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Not Enough Money and Too Many Thoughts: Exploring Perceptions of Mental Health in Two Ugandan Districts Through the Mental Health Literacy Framework

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Abstract
Mental health disorders account for a heavy disease burden in Uganda. In order to provide culturally appropriate mental health prevention and treatment approaches, it is necessary to understand how mental health is conceptualized in the population. Three focus group discussions (FGDs) and 31 in-depth interviews (IDIs) were conducted with men and women aged 14 to 62 years residing in rural, urban, and semi-urban low-income communities in central and western Uganda to explore perceptions and knowledge of mental health. Interpretive thematic analysis was undertaken; results were organized through the lens of the mental health literacy framework. Environmental and societal stressors were identified as primary underlying causes of poor mental health. While participants recognized symptoms of poor mental health, gaps in mental health literacy also emerged. Mental health resources are needed in this setting and additional qualitative work assessing knowledge and attitudes toward mental health care seeking behavior can inform the development of acceptable integrated services.

Keywords
mental health; qualitative data; qualitative research; Uganda; mental health literacy; sub-Saharan Africa; interpretive thematic analysis

Introduction
Mental health is defined by the World Health Organization (WHO, 2004) as “a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community” (p. 2). Conversely, non-self-realization of one’s own ability, to be productive and cope with the normal stress of life can be thought of as a state of poor mental health. The definitions above can be thought of as two opposite poles of a mental health gradient, with most individuals falling somewhere in between to varying degrees during their lives. Poor mental health encompasses mental health disorders (MHD), a spectrum of medical conditions ranging from mild distress to severe impairment. The etiology of MHDs is a complex interaction of genetic predisposition, underlying biomedical pathways (such as hormones and neurotransmitters like dopamine and serotonin), comorbidities, and psychological and social factors, including experienced trauma, substance use, and culture (Kirmayer, 2001; WHO, 2019).

MHDs are ubiquitous across populations despite cultural differences. Globally, more than 300 million people (~4% of the population) suffer from depression and a similar number suffer from anxiety disorders (WHO, 2017). Depression is the second leading cause of disability

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adjusted life years (DALYs) in the African region (WHO, 2017). MHDs account for 16% of Uganda’s years lived with disability (YLDs), a metric of disease burden (morbidity) that when added together with years of life lost (YLL) comprise DALYs (IHME, 2017). Primary factors contributing to the mental health burden in Uganda include scarcity of mental health services, widespread poverty, and a generalized HIV epidemic. Uganda’s national HIV prevalence is 6.2%, which translates to approximately 1.2 million persons living with HIV (Ministry of Health Uganda, 2019). Evidence suggests that the relationship between HIV and MHDs is bidirectional. Some MHDs are associated with increased risk of HIV infection (Machado Neto et al., 2015) and people living with HIV are at higher risk of experiencing stigmatization and poor mental health (Becker et al., 2019; Bernard et al., 2017; Nedelcovych et al., 2017). HIV directly impacts the brain by crossing the blood brain barrier, triggering a chronic inflammatory response and chemical changes (such as reduced tryptophan and serotonin) that increase risk of depression and suicide (Remien et al., 2019). Among persons living with HIV, depression can adversely impact health-seeking behavior which can hasten HIV disease progression (Antelman et al., 2007; Ayano et al., 2018; Remien et al., 2019; Wagner et al., 2017).

Ongoing rapid urbanization throughout Uganda, which has accelerated in recent years, also contributes to poor mental health through displacement and insecure housing, social marginalization (of the poor and ethnic groups seeking to maintain traditional lifestyles), loss of traditional family structures (and the accompanying social support), and increased substance use (“The Growth Challenge: Can Ugandan Cities Get to Work?,” 2015). Uganda has also experienced violent civil unrest, most recently in the form of a 20-year civil war in the north. These conflicts have led to internal displacement, widespread trauma, and high rates of post-traumatic stress disorder among survivors (Musisi & Kinyanda, 2020). As a result of these frequently overlapping comorbidities and risk factors, the burden of MHDs in Uganda is expected to increase in the coming decades and the public health implications of this increase will extend beyond mental health, impacting the HIV epidemic as well (Flisher et al., 2007; Szabo, 2018).

In order to provide context-sensitive mental health prevention and treatment approaches, it is necessary to understand how mental health is conceptualized in the population. While there are some universal emotions and manifestations of poor mental health in high- and low-income settings, perceptions (i.e., attitudes, awareness, and beliefs) of mental health and MHDs are also interpreted and understood through a cultural lens, which can influence emotional expression regulation and care seeking. Cultural concepts therefore have a huge impact on the presentation, diagnosis, and treatment of psychiatric conditions (Kirmayer, 2001; Quinn & Knifton, 2014).

