to identify people with mental health problems and how to refer them to JTH.

Private sector health facilities in Juba have some limited mental health services as well. For example Juba Medical Complex has a psychiatrist and other facilities are known to have doctors who can occasionally prescribe medications to people with mental health problems.

The use of informal health providers is common (Bo et al 2014). Previous assessments in South Sudan have identified the use of traditional healers and witch doctors to cure mental health problems (IMC 2013; Dutch 2015).

6. Methods

6.1 Study design

This qualitative research study relied on rapid assessment methods (RAP), which allowed for the collection of relevant information in a short period of time. To answer research questions, the study used multiple data sources and combined various data collection methods including in-depth interviews, focus group discussions and unstructured observation among a variety of independent sources. The key strength of this approach was the ability to crosscheck data from different sources (triangulate).

The study aimed to explore underlying concepts related to mental health and health seeking as a phenomenon rather than to establish quantifiable facts about it. The proposed study design determined the occurrence and nature of certain forms of behaviour, attitudes and perceptions, but not the absolute number of people involved in certain behaviours or with certain perceptions.

The study was based on open-ended questions that aimed to capture local concepts of mental health problems without trying to fit them into biomedical mental health categories. This emic approach was based on the understanding that local concepts are often difficult to classify into biomedical categories (Derulun 2004, Betancourt et al 2009).

6.2 Conceptual frameworks

The study design was based on three conceptual frameworks: Kleinman's (1988) exploratory models of illness, the stigma framework of Stangl et al 2014, as well as the conceptual measurement framework for helpseeking for mental health problems by Rickwood & Thomas (2012).

Exploratory models of mental health problems

The study design integrated anthropological work into public health by following the framework of Kleinman's (1988) exploratory models that differentiate between biomedical and lay models of illness. The framework was considered appropriate for the study purposes as it aims to understand how cultural and social context affects the ways people negotiate their experiences with illness. Explanatory models are created and recreated by individuals living within a cultural matrix of social values, expectations, beliefs, and relationships (Hewlett & Amola 2003).

The framework elicits community (lay) beliefs regarding mental health problems, the personal and social meanings attached to the illness, and expectations about what will happen to persons with mental health problems. The framework aims to identify how community practices and beliefs related to mental health problems influence service provisions and access. The community model (lay models) was elicited through a set of targeted open-ended questions to learn about causes, etiology, symptoms, pathophysiology, course and treatment. Questions included: What do you call common mental health problems? What causes these problems? What are signs and symptoms of these problems? How can such problems be prevented? How severe do you consider these problems?

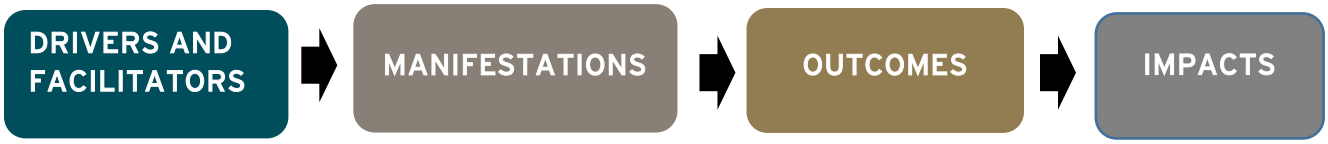
Stigma

Stigma toward people with mental health problems has been identified as a significant, culturally specific barrier to improving mental health services elsewhere in the world. As such, mental health-related stigma was explored by using the framework of Stangl et al.

(2013) which outlines the key domains of stigma that need to be measured in order to understand how it operates and ways to mitigate it in a particular setting. The framework breaks stigma into several parts including drivers of stigma, manifestations of stigma, outcomes, and impacts of stigma in the given context. Drivers of stigma are described as 'actionable' because they have been shown to shift as a result of interventions. Findings using the framework were used to develop evidence-based, anti-stigma interventions.

The framework differentiates between perceived stigma (community members' perceptions on stigma that is directed towards people with mental health problems) experienced stigma (the experience of stigma and discrimination of people with mental health problems) and internalized stigma (the acceptance among people with mental health problems and caregivers of negative attitudes and beliefs associated with themselves.

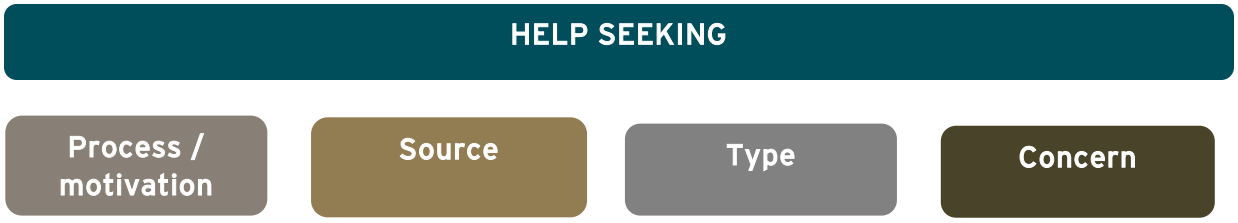
Figure 1: A conceptual framework of stigma (modified from Stangl et al 2013)



Conceptual measurement framework for mental health help-seeking

To ensure that health-seeking behaviour was investigated systematically, a framework for mental health help seeking was used to capture process, source, type and concern. Process refers to the aspect of the health-seeking process that explains how individuals became interested in or motivated to seek care. Source refers to the source of the assistance that is sought. Sources vary according to the level of professional expertise, medium (e.g., online), and the relationship with the person seeking help. Type of assistance refers to the actual form of support that is sought, such as psycho-education, referral, supportive counselling, and/or therapy. Concern refers to the type of mental health problem for which help is being sought. The problem can be specific or more generic.

Figure 2: Conceptual measurement framework for mental health help seeking modified from Rickwood & Thomas, 2012)



6.3 Study population

The study population was comprised of five target audiences: **1)** people with mental health problems, 2**)** caretakers of people with mental health problems, **3)** health/service providers including hospital and prison health/service providers, primary care level providers and traditional providers, 4**)** key community informants including those considered prominent and influential figures in their communities, and 5**)** community members that included men and women of various backgrounds.

Inclusion and exclusion criteria

People with mental health problems

Those eligible for the study were males and females +10 years old who had been diagnosed with mental health problems by healthcare personnel, informal health providers, community members, family members or they had self-identified as having problems in thinking, feeling or behaviour. Eligible persons lived in the HI project catchment area. People with mental problems who were less than 10 years old were excluded as it was believed that the interview questions were inappropriate for those under the age of 10.

Caretakers of people with mental health problems

Caretakers eligible for the study were men and women who identified themselves as caretakers of a person with mental health problems and who lived in the HI project catchment area.

Health providers

Eligible health/service providers included those from the public sector, NGO sector, private sector and traditional sector. Any type of health and service providers involved in the care of people with mental health problems was eligible to join the study.

Community members

Men and women of any ethnic origin, educational level + 10 year old residing in Juba Town, Kator, Munuki or Rajaf Payam were included in the study. Community members younger than 10 years old were excluded as it was believed that the interview questions were inappropriate for those under the age of 10.

Key community informants

Eligible key informants were respected members of their community and were familiar with social norms surrounding their communities. They resided in Juba Town, Kator, Munuki or Rajaf Payam.

6.4 Data collection tools

The study used in-depth interviews (IDIs) and focus group discussions (FGDs) to collect data. Use of multiple tools allowed for the triangulation of data. A separate question guide with semi-structured and open-ended questions was developed for each study population.

6.5 Sampling

Obtaining an adequate sample size was based on two principles: data saturation and a literature review of similar studies to ensure it was sufficient to answer the research questions (Mason 2010; Morse 2000). During data collection, the investigator followed the development of the data to ensure the main concepts and topics were captured, no additional items emerged, and data saturation was reached.

The principle of maximum variation was applied when identifying and recruiting study participants. The sampling aimed to include males and females (+10 years old) with mental health problems including women, men, educated and uneducated individuals from different

ethnic groups, caregivers including men and women of different ages, educational levels and ethnic background as well as service providers from various sectors and with different professional backgrounds.

Sampling of community members also followed the principle of maximum variation to include the most important population variants such as gender, age, ethnicity, education and location. As little demographic data was available about the residents of different areas of Juba, community leaders were consulted and requested to invite individuals from their communities that represented varying traits of society. The aim was to include a snapshot of the community.

6.6 Fieldwork

Data collection took place from March 28, 2016– April 11, 2016 by a team that consisted of the study investigator and a translator. The study investigator provided the translator with an orientation session to provide a good understanding of the aims and purpose of the study, allowing for efficient interpretation and translation of the interview questions. The translator had prior translation experience with similar studies.

The recruitment of study participants took place through the HI community mobilizer at all study sites. Community mobilizers were encouraged to use their contacts and knowledge of people in their project catchment areas in order to reach a wide variety of community members, influential people and service providers. The recruitment of people with mental health problems and their caregivers took place through the HI support group, a mixed group of caregivers and persons with mental health problems regularly facilitated by the community mobilizers. Community mobilizers also scheduled the interviews and coordinated with the HI project team to organize logistics such as transportation.

The team conducted from two to nine interviews or focus group discussions per day. The initial plan included one-to-one interviews with people with mental health problems and their caregivers because the objective was to obtain personal experiences while interviews with community members were to be conducted in groups as the aim was to capture social norms. However, in practice the situation did not always allow this division. For example,

interviews with people with mental health problems in prison were only possible in a group setting due to limited space and time.

All interviews were audio-recorded. Approximately half of the interviews were conducted in English and the other half were conducted in Juba Arabic and translated into English. The investigator and translator had daily informal discussions in between the interviews to reflect, clarify issues and highlight significant matters that came up during the interviews. For further quality control purposes, during the interviews the investigator frequently used a technique to summarize the answers of the study participants to ensure that there were no misunderstandings regarding the issues and concepts that arose.

6.7 Data analysis

The data was analysed by following thematic analysis, in which the major goal is to identify emerging themes and divergent data that appears significant (Brown & Clarke 2006). The process started with the transcription of the audio-tapes into summaries and familiarization with the data by reading the summaries multiple times. Initial coding was conducted following the analytic frameworks and research questions. For example, stigma was categorized into drivers, manifestations and outcomes, and illness explanations were categorized into signs and symptoms, causes and severity. Codes including words, phrases and sentences were highlighted in the transcripts. A chart was then developed onto which relevant codes were sorted. Through revisions, the codes were grouped into larger categories and themes that lead to the final interpretation of the data that answered the research questions. The analysis included looking at the main themes across different population groups.