The current evidence base regarding perceptions of mental health in sub-Saharan Africa (SSA) is limited. A 2015 review of community mental health literacy in SSA found a general lack of knowledge around the causation, presentation, and treatment of MHDs across populations, with the authors concluding that the existing evidence base was too narrow to make any profound statements on community mental health perceptions (Atilola, 2015). A 2019 review looking at attitudes and stigma toward MHDs among community members, stakeholders, and professionals in SSA identified a number of widely endorsed explanatory models for MHDs, including supernatural beliefs (e.g., witchcraft), substance use, stress, and poverty (Spittel et al., 2019). Belief in supernatural/spiritual causes of MHDs and strong negative attitudes and stigma toward persons with MHDs were widely held by people across study populations, including medical professionals. In both of the aforementioned reviews, the majority of studies identified were conducted in two countries, South Africa and Nigeria, limiting the generalizability of the findings to the broader context of SSA. A small but growing body of research has begun to identify risk factors for poor mental health and quantify the burden of specific MHDs in Uganda.

Surveys conducted among specific populations (e.g., persons living with HIV, university students) and geographic regions of Uganda have estimated the prevalence of specific MHDs, such as depression (Ovuga et al., 2006; Ssebunnya et al., 2019). Psychometric assessment work has also been completed on a number of depression screening and diagnostic tools (e.g., Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 2016), for improved accuracy in specific Ugandan languages and populations (A. P. Miller et al., 2020; Natamba et al., 2014). Other research groups have focused on identifying risk factors and correlates of depression in Uganda within specific populations, such as experiences of war torture, child abuse, and intimate partner violence (IPV) among those living in post-conflict settings (Amone-P’Olak et al., 2015) and sexual risk taking among university students (Agardh et al., 2012). While a picture is beginning to take shape regarding the burden of MHDs in Uganda, relatively few studies have qualitatively explored how mental health is understood in the general population. Understanding community level attitudes, awareness, and knowledge of MHDs is critical for programmatic planning. Most of the limited existing research on this topic was conducted over a decade ago.

Our review of qualitative studies in Uganda exploring the general population’s perceptions of mental health, found a focus on understanding how specific MHDs were understood and viewed (Abbo et al., 2008; Johnson et al.,
method open population-based cohort study conducted by Africa Medical and Behavioral Sciences Organization (AMBSO) across communities in Wakiso and Hoima districts in Uganda. AMBSO is a not for profit organization established with a goal of informing the design of evidence-based prevention, care, and treatment programs to reduce morbidity and mortality in the population. The main objective of PHS is to monitor trends in infectious and non-communicable diseases, family, and population structures and other health-related information. At the beginning of each round, census is completed in each household in the community to enumerate the population and collect household demographic, socioeconomic, mobility, and mortality data. Persons aged 13 to 80 years who provide written informed consent (or assent, for minors) are then invited to participate in the quantitative survey. A structured questionnaire is administered and biological samples including blood and vaginal swabs are collected for HIV and sexually transmitted infection (STI) testing. Participants are followed-up annually. Qualitative data are also collected using FGDs, and in-depth interviews (IDIs) to further explore a variety of health topics covered in the survey. The current manuscript presents findings from the PHS mental health module. The study was approved by the Clarke International University–Research Ethics Committee (CIU-REC) and the Uganda National Council for Science and Technology (UNCST).

Recruitment Sites and Procedure

Qualitative study participants were purposively selected from five low-income communities, including one fishing, two urban, one semi-urban, and one rural. These communities were chosen for their unique representation of Ugandan community characteristics and presence of key and priority populations (selected due to sociodemographic or behavioral characteristics that predispose them to higher risk of HIV acquisition and unequal access to health services). Population categories of interest included community leaders, substance users, younger and older residents, female sex workers, and fisher folk. In addition to working with local community leaders to identify eligible participants, snow-ball sampling (using peers) was used to identify and recruit key population participants (e.g., female sex workers). A list of participants who consented to be contacted for future studies during the survey was also used to identify eligible participants. Written informed consent (assent for minors) was elicited from all participants.