6.8 Ethical considerations

The main risks of the study were identified as breach of confidentiality and invasion of privacy. Therefore, all interviews were anonymous and conducted in a private room or space. All interviews started with verbal consent. The confidentiality of data was also maintained after data collection. The investigator destroyed all interview notes and data

grids after they were entered into the computer. The investigator stored the data in password protected computer. Hard copies were kept in locked cabinets. Two years after finalizing the study all data files (soft and hard copies) will be destroyed.

The unique ethical considerations related to research involving individuals with mental health problems were also considered including the varying impact of mental disorders on behaviour and cognitive function and the possible effects of mental illness on decisional capacity. Study participants' understanding of the consent process was determined by asking specific questions. Those who did not demonstrate adequate understanding of consent were excluded from the study. To ensure that the interviews did not further stigmatize study participants (people with mental health problems and their caregivers), interviews were conducted in a familiar and safe place where they were accustomed to meeting HI community mobilizers or have therapy sessions. Study participants were given a compensation of 35 South Sudanese Pounds (SSP), equal to the price of refreshment.

7. Findings

This section describes background characteristics of study participants, social norms surrounding local illness explanations, stigma and health seeking of those with mental health problems in South Sudan. The data is obtained through FGDs with community members and IDIs with key community members and service providers. The section also includes experiences of people with mental health problems their caregivers, stigma and health seeking.

7.1 Background characteristics of study participants

People with mental health problems

Our study included five men and five women (=10) with mental health problems ranging in age from 21-50 years old (mean age = 32.6). Their educational level varied from a few years of primary education to university level degree. Half of the study participants were living in

the prison while the other half lived with their caretakers. Two participants were married, four had never been married, three were divorced or separated and one was widower. Over half of the participants had been refugees in Khartoum or Uganda or both, and two had been internally displaced in South Sudan. The study participants hailed from different ethnic backgrounds. Four reported being Bari, two reported being Kakawa and others reported being Moro, Mali or Dinka. None of the study participants were working. Those who were in prison had been there from seven months to eight years. All study participants living in the prison regularly attended HI prison therapy and counselling activities, and all but one study participant living with a caretaker participated in HI community based support group meetings. All had been diagnosed with severe mental health problems.

Caretakers of people with mental health problems

The study included 15 caretakers of people with mental health problems. The majority were women (12/15), ranging in age from 60-28 years old (mean age= 42.0). Caretakers reported varying levels of education from no schooling to university level studies. However, most of them had either some primary school (6/15) or secondary school (6/15). All but two caretakers were married. Two had their son in prison because of mental health problems. Over half of the caretakers (8/15) had been refugees in either Sudan (Khartoum) or Uganda, two had been internally displaced in South Sudan, and the rest had not been displaced or refugees. The caregivers came from different ethnic backgrounds including Bari, Muru, Madi, Kuku and Kakwa. The majority were working (11/15) either as government employees or in the service sector as a cleaner or as laboratory assistant, or were self-employed. The rest of the caretakers (4/15) reported being supported by another family member such as husband, father or brother.

Service providers

The study also included 16 service providers. Nearly half of them (6/16) were working in the governmental health system including JTH, the Juba prison and primary healthcare centres, some worked in the NGO sector with mental health problems (4/16), and others provided healing services at churches (3/16). The sample included psychologists, social workers, clinical officers, nurses, pharmacists, advocacy officers, community mobilizer/outreach workers, pastors and church councillors.

Study participants from the traditional health sector included one female traditional healer, one male witch doctor and one female who performed both traditional healing and witchcraft (3/16). Traditional healing was based on treatment with herbs that both healers collected in the nearby forest and mountains, whereas witchcraft was based on contacting the spirits of the deceased through drumming and other rituals such as sacrificing a chicken or sheep. All of the healers had worked in their profession for several years and gained their customers through word of mouth. The two female healers were Sudanese and the male healer was originally from Burundi.

Key community members

The study included 10 key community members including five male community leaders who had been in their position from three to 10 years. The sample also included one male teacher who had been working in primary schools in Juba for over seven years, one female religious leader "Mothers Union" whose responsibility for the past two years was to conduct specific activities for mothers in the community, and two pastors of protestant churches who had been serving their community for over five years.

Community members

Eight FGDs were conducted with a total of 83 community members, including 43 women and 40 men ranging in age from 14-55 years old. One group included students in a primary school who were between13-17 years old. The FGDs were distributed between Juba Town, Kator, Munuki and Rajaf Payam. The vast majority of participants had either no schooling (34/83) or a varying number of years of primary school education (30/83), several (13/83) had attended secondary school but not necessarily completed it, and only a few participants(6/83) had a university level education. More than half of participants (50/83) were married, the rest were either single (15/83), divorced, separated or widowed (16/83) and a couple of community members did not report their marital status (2/83). Study participants represented different ethnic origins including Acholi, Balanda, Bari, Dinka, Kuku, Lotuko, Madi, Moro, Mundari and Pojulu.

7.2 Local illness explanations

Key findings on local illness explanations

- People with mental health problems are categorized into those who are mad (majnun) and those who are sad and tired (mariid = sick).
- Mild signs and symptoms are not recognized as mental health problems.
- Causes of mental health problems are many and they are complex.
- Mental health problems are believed to be common in South Sudan.
- Mental health problems with strong symptoms are not believed to be incurable.

Community members, key community informants and service providers were asked to describe common problems among people in their communities related to thinking, feelings and behaviour.

7.2.1 Illness categories and symptoms

In general, respondents categorized problems into two wide groups: madness and tiredness/sadness. There did not seem to be specialized local terminology to address these conditions. As such, respondents simply referred to people with these types of problems as *majnun*in Juba Arabic, which means mad. In some FGDs, respondents disagreed by elaborating that tired/sad people should not be called *majnun* because they are only ill (*mariid*). In one FGD, respondents explained that a sad person has not yet reached the level of being *majnun,* but could become *majnun* if not treated. Respondents with biomedical backgrounds such as nurses and psychologists mentioned depression, post traumatic disorder and schizophrenia as common mental health problems among community members.

In all FGDs, respondents also mentioned a "shaking illness" (*maratsarra* in Juba Arabic) that repeatedly afflicted some community members. Respondents with biomedical backgrounds referred to the condition as epilepsy.

Table 1 - Illness categories and symptoms

Category	Symptoms
Madness (*majnun*)	Talking to oneself, talking in a nonsensical way, walking around, moving a lot, laughing to oneself, laughing without a reason, not listening to anyone, not understanding normal conversation, aggressive, dangerously violent, abnormal behavior such as picking up trash in the street
Tiredness /sadness (*majnun, mariid*)	Self-isolation, not talking, unresponsive to questions, not eating, not sleeping well
Epilepsy (*maratsarra*)	Bouts of shaking

7.2.2 Causes of mental problems

Respondents agreed that there were **multiple ways to become mad or tired and sad.** In all FGDs and in the majority of IDIs, poverty was widely discussed as important overarching problems that lead to madness. A frequently cited cause was "too much thinking" about difficult life circumstances with limited economic or educational opportunities.

Testimonies

"People find themselves in an impossible situation in which nothing is working. They try hard to improve their lives but they can't find a job and don't know how to educate their children. They keep failing time after time. In the end, they turn mad." (Man, Juba Town).

"The other thing is stress, hunger, sickness, and lack of food and water; when people begin to think about these things it creates mental sickness. You see everyone suffering, in trouble, fighting." (Christian religious leader)

Respondents in all FGDs and most IDIs also mentioned trauma related to long-term war in the country as one of the main drivers of madness. They explained that people have lost

loved ones, seen loved ones die, and have experienced violence and injustice that are all potential drivers for madness. Traumatic experiences were also considered as the main cause of tiredness and sadness.

Testimonies

"They may have had a good life before the war, but because of the war they lost everything. They have experienced a lot, they have lost loved ones. Such experiences traumatize you." (A man, Rajaf Payam)

"War separated many people, there has been unnecessary killing, and people saw killings. Some people have been really affected by war." (Christian religious leader)

In one FGD in Rajaf Payam, respondents had a lengthy discussion about children who have gone mad as a consequence of the war. It was seen a common and devastating problem.

Testimony

"Some children are orphans and there is no one to care for them. They are hungry, they may be sick and when they are mad, there is still no one to care for them." (A man, Rajaf Payam)

In all FGDs, respondents also mentioned chronic or untreated infectious diseases, such as malaria or yellow fever which were believed to make people mad.

Testimony

"It is common that malaria attacks brain. When you do not treat malaria it goes to your brain." (A woman from Kator block, Juba)

Extensive use of alcohol and drugs that create mental problems was a common worry discussed in all FGDs and several IDIs with key community members and service providers. Drug-related mental health problems were a significant community concern as people repeatedly raised the issue. Often respondents linked drug use to poverty-related problems

or war-related trauma. Some expressed worry about extensive drug use and mental health problems because they see it as a growing issue and because they seem to be severe problems among the youth.

Testimony

"There are illnesses that people created themselves, such as taking drugs. Drugs were not always in South Sudan. I don't know when these things came to South Sudan." (Community leader, Rajaf Payam)

In all FGDs, respondents explained that evil spirits and ancestral spirits could attack person causing mental health problems. Social relations played an important role in these cases because, according to respondents, when someone causes trouble for someone else spirits appear causing madness in the alleged perpetrator. Family members of the mad person could also have caused madness by doing wrong to another person. In some FGDs, respondents explained that a person wanting to harm someone could visit a witch doctor and request a spell be cast on that person to make him or her mad. Respondents further elaborated that it was possible to have evil spirit-related madness even if the cause of the illness was linked to poverty-related "too much thinking", war-related trauma or the use of alcohol and drugs.

Testimonies

"There are so many problems in this country and so many people who came mad because of bad spirits or because someone did something wrong to them." (Christian religious leader, Juba Town)

"We know that these things come from evil spirits and sometimes the evil is associated with somebody. Spirits can interrupt you, annoy you or make you mad." (Christian religious leader, Munuki)

"If he speaks strange languages nobody has never heard of, then this is a kind of spiritual problem, and I can help." (Witch doctor, Juba)

7.2.3 Severity and cure of mental health problems

All community informants and service providers believed that mental health problems were common in their communities. Respondents also had a united view that mental health problems were a visible and growing problem in the country.