Sampling of participants was geared toward meeting the aims of the overarching qualitative study. However, there is concert between the present analysis and the overarching study; both aim to understand how perspectives on health issues converge and diverge among

Methods

Study Design

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2009; Okello & Musisi, 2006; Okello & Ekblad, 2006; Shah et al., 2017). Study approaches included using case vignettes to explore the etiology, epidemiology, and treatment of MHDs and conducting FGDs to explore perceptions of the underlying causes of MHDs among specific ethnic groups. Participants in these studies identified mental illness as having both extrinsic (e.g., substance use, spiritual forces) and intrinsic (e.g., individual weakness, “thinking too much”) causes. A more recent study exploring perceptions of mental health among women attending a maternal clinic found a similar conceptualization of depressive symptomology (referred to as “sickness of thoughts”) citing poverty, unsupportive partners, and IPV as extrinsic causes of mental distress (Tol et al., 2018).

Qualitative studies have also explored attitudes and knowledge around mental health care provision. FGDs conducted with community residents in Bwindi hospital catchment area found that the preferred type of provider and treatment were dependent on the perceived cause (Shah et al., 2017). Participants believed that successful treatment and its application (e.g., prayer and treatment by a traditional healer for distress caused by a spell or western medicine for the treatment of epilepsy) was contingent on accurate identification of the underlying cause. Many participants believed a tailored hybrid approach of both medical and non-medical interventions was often most effective. This is consistent with earlier work among persons in psychiatric care for depression in Kampala where patients described the complexities of navigating help-seeking when family members hold disparate beliefs (e.g., Christianity vs. traditional religions) regarding the underlying causes and appropriate treatments (Okello & Neema, 2007).

While the studies described above begin to shed light on how mental health and mental health care are understood by a number of ethnic groups and communities, the evidence base is still sparse. We seek to contribute to the limited but growing evidence base regarding perceptions of mental health in Uganda by exploring how mental health is understood by men and women residing in low-income urban, semi-urban, rural, and fishing (rural villages along the lake shore) communities in two districts in central and western Uganda; we capture perspectives of a diverse array of community members to present a comprehensive picture of the views held.

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community members in order to capture the breadth of perspectives held. To do this, we focused on recruiting general community members while also highlighting members of marginalized communities that experience a disproportionate health burden (e.g., drug users) as well as community leaders who, due to their position, are typically more aware of ongoing community issues and concerns than the general populace. Our disproportionate sampling of these groups may reduce the generalizability of our findings, but it allowed us to capture the unique perspectives and voices of a wider array of community members, including hidden populations.

**Data Collection**

The purpose of the overarching qualitative study was to explore community-level (i.e., FGDs) and individual-level (i.e., IDIs) understanding of the local conceptualizations, perceptions, and practices on health and social issues. The data corpus included a total of 42 IDIs and 9 FGDs; the dataset of FGDs and IDIs included in this manuscript, selected for their inclusion of the mental health module, were conducted between November 2018 and October 2019. This included three FGDs (10–11 participants each), conducted with specific populations in Wakiso district, whose unique perspectives were considered important for understanding community perceptions of health: community leaders (an important population given their community influence), drug users, and sex workers (key populations due to their unique health risks). Thirty-one IDIs were conducted with men and women across the five communities. Participants represented general members of the community as well as members of key and priority populations (e.g., fisher folk).

Data were collected by experienced qualitative AMBSO research assistants who were fluent in the local dialect of their respective communities, including Luganda in Wakiso, and Runyoro in Hoima. FGDs were facilitated by a moderator and note-taker and lasted between 87 and 109 minutes (median duration of 101 minutes). IDIs were one-on-one and lasted between 41 and 110 minutes (median duration of 62 minutes). All sessions were audio-recorded. Semi-structured guides were used, allowing for improved flow and flexible discussion. Questions for the mental health module focused on perceptions, knowledge, epidemiology of mental health in the community, and personal experiences related to MHDs. Questions did not differ between FGDs and IDIs. In order to avoid influencing participant responses, this domain was positioned at the beginning of the interview prior to the discussion of other related topics such as HIV, IPV, and substance use. This allowed us to ensure any connection made by participants between mental health and these topics was unforced. Table 1 contains the module questions mapped onto the six domains from the mental health literacy framework (described below).

Participants were compensated for their time and travel costs with 7,000 UGX ($1.85 USD) and 3,000 UGX ($0.79 USD). Research assistants transcribed and translated the audio recordings from the local languages to English.