Testimony

"We have mad people everywhere. You only need to look around and you can see one talking to him, another one running around. Juba has so many problems, and so much madness." (A woman, Manuki)

Respondents frequently cited that persons who had strong symptoms of madness were not curable, whereas people with mild symptoms may get well with treatment. Respondents also commonly explained that traumatized people could recover if the root causes of their problems were solved. For example, respondents in one FGD explained that if unemployment was the reason for sadness, then finding a job would cure the person. They noted that often sad people just needed someone to talk to them and solve their problems to be cured. Respondents also frequently mentioned incurable cases of *maratsarra.*

Testimonies

"But there are those whom nobody can help. That's why you find them at home or in the street. When you became so mad that you just walk around, that's when there is nothing to be done." (A man, Rajaf Payam)

"Medications don't help treat sarra. I used to give medication to my daughter but the illness came back." (A woman, Munuki)

Recommendations

Program level

- To educate HI and other stake holders involved in mental health in South Sudan about local illness explanation and terminology to improve communication and to identify culturally appropriate strategies to improve services.
- To improve case detection and early diagnosis of mental health problems by focusing on raising awareness of common symptoms as well as mild symptoms and of effectiveness and necessity of treatment.
- Revisit the contents of the community outreach/ awareness activities to ensure that it addresses local concepts and causes of mental illness culturally meaningfully.
- Develop strategies to improve access to treatment of people with epilepsy by focused awareness raising about available treatment options.
- Promote terminology that refers to mental health problems instead of madness as using it can be highly stigmatizing.
- Promote the benefits of treatment and psychosocial support for all people who have mental health problems (not only for those that are quiet and isolated).
- Consider establishment of community level alcohol and drug rehabilitation services.

Policy level

- Advocate for addressing structural causes of mental health problems (social determinants of mental health).
- Advocate for school based skills-building programs to enhance both prevention and early detection of mental health problems and substance use.
- Advocate for substance use related rehabilitation programming for South Sudan.

7.3 Community perception linked to a person with mental health problems

Key findings of community perceptions linked to a person with mental health problems

- Stigmatizing attitudes towards *majnun* (mad people) and those who have *maratsarra* are common.
- Stigma is driven by different fears and beliefs associated with mental problems.
- Stigma manifests in distancing, isolation of people with mental problems and gossiping.
- Stigma results in increasing psychological distress.

7.3.1 Anticipated stigma

To gain a better understanding about stigma toward people with mental health problems, community respondents and service providers were asked about negative attitudes toward people with mental health problems in the context of South Sudan. They noted that negative attitudes were mainly directed toward *maganiin* (mad people) and people with *maratsarra* (epilepsy). Many respondents were confident that sad and tired people were not stigmatized or discriminated. The following describes drivers, manifestations and outcomes of anticipated stigma.

7.3.2 Drivers and facilitators of stigma

Many respondents believed that people can easily stigmatize those with mental health problems because they have **little knowledge** about these problems, **lack familiarity in dealing with people with mental health problems and fear the unknown.** Respondents in the FGDs explained that people often don't know how to deal with someone who is acting differently and they don't understand that people who act abnormally do not necessarily know what they are doing. Some behaviors, such as walking naked in the streets, were found too difficult to comprehend any other way but negatively.

Testimony

"This person has changed his behavior, does not talk to people, causes destruction around him, and does not understand others, so people don't know what to do. These behaviors make people to go away." (A woman, Juba Town)

Another reason for stigma was a **fear of physical violence**. Many respondents in various FGDs and IDIs mentioned that those with mental health problems were dangerous as they could physically harm others and even kill.

Testimonies

"He (person with mental health problems) can even kill you because he does not understand." (A man, Kator)

"Such a person cannot be left alone with children, she may kill your child." (A man, Juba Town)

"They (people with mental health problems) have unpredictable behavior. If you say something wrong they may attack you." (A woman, Juba Town)

Respondents also frequently linked **criminality and drug use** with mental health problems that, in turn, increased stigma toward them. For example, some respondents mentioned that people generally believe that those with mental health problems could steal or that they belonged to criminal groups.

The **unpleasant and unhygienic appearance** of people with mental health problems was also mentioned by several community members as well as service providers as a reason for stigma.

Testimony

"People despise her and ask how she can walk around without bathing." (A woman, Juba town)

In some FGDs, respondents mentioned that a **concept of "bad and evil"** was sometimes linked to people with mental health problems. Respondents found it difficult to explain the underlying concepts but they believed that the ideas came from the connections to evil spirits.

Testimony

"Well, if that person has an evil spirit and he does not like you, maybe he can do something." (A man, Juba Town)

Respondents also frequently referred them as "useless".

Testimony

"People in South Sudan think that such a person is useless. You have lost hope that such a person could do anything in his life. He cannot help himself or others and he is seen as a burden on the community and to his family." (A woman, Rajaf Payam)

The majority of respondents did not believe that evil spirits could transfer from mad persons to others. However, some respondents cited that it was better to be cautious when dealing with people that had evil spirits.

Testimony

"Sometimes people avoid speaking about madness if it is linked to evil spirits. It is not good to talk too much." (A woman, Munuki)

There was also **victim blaming** for the illness. Several respondents explained that those with mental health problems brought it on themselves or have family members that created these problems.

Testimonies

"People may think that one of these family members has done something wrong. Sometimes people gossip that the father of this and that person has done this or that and caused the illness." (A man Rajaf Payam)

"Sometimes people may blame the person who got the illness for the condition as well. People say that he or she has done something wrong." (A woman, Rajaf Payam)

Many respondents highlighted that severe madness had no cure.

In general, people did not believe that mental health problems were contagious with the exception of marat*sarra*, which was believed to infect others in close contact.

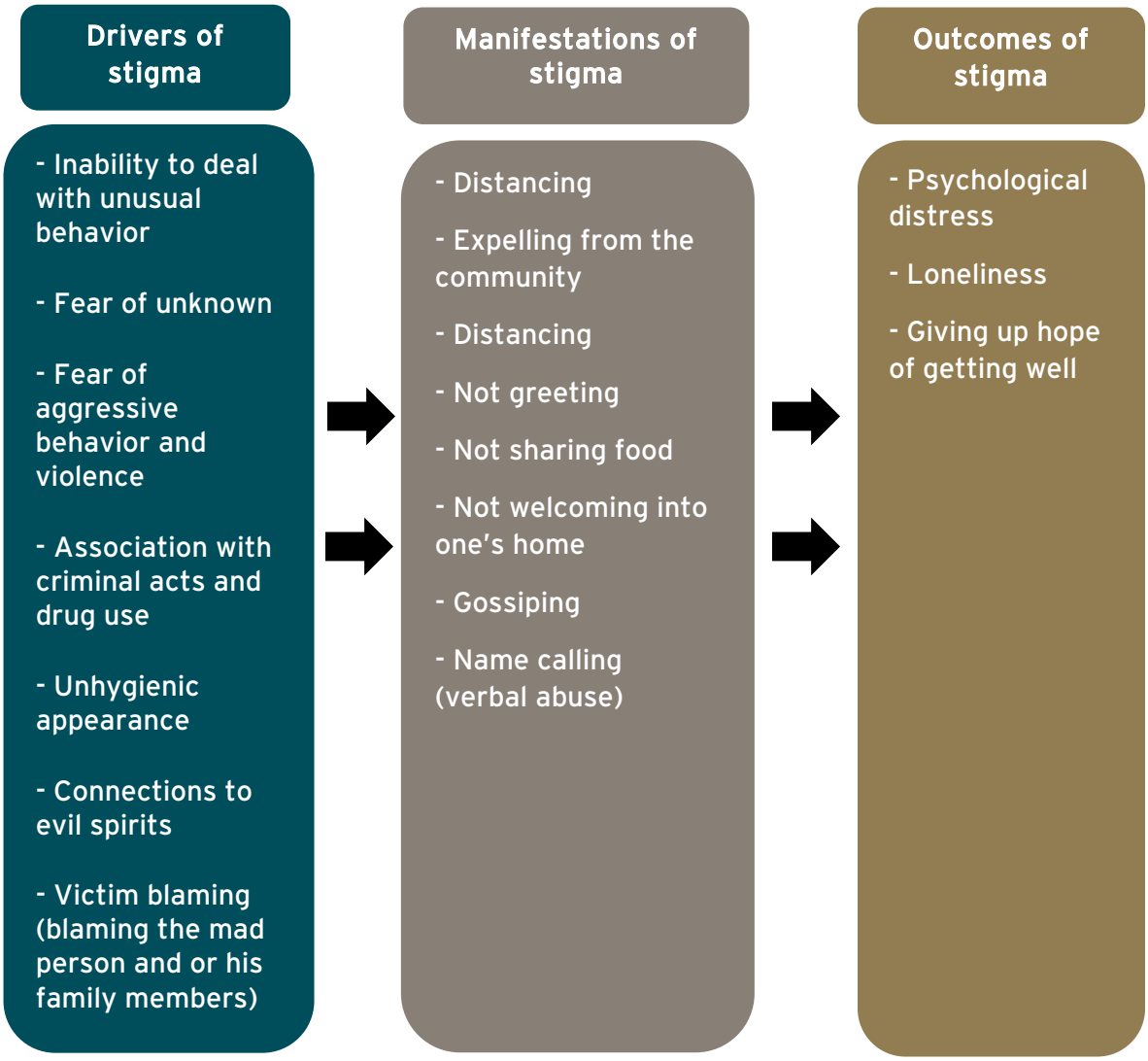
Testimony

"They fear that children in the same household will get sarra." (Service provider, Juba)

7.3.3 Stigma outcomes

Community members did not offer many observations regarding the outcomes of stigma. However, service providers often offered in-depth descriptions of the psychological distress that stigma caused. Some service providers explained that stigma was likely to influence the recovery of young people with mental health problems as they did not feel accepted. Other service providers mentioned that people with mental health problems were often lonely and did not easily seek the company of other people due to fear of anticipated stigma. Others cited that stigma made people give up hope that they would ever get better.

Figure 3: Stigma framework - Anticipated stigma toward people with mental health problems



Recommendations

Program level

- **Develop a stigma reduction strategy** that uses evidence-based approaches (RAND, 2012) to change behaviour and community norms as follows:

  1) Use the drivers and facilitators of stigma to change misconceptions about mental health problems by providing the public with accurate information to help alleviate fears and dispel myths.

  2) Include face-to-face interaction with people who have mental health problems to achieve greater impact (contact interventions).

  3) Use a re-categorization intervention approach that aims to break down or rearrange social categories. For example, it can emphasize that "anyone can have mental health problems" or that "many mental conditions can be managed cured regardless of the severity of the symptoms". Changing these beliefs is likely to break down perceptions of "us" and "them".

  4) Educate the public about prejudice to help reduce stereotyping, induce empathy and promote empowerment of those who have mental health problems.

  5) Ensure behaviour change communication targets specific populations/groups of people with locally delivered, continuous and credible messages (avoid generic).

Policy level

- Advocate against mental health related stigma in the areas of healthcare professionals, media, and youth.
- Share current research, programs, best practices and personal stories with policy makers to advocate for anti- stigma policies.

7.4 Experiences of people with mental problems and their caregivers

Key findings on experiences with mental health problems

- Common challenges of caregivers and people with mental problems included lack of knowledge about where to seek care, lack of social support, financial problems as well as lack of skills to deal with people with mental health problems.
- People with mental problems often have to put their educational and employment plans aside.
- Experiences of stigma included verbal abuse and gossiping.
- Caregivers can also experience stigma (secondary stigma).
- Stigma coping mechanisms included ignoring negative and stigmatizing comments and avoiding situations where stigma may occur.

7.4.1 Challenges

Respondents with mental problems and caregivers were asked to elaborate on the challenges they experienced during the time they had mental health problems or during the time they cared for someone with mental health problems. The discussions identified challenges linked to lack of knowledge about where to seek care, lack of social support, financial problems as well as lack of skills to deal with people with mental health problems.

Most caregivers discussed lack of knowledge about what to do and where to go when the symptoms of mental health problems appeared and became stronger.

Testimony

"In Africa, people don't think that mental problems are a big thing. We have so few doctors. We did not know who could help us, for long we did not know anything." (Caregiver ofa 26-year-old woman with mental health problems)

Many respondents that had experienced mental health problems mentioned that it was difficult to share their feelings or let anyone know what was going on by the time they did not feel well.

Testimonies

"I could not talk to my friends. They did not understand what I was talking about." (26-year-old woman with mental health problems)

"People have their own problems so nobody has time to support you with yours." (Caregiver of a 27-year-old woman with mental health problems)

Many people with mental health problems and caregivers also mentioned that medication had been a problem at some point and, for some, it continues to be a problem due to the unavailability of the medication or the cost when they are obliged to purchase it from private pharmacies.

Testimony

"Sometimes we have it and sometimes we don't. They used to prescribe it and then they stopped. I haven't received any medication for a few months. I don't know what happened." (20-year-old woman with mental health problems)

Overall, financial problems were mentioned frequently. Having household members who were unable to support themselves was difficult as families were already having financial problems.

Testimonies

"Who has money nowadays in South Sudan? There is nobody who can manage, so what about us with the extra cost of trying to help him [brother with mental health problem]?" (Caregiver of a 49-year-old man with mental health problems)

"I go to my son in prison when I have the money to bring him food. That doesn't happen all the time. Sometimes I have nothing to give." (Caregiver of 25-year-old man with mental health problems)

Several caregivers also expressed concern about not knowing enough about mental health problems or how to deal with them. Dealing and managing with aggressive behavior was frequently mentioned.

Testimonies

"She has gained so much weight. It feels that something else is going on because she has gained so much weight. She was not like this before. I don't know what to do. I don't know why we are having this problem now." (Caregiver of 26-year-old woman with mental health problems)

"We have many difficulties. For example, the fact that he is so big. It makes it difficult for us to handle him or hold him. They had hard times dealing with his aggressive behaviour. Sometimes they had to run out of the house. The only one who could handle him was his father." (Caregiver of a 25-year-old man with mental health problems)

Another common challenge was relapse in substance use disorder including drugs and alcohol use that lead to another episode of mental health problems. Some caregivers had to deal with several relapses that led to the re-emergence of mental health problems and even readmission to prison.

Testimony

"We could not stop him. He went back to his friends - he likes them - and there he was back to using alcohol and drugs. We couldn't stop him." (Caregiver of a 24-year-old man with mental health problems)

7.4.2 Impact on life

Most persons with mental health problems cited that their life was on hold during the time they had mental health problems in terms of studies, employment and marriage.

For some caregivers it was extremely painful to remember the times their son or daughter had mental health problems and the delays in education and work they had experienced. Many caregivers also believed that the person in their care would not get well enough to resume their studies or work.

Testimony

"My son has not done anything since he's had these problems. Doctors said he is weak and he needs to rest. I don't know where this will lead us. He was a good boy. Look at him now." (Caretaker of a 25-year-old man with mental health problems)

Recommendations

Program level

- Scale up support group for caregivers and people with mental health problems to ensure that more people have access to social support.
- Raise awareness of symptoms and signs linked with mental health problems as well as available care options.
- Include knowledge and skills building in support group activities to raise the confidence of caregivers, including how to deal with aggression and violence and how to help those with mental health problems avoid relapsing to destructive behaviours such as drug and alcohol use.
- Develop a prevention plan to provide caregivers and people with mental health problems targeted counselling on how to avoid substance use relapse. Cognitive behavioural models can be used including identifying specific high-risk situations for

substance use and enhancing coping skills regarding the effect of drugs and alcohol and managing lapses.

- Support people with mental health problems in their efforts to resume their everyday lives by assisting with educational and vocational training opportunities.

Policy level

- Promoting the rights of people with mental health problems.
- Advocate for increasing opportunities for improved livelihood to benefit the financial situation of people with mental health problems and their caregivers.
- Advocate for improved educational and vocational training opportunities.
- Advocate for improved mental health services including uninterrupted availability of medications.

7.4.3 Stigma

Manifestations of experienced stigma

Overall, most respondents with mental problems had limited recollection of the time they had these problems and therefore could not recall experiences with stigma. However, caregivers were able to give detailed accounts. The most common manifestations of stigma mentioned were verbal abuse and gossiping. Many respondents also mentioned the distancing behavior exhibited by others.

Testimonies

"People did not come close to him to talk to him or advise him, although he needed it badly. Some of his friends were even afraid to come and visit him." (Caregiver of a 25-year-old man with mental health problems)

"So many people were saying so many bad things about my sister and us. They feel embarrassed now because she is well." (Caregiver of a 24-year-old woman with mental health problems)

"They talk behind my back and say that this man must be taken to prison and so on." (A caretaker of 49 years old man with mental health problems)

"They ask me how long I am going to help my son and bring him food in the prison. They think my son is useless and I am useless for going up visiting him and spending money." (Caregiver of a 27-year-old man with mental health problems)

Many caregivers believed that people gossiped about them as much as they gossiped about the person with mental illness. However, others did not agree with that view and did not feel stigmatized.

Testimony

"They used to talk to me but then started to avoid me. They think there is something wrong in our house because we have majnun (a mad person) with us."(Caretaker of a 49-year-old man with mental health problems)

Outcome of experienced stigma

Some respondents with mental health problems mentioned minimal feelings of self-worth due to their experiences with stigma. Caregivers explained that stigmatizing experiences delayed recovery and the desire to get well. Some caregivers that had experienced stigma felt disrespected and patronized.

Coping mechanism

Caregivers mentioned a few mechanisms they used to manage stigmatizing attitudes and protect people with mental health problems from verbal abuse and gossiping. Some family members made sure the person with mental health problem was never left alone and escorted her everywhere. Others coped by convincing themselves that the gossip was nonsense and/or avoiding talking with people who had negative attitudes.

Testimonies

"My family did not really leave me alone. My brothers were always with me to make sure that nobody would hurt me by any means." (26-year-old woman with mental health problems)

"If I care about everything people say, I wouldn't be sane anymore. The truth is, I don't listen to what people say and I just don't care." (Caregiver, Juba Town)

Manifestations of self-stigma

Several respondents explained that they had frequent negative feelings toward themselves because of mental health problems.

Testimonies

"Hardest part is not being able to take the responsibility, being down, not being able to work. I felt useless." (34-year-old man with mental health problems)

"I don't understand how I ended up like this. I often want to just hide and forget that I am here." (26-year-old man with mental health problem)

Recommendations

Programming level

- Address experienced stigma and self-stigma with evidence-based stigma reduction strategies such as:
  1) Interventions that enhance coping with self-stigma through improvements in self-esteem and empowerment,
  2) Interventions that attempt to alter the stigmatizing beliefs and attitudes of people with mental health problems.
- Include caregivers in stigma reduction interventions (secondary stigma).

- Consider modifying, piloting and testing stigma reduction intervention approaches that have worked elsewhere, such as peer education, photo-voice intervention, narrative enhancement or cognitive theory.
- Provide opportunities for caregivers and people with mental health problems to discuss and share their stigma coping mechanisms.

Policy level

- Promote social inclusion of people with mental health problems.

7.5 Health seeking behaviours

Key findings - Health seeking

- There are a number of different sources for care for people with mental problems.
- People can seek care in one source or several sources in various orders that often depends on contextual factors and family preferences and habits.
- Selection of the source of care is frequently based on the cause of the mental problem.
- Mental health services in Juba remain limited.
- The Juba Prison is lacking essential services for people with mental problems.

7.5.1 Sources of care

Community members and service providers were asked where people with mental health problems can seek care. Multiple sources of care were identified including formal healthcare providers and prison, traditional healthcare providers including church and self-care/homecare. Respondents explained that families of those with mental health problems could seek care through one or multiple sources.

A few respondents in all FGDs believed that people only sought biomedical care because South Sudan was becoming increasingly modern and traditional health providers were seen as a thing of the past.

Figure 4: Sources of care for people with mental problems

7.5.2 Selection of sources of care

Respondents who believed that those with mental health problems seek care from different sources were further questioned about how they choose the provider. Respondents explained that the selection of service provider depends on the cause of the illness.

Testimony

"There are so many ways to get well. You can get help at the hospital, from a traditional healer and/or in the church. If you know the cause of the illness, it will help you to choose the right provider. If you know that the cause is evil spirit, you must go to a traditional healer." (A woman, Rajaf Payam)

7.5.3 Hospitals and health centres

Hospitals, health centres and JTH specifically were sought when there was suspicion that the mental health problem might be linked to malaria, yellow fever or other infectious diseases. Untreated malaria was seen as a frequent cause of mental health problems.

Some respondents explained that those with mental health problems often first went to a hospital or nearby health centre or clinic to determine if the cause was malaria or another infectious disease. If the results were negative, they would eventually seek care from traditional healers.

Testimony

"You can go to a small clinic first and tell them about your symptoms to see if you have malaria and you will get medications accordingly. If you don't feel well, you will take the next step and look for care at a hospital and with traditional healers."(Community leader, Rajaf Payam)

However, other respondents acknowledged that the order in which one should seek care, including hospital care, varied from house to house depending on many contextual factors such as distance to the health facility and the cost of the visit.

A couple of community leaders stressed that the quality of care provided at the hospitals also determined whether or not people would seek treatment there.

Testimony

"If you go to the hospital and the doctors are not there, and they don't have medications, you won't go there again." (Community leader, Juba Town)

Experiences with hospital-based care

All respondents (caregivers and people with mental health problems) had used JTH services at some point during the duration of their problem. Those that had resources had obtained services from a psychiatric hospital in Khartoum, Sudan or from a specialist centre in Kampala, Uganda. Respondents explained that JTH did not have specialized facilities to cure people with mental health problems, which made them seek care outside of South Sudan. Respondents also explained that medications were not always available in JTH, whereas in Khartoum and Uganda the supply of medications was uninterrupted.

Some caregivers explained that medications they had received from JTH did not help, while others mentioned that medications were no longer available and buying them from a private pharmacy was costly and therefore often impossible.

In many health-seeking narratives caregivers stressed the importance of visiting JTH at the beginning of an illness episode to ensure the cause was not malaria or any other infectious disease that required medical attention.

7.5.4 Traditional health providers

In all FGDs and in majority of IDIs, respondents explained that when families suspected the cause of mental health problems was due to ancestral spirits, evil spirits or a spell then witches that used witchcraft and traditional healers that mainly used traditional herbs were sought for treatment.

Testimonies

"Everyone in Sudan knows that if you have this kind of traditional mental problem, you must go to look for spiritual help." (A man, Juba town)

"Sometimes people think the illness is linked to something that the person or family members did, so they don't need to take them to hospital." (A man, Kator)

Several respondents explained that it was typically not difficult for families to identify these types of causes of mental health problems as they usually jointly reviewed and discussed past issues between different family members to come up with the cause.

Testimony

"Some families have long-term problems that they have not sorted out, so this kind of family situation may cause mental problems in the family. These problems may have occurred generations ago. For example, someone's grandfather did something. Families always know what is going on." (A woman, Kator)

Alternatively, a few respondents explained that it was possible to go to a traditional healer to identify the cause of the problem.

Testimony

"The witch doctor will find the cause of the illness. If it is something that the person himself did or if it was his mother or father who did something." (A man, Rajaf Payam)

Many respondents agreed that families often first visited the hospital to determine if the cause of mental problems was malaria, followed by visit to traditional healer. However, in cases where family members were convinced that there were problems with ancestors, a traditional healer could be visited first.

Several respondents noted that people of Christian faith did not believe in traditional healers who used witchcraft, and accordingly did not use them or want to use them. Some respondents explained, however, that true Christian believers might visit traditional healers only after everything else had failed because it was considered sinful to use them.

Testimonies

"Those people that have faith in God maybe looking for help in the hospitals but others may seek care through witchcraft." (Religious leader, Munuki)

"People who are Christians do not prefer to use witch doctors." (A woman, Rajaf Payam)

Others stressed that use of traditional healers was a thing of the past.

Testimony

"This is an old thing. We only deal with hospitals and people in this area." (A man, Munuki)

Some respondents noted that the location of traditional healers and their financial requirements were sometimes a barrier. Respondents believed that Juba did not have many traditional healers or witch doctors and they were more common in rural areas of South Sudan, which made it difficult to reach them. Several respondents also explained that sometimes the fees that traditional healers charge were considerable as they could include sacrificing a chicken or sheep.

Experiences with traditional healing

The health-seeking narratives of most caregivers mentioned visits to traditional practitioners either because the cause of the problem was believed to be spiritual or because all other options had failed. Those whose family was linked to church had not made attempts to visit any traditional practitioners. Many caregivers were not satisfied with traditional practitioners as mental health problem had not disappeared. However, male caregivers explained they were advised and even pressured to visit traditional practitioners.

Testimony

"My sister kept telling me that I have to visit a kudjur (witch) because at the hospital they were not able to help us. I did not want to go but she kept talking about it. Finally she is the one who is my son there. After all this, it did not help my son either." (Male caregiver of 25-year-old man with mental health problems)

Practicing traditional healing

Three traditional practitioners were visited and interviewed during the study. One was a male from Burundi who relied on witchcraft. Two others were South Sudanese, one of which used only traditional herbal medications for healing while the other used a mix of witchcraft and traditional medications.

All of these traditional practitioners cited having started healing a number of years ago after gaining the skills to heal people with mental health problems through a revelation of spirits. These revelations of spirits gave healing powers through strong onsets of symptoms. For example one healer explained that strong headaches preceded his ability to heal, whereas another explained that strong nausea, vomiting and strange digestion problems preceded the onset of her healing skills.

The traditional practitioners gained their clients/patients through word of mouth. All of them explained seeing a number of clients daily. During the study field visit, one practitioner had several visitors waiting, and another was busy with a house visit. According to the traditional healers, their clients included men and women, older and younger with symptoms of madness or sad and tired people.

All of the traditional practitioners explained that they were able to identify the cause of mental problems by talking with family members. One of them explained that she could also see the cause of mental health problems by just looking at the client. Two explained that they could cure people if the cause was traditional - related to ancestors, spirits and/or social relations of the families - but they could not heal if the problem was substance use (drugs and alcohol) or if the problem was linked to malaria. One of them claimed being able to heal all types of cases regardless of the cause of the problem.

Healing practices varied in their length and content depending on the problem. All healers had an "in-patient" option if treatment was required over a long period of time. A male healer from Burundi said that some people travel from far away and need to stay at least a few days to rest, while some patients were treated for more than 10 days. The length of treatment also often depended on the financial resources of the family of the person with mental health problems. Similarly, the cost of treatment varies depending on the content and requirements.

Testimony

"Treatment is not very expensive if people don't overnight here and I need to provide them with food and everything. And you see the money is not just for me. I will buy things that are needed. The ancestors need to speak up first and say what their requirements are. Accordingly, I advise the family what I need. If I need to sacrifice a chicken or other thing". (A male witch doctor, Juba)

The traditional healers operated daily except one who closed her practice on Sundays when she went to church.

All traditional healers were aware of prejudices against them and claim they are against the Christian faith. They did not believe that collaboration between different types of mental health service providers would be possible as other types of providers such as doctors, nurses or church-based healers would not agree to collaborate with them.

None of the traditional practitioners claimed to refer clients to other service providers if they were not able to help the client.

7.5.5 Church-based healing

In all FGDs, respondents explained that people also frequently resorted to church to cure mental illness when the cause was believed to be due to evil spirits. Again, respondents stressed that it depended on family preference and whether they wanted to try prayer. They noted that families typically had a church is close proximity so access was easy.

A couple of respondents explained that sometimes people may ask the priest to pray for the person with mental health problems before visiting hospital or any other provider, whereas others may turn to church when other sources of care have failed. Many respondents also stressed that people who go to seek church-based care must be of Christian faith and believe in the power of prayer.

Testimony

"If a person with mental illness is taken to church, he can get well if he has faith. If he is not a believer, he won't get well. However, people with any kind of illness can be taken to church." (A woman, Rajaf Payam)

Practicing church-based healing

A group of four church-based healers that actively work with people with mental health problems were interviewed and visited during the study. They believed that prayer can solve any kind of mental health problem and gave a number of examples of people with severe symptoms of mental health problems whom they had treated. The healing process included talking to family members to identify the cause of the mental health problems. Church-based practitioners believed that family problems such as violence and marital issues were areas where church counseling and prayer sessions were most effective.

Testimony

"We Christians know that a person with mental problems is possessed by an evil spirit, so what we do is to pray and pray. We don't give up, because we know that finally our prayers will help and will change the person. So all we do is to pray. We get together and pray together. Together we are strong." (Male Church-based healer)

The church-based healers did not recall referring patients to other types of health providers often. They found collaborating with other service providers an important and interesting concept, however they also found it challenging as the various providers' basic principles of healing were so different.

Testimony

"Psychosocial counselling is different; it is not based on your faith. They are different from us." A female (Church-based healer)

7.5.6 Prison

Treatment in prison was sought when the person with mental health problems was violent and family and community had difficulty controlling the person. Prison was frequently considered a place that provided safety for the person with mental health problems and people around him or her. Many respondents clarified that prison was considered a necessity when family members and the surrounding community could no longer manage the violent and aggressive behaviour of the person with mental health problems. Respondents did not think that prison was stigmatizing by linking people with mental health problems to criminal activity. Respondents also explained that admission to prison was always a joint agreement between family members, the JTH doctor and local police department as it required a court order. Sometimes neighbours joined forces and took a violent or aggressive person to the police station.

Testimony

"We captured our neighbour and took him to the police station for them to see if he was a criminal or if he had mental problems. Accordingly, he would be further referred to another police station or prison." (Community leader, Rajaf Payam)

Most respondents did not think that hospitals were a better option for people with mental health problems than prison because they believed that hospitals were not equipped to deal with aggressive cases. Many respondents believed that the prison setting could also cure people with mental health problems as they believed that people with mental health problems had access to medications and doctors. Some respondents gave examples of people that had been admitted to prison because of mental health problems and who had been released after recovery.

Testimony

"Prison is not a prison. It is a place for us to keep those that are aggressive. They can get cured there." (A man, Munuki)

Others however, did not perceive prison has a place to be cured, but as a place to be contained because of the dangers that person posed to himself and his family. These respondents explained that people with mental health problems in prison had waited too long for treatment and were no longer curable.

Testimony

"Prison is the place for people who are dangerous. Where else we should put them?" (A woman, Kator)

Experiences with prison care

A group of four men admitted to prison because of mental health problems were interviewed during the study. All of them had been admitted to prison against their will and without understanding why they were in prison. None of these men were able to highlight factors that supported their mental health recovery in prison. However, they were able to elaborate on a number of challenges they face in prison including poor hygiene that led to infections, especially skin infections, inadequate food, inability to obtain medications, inadequate clothing and irregular visits from a psychiatrist. There were no leisure activities except the HI's prison-based therapy and training activities that were being conducted twice a week during the study.

Two of the men who had stayed in the prison 7 months and 8 years respectively, had not had any visitors during their time in prison. They complained about insufficient amount and irregular supply of food. They also had no access to medications as they could only be obtained if family members purchased them.

Testimony

"You ask me how I feel. Well, I don't feel very well because I am hungry. I haven't got any food today and normally what I get is not enough." (A 38 years old man with mental health problems, admitted for 8 years in Juba central prison)

7.5.7 Pharmacies / medications

Respondents clarified that psychotropic medications were not available without a prescription. Therefore, it was not common to go to pharmacies to buy medications for people with mental health problems unless they were prescribed by doctors. Some community members and a pharmacist who was interviewed as a key community member noted that sometimes family members of people with mental health problems sought sleeping pills for those suffering of insomnia or anxiety. Overall, respondents believed that use of pharmaceuticals was low due to their cost. In one FGD, respondents had an in-depth discussion about the low quality of medications in South Sudan.

Testimony

"People are poor here. How do you think people pay for medications? It is not common in our communities to use medications. People can't afford it."(A man, Kator)

7.5.8 Community based care

Respondents explained that usually only a few people, mainly family members, were involved in the care of those with mental health problems. Respondents noted that the person with mental health problems often had some favourite people who got involved in his/her care. In addition, respondents mentioned that people could get involved with caretaking after discovering that they were able to deal with that person easily. In several FGDs, respondents also stressed that families were usually supportive.

Testimony

"Often family networks are tight so people are not necessarily so alone with this problem. But it is also true that the war has broken many families and there are those that no longer have family members around." (Religious leader, Munuki)

Many respondents mentioned that in generally people tried to avoid getting involved in any way with those with mental health problems, especially if the person had family around, because involvement with those with mental health problems might make him/her responsible for him/her in the eyes of the community, police and the law.

Testimony

"If he [person with mental health problems] goes and kills someone, they can hold me accountable for it if I take care of that person. So it is not good to deal with maganiin and preferable to avoid them." (A man, Kator)

Several respondents explained that if mental health problems were the result of someone putting spell of evil spirits on another person then that is an indicator of problems between people in the family. Therefore, family reconciliation was used to solve the problems. Respondents noted that such a family problem required identification of the problem and asking for forgiveness.

Testimony

"If a person has mental problems because he did something to someone in the family or he took something from someone, he may give back those things and even ask for forgiveness." (A man, Kator)

In both FGDs conducted in Rajaf Payam (rural area), respondents discussed the need to resort to local herbs when treating *maratsarra* (epilepsy) because hospital medication was ineffective.

Testimony

"What our neighbors do now is use some traditional stuff that one can get from the bush. So if she feels that the attack (epilepsy) is coming, she goes to the bush to get some medication." (A man, Rajaf Payam)

However, in general community members did not think that people in their communities used traditional medications or herbs to treat those with mental health problems.

Testimonies

"No, using herbs is not common. We have something for pain and fever but we have nothing for madness." (A woman, Munki)

"We have [herbs] for other illnesses, it is called dikertimalo that can be used for pain in stomach, headache, yellow fever and malaria, but not for madness." (Woman religious leader)

Respondents frequently noted that families of those with mental health problems had a number of different practices depending on which part of South Sudan they're from.

Testimony

"All houses are different. The country where I come from, we may make a sacrifice if someone is sick with malaria or diarrhea. So we may bring a sheep. This is not witchcraft. After the animal is killed, people start talking to God 'Why did you do that?', 'Why is he sick?', 'This man is good for us. Why did you make him sick?'" (A man, Rajaf Payam)

Several community members discussed the presence of many violent people with mental health problems in their village. Often the decision to take the violent person to prison was made jointly by the family members and the community. Many community members also explained that strong men were often recruited to capture the person to be taken to the police station and then to prison.

Testimony

"The only option to deal with such a case is to tie him or take him to prison. Neighbors often join forces to capture someone like that." (A man, Juba Town)

In one FGD, participants explained that it was the job of the local police officer to evaluate the person with mental health problems.

Testimony

"If there is an aggressive person, usually strong people from the village capture that person to be taken to the police station. There, the police will assess why this person is violent if he is sick. So it is for the police to deal with such a person. If the person does not have mental problems, it means that it is a police matter."(A man, Rajaf Payam)

Respondents noted that those with mental health problems were not taken to prison immediately. Often, family tried to tie or chain the person at home for his/her own protection and that of others. If that doesn't work, other options, including prison, were evaluated.

Testimony

"People take their time, they always hope that things get better, prison is the last option." (A man, Rajaf Payam)

A few respondents mentioned that elderly community members were sometimes consulted and asked to use their influence to talk to the person with mental health problems, especially when the issue was bad behaviour or alcohol and drug use.

Testimony

"Elderly people can also help by talking to them [those with mental health problems]. A person who is younger is not a good option because he [person with mental health problems] may not listen. He may say, you don't know or understand me because you haven't been through what I have."(A woman, Rajaf Payam)

Reasons for delay in care seeking

Respondents were asked to explain reasons for delayed care seeking. Barriers to seeking care differed based on the strength of the symptoms.

Mild and temporary signs and symptoms

Respondents explained that when the symptoms and signs of mental problems were mild or seemed temporary, the main reasons for not seeking care were because it was not recognized as a mental health problem, belief that the condition will resolve itself, and because people often had no idea where to find help.

Moderate, regular signs and symptoms

The majority of respondents revealed that once the symptoms and signs became stronger and more regular, people usually understood that it was a mental health problem but they still did not necessarily seek care because they did not know where to go for help, they feared stigma, and they may have financial and other logistical constraints.

Severe, prolonged signs symptoms

Most respondents agreed on the reasons for delayed care seeking when signs and symptoms were severe. They included many similar problems as with mild and moderate signs and symptoms such as lack of knowledge about where to find care, fear of stigma and financial and logistical problems. They also included additional reasons such as belief that late stage mental health problems cannot be cured, lack of respect toward persons with mental health problems, perceptions that those with mental health problems are useless and are not worth the resources it would take to treat him/her. Lastly, many respondents also mentioned that people had reservations regarding the quality of care in health facilities due to lack of medications and other supplies.

Recommendations

Program level

- Improve coordination among different service providers by incorporating knowledge of health seeking behaviours into healthcare service delivery strategies in a way that is sensitive to the local dynamics of community. Specifically:

- Project planning should consider all types of service providers in order to improve case diagnostics.
- Project planning should consider perceived challenges those with mental health problems experience with various service providers.

- Train key community members, including local police, judges and others, who are involved in the care of people with mental health problems.
- Intervene and develop strategies to facilitate care seeking.

Policy level

- Advocate for networking and collaboration between different types of service/health providers.
- Advocate admissions of people with mental problems to appropriate institutions.
- Advocate for improved mental health services at all levels (hospitals, community).
- Advocate for improved policies and services for people with mental health problems in prison.

Figure 5: Reasons for delay in care seeking

8. Discussion

This study provided valuable insights into how people in Juba, South Sudan understand mental health problems and related factors that influence health seeking behaviors. As the study participants included those with different demographic backgrounds and ethnic origins, it is likely that the findings are also applicable to other parts of South Sudan.

The study identified two broad categories of mental illness: mad people and sad and tired people. Many of the symptoms of these local syndromes were identical to psychiatric disorders of mood, anxiety and conduct problems. Yet it is important to realize that even if these cultural categories are closely aligned with biomedical concepts, they are not identical. These concepts are localized and, as a result, reveal how contextual factors shape illness experiences as identified in a number of ethnographic studies (Vendevogel et al 2013; Betancourt et al 2009). For programming purposes, this requires continuous cooperation and dialogue between health care professionals and community members to maintain a mutual understanding of the concepts and terms that are used by both parties.

This study also has other important implications for mental health programming. It finds that the people of Juba are concerned about mental health problems, but there are a number of barriers that delay care and treatment seeking. The study also reveals how people choose service/health providers in holistic health systems with informal and formal health providers based on their perceptions about the cause and severity of the problem. Conditions that are not seen as medical problems are deemed to require mainly home and community interventions as identified in previous studies in the region (De Jong & Kamprose, 2002, Ventevogel et al 2013). Programming for the prevention and early detection of mental health problems can use this information to ensure the locations and approaches are meaningful.

The study also captured drivers, manifestations and outcomes of anticipated stigma, experiences of stigma and self-stigma. The findings can be used to develop culturally appropriate and effective stigma reduction interventions among various target audiences including service providers, caregivers and people with mental health problems.

The study results strongly highlight that people with mental health problems and their caregivers face multiple challenges and require support. Therefore, it is essential that evidence based empowerment strategies that incorporate the promotion of human rights are included in programming. Programming that engages those with mental health problems and caretakers is essential to learning how people themselves define what is going on in at stage for their own lives.

Limitations

The methods presented in this study involve the use of just two qualitative methods of data collection and only a team of two, consisting of the study investigators and translator. The intent in using only two methods and one investigator was to develop a rapid approach that would be feasible in programming for mental health in Juba. By limiting the methods and research personnel, it was possible to collect the data within three weeks. Under the circumstances of increased time and resources, additional methods and a data collection team would have provided greater data depth and data triangulation.

Data collection and analysis using translated data was another limitation in this study. To avoid bias, the investigator used an interview technique in which she asked interviewees to summarize the concepts and ideas that were discussed to ensure that they were interpreted correctly.

Key informant interviews did not include government officials responsible for mental health or psychiatrists working at JTH and Juba Central Prison, which is likely to constitute a limitation in the data as such information would be critical for informing additional models and how biomedical and local models can be used in programming.

9. Conclusions

The study has demonstrated that rapid ethnographic assessment methods can be applied to describe and explore local perceptions of mental health. The recommendations of this study addressed the immediate mental health service and program needs of people in Juba, South Sudan. The study has shown that more financial and human resources should be dedicated within existing programs to engage people with mental health problems and respond to their health and social needs.

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Appendices

Research protocol

Exploring understanding of mental health problems among communities in Juba, South Sudan: Socio-anthropological study

Anna-Leena Lohiniva

Appendix 1 – Tools

Interview guide - Person with mental problems

I. DEMOGRAPHC DATA

I would like to start this interview by asking you a few questions about your background

Q1	How old are you?	..... Years
Q2	Gender?	Female 1 Male 2
Q3	What is your relationship status?	Married 1 Separated 2 Divorced 3 Widowed 4 Never married 5 Do not know 99 Refused 88
Q4	What is your ethnic group?	
Q5	What is the highest school you have completed?	Never attended school 1 Completed or partially primary school (6 years of schooling) 2 Completed or partially/ completed secondary school (9 years of schooling) 3 Completed post-secondary school) 4 Do not know 99 Refused 88

Q6	Have you ever been displaced/ refugee?	Never forcibly displaced	1
		Previously displaced as refugee	2
		Do not know	99
		Refused	88
Q7	Where do you live currently?	Juba city	1
		Outside of Juba city	2
		Other	77
Q8	How long have you been living in the current location?	..... Years / ..... Months	
		Does not remember	99
		Refused	88
Q9	With whom do you live?	With family members	1
		With friends	2
		Alone	3
		With other refugees in camp	4
		Other	77
		Do not know	99
		Refused	88
Q10	What is your main income?	Government employee	1
		Service sector	2
		Agriculture	3
		Military	4
		Family support	5
		Do not know	6
		Refused	7

II. EXPLANATORY MODELSS OF ILLNESS AND HEALTH SEEKING BEHAVIOR

I would like to talk to you about your problems that manifests in thinking, feeling or behavior?

1) What kind of problems do you have?

2) What do you call these problems?

3) How long ago did you notice these problems?

4) Why do you think these problems started when they did?

5) What is the cause of you getting these problems?

6) What do you fear most about your problems?

7) What does this illness do to you? How does it work?

8) How these problems have affected your life?
   Probes: social life, work, home life, economy

9) Where have you been looking for care?
   Probes: hospital, health unit, informal health providers, friends, family members, self-help, medications

10) What type of care you have received?
    Probes instrumental, information, emotional, treatment

11) What triggered you to seek for care?

12) When did you go to seek this care?
Probes: after symptoms appeared 4 weeks, 3m, 12m

13) What do you hope to gain from your current treatment?

14) What kind of care do you think you should receive?

15) What are the main problems for you to seek for care?

III. COMMUNITY ATTITUDES AND STIGMA AND DISCRIMINATION

16) What do you think people think about you and your problems?

17) How do people behave towards you? How do they treat you?

18) Why do you people think and behave towards you the way they do?

19) How does the way people think of you and behave towards you influence your life?
Probes: self- hate, shyness, isolation, fear, inability to socialize with others

20) How do you deal with the negative attitudes and behavior of people?

21) What do you think can be done to change these negative attitudes of people?

22) Thank you for the time you are giving us for this interview. Do you have anything else you would like to tell us?

Interview guide – Caretaker

I. DEMOGRAPHC DATA

I would like to start this interview by asking you a few questions about your background

Q1	How old are you?	..... Years
Q2	Gender?	Female 1 Male 2
Q3	What is your relationship status?	Married 1 Separated 2 Divorced 3 Widowed 4 Never married 5 Do not know 99 Refused 88
Q4	What is your ethic group?	
Q5	What is the highest school you have completed?	Never attended school 1 Completed or partially primary school (6 years of schooling) 2 Completed or partially / completed secondary school (9 years of schooling) 3 Completed post-secondary school) 4 Do not know 99 Refused 88
Q6	Have you ever been displaced/ refugee?	Never forcibly displaced 1 Previously displaced as refugee 2 Do not know 99 Refused 88

Q7	Where do you live currently?	Juba city	1
		Outside of Juba city	2
		Other	77
Q8	How long have you been living in the current location?	…… Years / ….. Months	
		Does not remember	99
		Refused	88
Q9	With whom do you live?	With family members	1
		With friends	2
		Alone	3
		With other refugees in camp	4
		Other	77
		Do not know	99
		Refused	88
Q10	What is your main income?	Government employee	1
		Service sector	2
		Agriculture	3
		Military	4
		Family support	5
		Do not know	6
		Refused	7

II. EXPLANATORY MODELSS OF ILLNESS AND HEALTH SEEKING BEHAVIOR

I would like to talk to you about the person whom you care for. Can you start telling me what kind of problem she / he has that manifests in thinking, feeling or behavior?

1) What kind of problems s/he has?

2) What do you call this problem?

3) How long ago did you notice this problem?

4) Why do you think this problem started when it did?

5) What is the cause of s/he is getting this problem?

6) What do fear most about this problem?

7) What does this problem do to her/him? How does it work?

8) How these problems have affected her/his life?
   Probes: social life, work, home life, economy

9) Can you tell me what kind of care you provide for her?
   Probes: housing, cleaning, financial, social, emotional

10) What kind of problems you face in caring for her/him?
    Probes: financial, lack of knowledge, fear, stigma, time. Logistics, lack of medications, lack of psychiatric care to refer.

11) Are there some common practices that are performed when people have such a problem?

12) Can you tell me what kind of changes do you see in such practices and traditions?

13) What kind of care do you think should person with xx problem to receive?

14) What kinds of problems do you think people have in accessing care and treatment?

III. COMMUNITY ATTITUDES AND STIGMA AND DISCRIMINATION

(Secondary stigma= towards caretaker)

15) What do you think people think about you as a caretaker of her/him?

16) How do people behave towards you? How do they treat you?

17) Why do you people think and behave towards you the way they do?

18) How does the way people think of you and behave towards you influence your life?
Probes: self- hate, shyness, isolation, fear, inability to socialize with others

19) How do you deal with the negative attitudes and behavior of people?

(Stigma towards person with mental illness)

20) How do people behave towards the person you care for?

21) Why do you think people behave towards her/him the way they do?

22) How does these attitudes and behavior influence her/his life?

23) How do you deal with the negative attitudes and behavior of people towards her/him?

24) What do you think can be done to change these negative attitudes of people?

25) Thank you for the time you are giving us for this interview. Do you have anything else you would like to tell us?

Focus group guide - Community members

I. DEMOGRAPHC DATA

I would like to start this discussion by asking each one of you a few questions about your background

	Age	Marital status	Education	Ethnicity	Resident in Juba / m/y
1					
2					
3					
4					
5					
6					
7					
9					
10					

What is the highest school you have completed?

Never attended school	1
Completed or partially primary school (6 years)	2
Completed or partially/ completed secondary school (9 years)	3
Completed post-secondary school)	4
Do not know	99
Refused	88

What is your relationship status?

Married	1
Separated	2
Divorced	3
Widowed	4
Never married	5
Do not know	99
Refused	88

II. EXPLANATORY MODELSS OF ILLNESS AND HEALTH SEEKING BEHAVIOR

I would like to talk to you about problems that people in your community have that manifests in thinking, feeling or behavior?

1) What kind of problems are common in your community?

2) What do you call these problems?
   (List all problems (name the problems) and then continue asking q 3 – q 5 regarding each problem one by one)

3) What are the specific signs and symptoms of xx?

4) What is the cause people get these problems?

5) How serious do you think this problem is and why?

6) What does this illness do to people? How does it work?

7) How do you think this problem affects the life of the person with the problem?
   Probes: social life, work, home life, economy

8) Where people with such a problem and look for care and why?
   Probes: hospital, health unit, informal health providers, friends, family members, self-help, medications

9) What type of care people can receive for such a problem (ask about each health providers that was mentioned in Q7 separately)?
   Probes instrumental, information, emotional, treatment

10) What do you think can trigger people searching for care? (ask about different providers that are mentioned in Q7 separately

11) What kind of traditional practices are there in your community to care for a person with xx problem?

12) What kind of changes are taking place in such traditions?

13) What kind of care do you think people should receive and why?
   Probes: provider, type of care

14) What kinds of barriers people have to receive care?

15) Why do you think people sometimes search for care late?

III. COMMUNITY ATTITUDES AND STIGMA AND DISCRIMINATION

(Ask these questions regarding each illness that was mentioned earlier in the discussion)

16) What do you think people in community think about person who has xx?

17) How do people in your community treat person with xx?

18) Why do you think people have this type of attitudes?
Probes: fear, not familiar

19) How do you think these types of attitudes and treatment of person with xx influences his/ her life?
Probes: social, economic, psychological well- being, physical health

20) Do you know how people with xx cope with such attitudes and behaviors?

21) What do you think can be done to change these negative attitudes of people?

22) Thank you for the time you are giving us for this interview. Do you have anything else you would like to tell us?

Interview guide – Service providers

I. DEMOGRAPHC DATA

I would like to start this interview by asking you a few questions about your background

Q1	How many years you have been providing services for people who have problems in thinking and behavior / mental problems?	..... Years	
Q2	Gender?	Female	1
		Male	2
Q3	What is your occupation/ title?	Psychiatrist	1
		Psychologist	2
		Counselor	3
		Nurse	4
		Traditional healer	5
		Witch	6
		Social worker	7
		Other	77
		Refused	88
Q4	What is your ethnic group?		
Q5	What is the highest school you have completed?	Never attended school	1
		Completed/ partially primary school (6 Y)	2
		Completed or partially/ completed secondary school (9 y)	3
		Completed post-secondary school)	4
		Do not know	99
		Refused	88

Q6	Have you ever been displaced/ refugee?	Never forcibly displaced	1
		Previously displaced as refugee	2
		Do not know	99
		Refused	88
Q7	Where do you live currently?	Juba city	1
		Outside of Juba city	2
		Other	77

II. EXPLANATORY MODELSS OF ILLNESS AND HEALTH SEEKING BEHAVIOR

1) Tell me about your work?
   Probes: How is your work linked to people who have problems in thinking, behavior?

2) What kind of problems are common?
   (Ask Q 3-Q5 one by one regarding each problem mentioned)

3) Why do you think xx is a common problem?
   Probe: what is causing it?

4) What kind of signs and symptoms are linked to it?

5) Where do people usually seek care for this problem and why?
   Probe: type of health provider/ type of care

6) How do people perceive different types of services?

7) What do you think about current service provision for people who have problems in thinking and behavior in South Sudan?

8) What do you think are challenges for people with mental problem to access services?

9) Why people seek care late?

10) How do you think different service providers could better co-operate to improve mental health?

11) What kind of community practices or traditions you consider harmful for people with mental problems?

12) What kind of community traditions or practices do you consider positive and could be promoted to improve mental status of people who have problems?

13) What kind of community practices and traditions could be promoted to prevent mental illness?

14) What kind of service provision would be needed in South Sudan?

III. COMMUNITY ATTITUDES AND STIGMA AND DISCRIMINATION

(Stigma towards people with mental problems)

(Ask Q 14-Q 17 one by one regarding each mental problem that is mentioned in Q2)

15) What do you think service providers in generally think about people with xx problem?

16) How do they behave towards people with xx problem?

17) Why do you service providers think and behave towards people with xx problem the way they do?

18) How do you think these attitudes and behaviors influence the life of people with xx problem? The way people think of you and behave towards you influence your life?
Probes: self-hate, shyness, isolation, fear, inability to socialize with others

(Secondary stigma= stigma towards service providers)

19) What do you think people think about you as a service provider for people who have xx problem?
Probes: any negative attitudes

20) How do they behave towards you?
Probes: any negative behaviors

21) Why do you think people think of and behave towards you the way they do?

22) How do these attitudes and behavior influence you?
Probe: reluctant to work, careless at work, not interested

23) How do you deal with the negative attitudes and behavior of people towards you?

24) What do you think can be done to change these negative attitudes of people?

25) Thank you for the time you are giving us for this interview. Do you have anything else you would like to tell us?

Interview guide – Community influencers

I. DEMOGRAPHC DATA

I would like to start this interview by asking you a few questions about your background (questions that are not appropriate will be skipped)

Q1	What is your occupation/ title? **OR** Function in the community?	
Q2	How many years you have been working in your current job/ position? **OR** How many years you have worked in serving your community?	..... Years
Q3	Gender?	Female 1 Male 2
Q4	What is your ethnic group?	
Q5	What is the highest school you have completed?	Never attended school 1 Completed/ partially primary school (6 Y) 2 Completed or partially/ completed secondary school (9 y) 3 Completed post-secondary school) 4 Do not know 99 Refused 88
Q6	Have you ever been displaced/ refugee?	Never forcibly displaced 1 Previously displaced as refugee 2 Do not know 99 Refused 88
	Where do you live currently?	Juba city 1 Outside of Juba city 2 Other 77

II. EXPLANATORY MODELSS OF ILLNESS AND HEALTH SEEKING BEHAVIOR

1) What can you tell me about people in your community who have problems in thinking and behavior?

2) What kind of problems are common?
   Probe: how do you name these problems?
   (Ask Q 3-Q5 one by one regarding each problem mentioned)

3) Why do you think xx is a common problem?
   Probe: what is causing it?

4) What kind of signs and symptoms are linked to it?

5) Where do people usually seek care for this problem and why?
   Probe: type of health provider/ type of care

6) How do people perceive different types of services?
   Probe: fear stigma, bad treatment, lack of trust,

7) What do you think about current service provision for people who have problems in thinking and behavior / mental problems in South Sudan?

8) What do you think are challenges for people accessing services?

9) Why do people seek care late?

10) What kind of community practices or traditions you consider harmful for people with mental problems?

11) What kind of community traditions or practices do you consider positive and could be promoted to improve mental status of people who have problems?

12) What kind of community practices and traditions could be promoted to prevent mental illness?

13) What kind of service provision would be needed in South Sudan?

III. COMMUNITY ATTITUDES AND STIGMA AND DISCRIMINATION

(Stigma towards people with mental problems)

(Ask Q 14-Q 17 one by one regarding each mental problem that is mentioned in Q2)

14) What do you think people in generally think about people with xx problem??

15) How do people behave towards people with xx problem?

16) Why do people think and behave towards people with xx problem the way they do?

17) How do you think these attitudes and behaviors influence the life of people with xx problem

Probes: self- hate, shyness, isolation, fear, inability to socialize with others

18) What do you think can be done to change these negative attitudes of people?

19) Thank you for the time you are giving us for this interview. Do you have anything else you would like to tell us?

Appendix 2 – Consent forms

INFORMED CONSENT - In-depth Interview (person with a mental problem)

My name is ..... and this is..... We are working in a research project that is conducted by the Handicap International which is an international NGO. This study aims to learn about community perceptions regarding problems that manifests in thinking, feeling and behavior among people in Juba.

You are kindly asked to volunteer in this study by participating in an interview. We will be asking some background information about you followed by questions about your problems that manifests in thinking, feeling and behavior, your health seeking for these problems as well as community attitudes and behaviors of people towards you.

Your input is very important. The benefits of enrolling in the study is that with the findings of this study can be used by the ministry of health as well as other relevant ministries and international organizations such as handicap international that work on improving healthcare to develop culturally competent and relevant interventions and programs in Juba, South Sudan. There are no personal benefit for you to join the study.

The investigators of the study believe that there are no risks from participating in this interview; it will take less than an hour from your time. I will be taking notes about what you say. The interview is also audio-recorded in order not to miss any important information you give us.

All information that you will give us as part of this study will be kept completely confidential and the notes will be kept in a safe place. No-one but the study investigators have access to them.

The audio-tapes and all notes will be destroyed in the end of this study. No information that identifies you will be disclosed in any report or publications that result from this study. Your confidentiality during and after the study will be ensured by using a research identification number.

While we have put measures in place to protect your identity and that of the people who are interviewed for this research, we understand that you may feel uncomfortable in telling us about you, your thoughts and your activities. Your participation is voluntary, there will be no penalty if you do not want to participate; you are free to skip questions, or stop the interview at any time.

If you have questions about the study, you can contact xxx

By your verbal approval, you give your voluntary informed consent to participate in the research as it has been explained to you. Do you agree to participate in this study?
Yes [.....] No [.....]

Signature of research interviewer

Name: ..... Date..... /..... /2016

INFORMED CONSENT - In-depth Interview

My name is ..... and this is..... We are working in a research project that is conducted by the Handicap International which is an international NGO. This study aims to learn about community perceptions regarding problems that manifests in thinking, feeling and behavior among people in Juba.

You are kindly asked to volunteer in this study by participating in an interview. We will be asking some background information about you followed by questions about problems that manifests in thinking, feeling and behavior, health seeking behavior of people with these problems as well as community practices and attitudes towards people that have problems in thinking, feeling and behavior.

Your input is very important. The benefits of enrolling in the study is that with the findings of this study can be used by the ministry of health as well as other relevant ministries and international organizations such as handicap international that work on improving healthcare to develop culturally competent and relevant interventions and programs in South Sudan. There are no personal benefit for you to join the study.

The investigators of the study believe that there are no risks from participating in this interview; it will take less than an hour from your time. I will be taking notes about what you say. The interview is also audio-recorded in order not to miss any important information you give us.

All information that you will give us as part of this study will be kept completely confidential and the notes will be kept in a safe place. No-one but the study investigators have access to them.

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If you have questions about the study, you can contact xxx

By your verbal approval, you give your voluntary informed consent to participate in the research as it has been explained to you. Do you agree to participate in this study? Yes [.....] No [.....]

Signature of research interviewer

Name: ..... Date..... /..... /2016

INFORMED CONSENT - Focus group discussion

My name is ..... and this is..... We are working in a research project that is conducted by the Handicap International which is an international NGO. This study aims to learn about community perceptions regarding problems that manifests in thinking, feeling and behavior among people in Juba.

You are kindly asked to volunteer in this study by participating in a focus group discussion that is a group discussion where you will be sharing your thoughts with others. We will be asking some background information about you followed by discussion about problems that manifests in thinking, feeling and behavior, your opinions about health seeking behavior of people with these problems as well as community practices and attitudes towards people that have problems in thinking, feeling and behavior.

Your input is very important. The benefits of enrolling in the study is that with the findings of this study can be used by the ministry of health as well as other relevant ministries and international organizations such as handicap international that work on improving healthcare to develop culturally competent and relevant interventions and projects in Juba. There are no personal benefit for you to join the study.

The investigators of the study believe that there are no risks from participating in this interview; it will take less than an hour from your time. I will be taking notes about what you say. The interview is also audio-recorded in order not to miss any important information you give us.

All information that you will give us as part of this study will be kept completely confidential and the notes will be kept in a safe place. No-one but the study investigators have access to them.

The audio-tapes and all notes will be destroyed in the end of this study. No information that identifies you will be disclosed in any report or publications that result from this study.

Your confidentiality during and after the study will be ensured by using a research identification number.

While we have put measures in place to protect your identity and that of the people who are interviewed for this research, we understand that you may feel uncomfortable in telling us about you, your thoughts and your activities. Your participation is voluntary, there will be no penalty if you do not want to participate; you are free to skip questions, or stop the interview at any time.

If you have questions about the study, you can contact xxx

By your verbal approval, you give your voluntary informed consent to participate in the research as it has been explained to you. Do you agree to participate in this study?
Yes [.....] No [.....]

Signature of research interviewer

Name: ..... Date..... /..... /2016

Mental health problems in Juba, South Sudan: local perceptions, attitudes and patient care

A socio-anthropological study

Handicap International is currently implementing a project entitled "Touching Mind, Raising Dignity; to stop the stigma toward people with mental health problems" which aims to improve the social and community involvement of people living with mental health problems.

In this context, a qualitative research study was conducted to understand local concepts linked to mental health problems and health-seeking in order to develop effective mental health interventions in the context of Juba, South Sudan.

The study was conducted in four locations in Juba among community members, people with mental health problems, their caregivers and service providers. Focus group discussions & in-depth interviews were conducted with a total of 130 study participants.

The findings prposed in this document can be used to maintain understanding between health professionals and the local community and when developing specific communication messages or behavior change strategies. The findings can also be used specifically for the prevention and early detection of mental health problems.

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