**Data Analysis**

Our primary analytic objective was to capture and give meaning to the individual lived experiences and beliefs of community members. Through the interpretivist paradigm, we applied the framework method in the organization and interpretation of our results (Ritchie & Lewis, 2003). The construct of mental health literacy was defined by Jorm et al. (1997) as “knowledge and beliefs about mental disorders which aid in their recognition, management and prevention” (Jorm et al., 1997, p. 184). Having high mental health literacy (i.e., the ability to recognize causes and manifestations of MHDs and access resources) is paramount to maintaining good mental health (Jorm, 2000). Three components (recognition, knowledge, and attitudes) comprise mental health literacy each of which can be thought of as a potential target for intervention (Jorm, 2000; Jorm et al., 1997; O’Connor et al., 2014). Given the importance of mental health literacy as a proxy for assessing community understanding of mental health, the mental health literacy framework developed by Jorm et al. (1997), was used throughout our analytic process.

This conceptual framework was selected because it captures the three components of mental health literacy in six domains that lend themselves to identifying gaps in literacy while allowing us to situate our findings in each domain within the larger evidence base. The domains are as follows: (a) The ability to recognize different disorders and different types of psychological distress, (b) knowledge and beliefs about risk factors and causes, (c) knowledge and beliefs about self-help interventions, (d) knowledge and beliefs about professional help available, (e) attitudes which facilitate recognition and appropriate help seeking, and (f) knowledge of how to seek mental health information. Per the steps of framework analysis described by Gale et al., 2013, our coded content was charted onto these domains (Gale et al., 2013).

Analysis was completed using Dedoose and NVivo 11 qualitative software. We applied interpretive thematic analysis as defined by Braun and Clarke (2006), a flexible methodology that can be applied across theoretical and epistemological approaches and qualitative paradigms (Braun & Clarke, 2006). We used a deductive approach to codebook development; a codebook was
developed a priori based on anticipated themes and our framework. After, two researchers coded the same subset of transcripts (four transcripts), code definitions were refined to ensure consistent application; as needed, emergent child codes were iteratively added throughout the coding process. After data were coded, three researchers analyzed and synthesized the data around the thematic areas identified as most salient to our research questions and framework.

To enhance the rigor and trustworthiness of these findings, the multi-disciplinary team of researchers utilized peer debriefing during the coding and analytic process to exchange feedback and control personal biases. In addition, researchers checked with the local data collectors throughout the analytic process to verify initial findings and ensure interpretation of findings was both culturally and contextually appropriate. Finally, an audit trail was conducted throughout the analysis process and documented steps taken during data analysis. All three of these strategies have positive effects in reducing threats to validity (Creswell & Poth, 2018; Padgett, 2016).

Results
A total of 62 men and women (n = 31 for three FGDs and n = 31 from IDIs) participated in the study. Participants in the community leader (n = 11) and drug using FGDs (n = 10) were male (in this setting the overwhelming majority of drug users and community leaders are men) while participants in the sex worker FGD (n = 11) were female. Forty-five percent of IDI participants were male and 55% were female. Participants ranged from 14 to 62
years in age. At the beginning of the mental health module, participants were asked what “mental health” meant to them. All participants were subsequently provided with the WHO definition of mental health in order to facilitate the rest of the discussion.

Mental Health Literacy, Domain 1: The ability to recognize different disorders and different types of psychological distress

All participants were familiar with the concepts of poor mental health and MHDs. Participants across communities felt there were persons experiencing MHDs in their community and multiple participants described MHDs as being common. However, not all participants felt that it was possible in their community to recognize persons experiencing poor mental health or MHDs. A few participants in Wakiso district (general community members, drug users and sex workers) indicated that they suspected that there were people experiencing MHDs in their community, but they could not be certain because people didn’t talk about their problems outside of their immediate household. This perceived inability to confide in friends and neighbors regarding personal topics such as mental health was not mentioned by participants in Hoima district:

I think [persons experiencing MHDs] are there among people in this community but because people do not talk about their problems, it is really very difficult for me to tell that such people are affected although we hear that they are there. (Female sex worker)

Participants described symptoms among community members which they felt were indicative of an MHD. Most focused on observed changes in a person’s appearance or demeanor, describing shifts away from one’s normal state (changes in personal upkeep, weight loss) as well as away from accepted societal norms (e.g., changes in personal hygiene). Common changes in demeanor described across community settings included inappropriate behavior (such as the use of vulgar language in public), erratic behavior, increased substance use, and increased sadness and crying:

Some of the common symptoms I usually see is that someone who used to bathe is no longer bathing now, someone who used to wash clothes is no longer washing. [. . . ] Then I just know that he is suffering from mental problems. (Male drug user)

A commonly described behavior change thought to characterize poor mental health was a shift toward more introverted behavior and social withdrawal. A recurring vignette involved walking by someone you knew who would previously greet you upon passing, only to have them continue by without acknowledging they had seen you. This was attributed to the individual having “too many thoughts,” forgetfulness and not being present in the moment:

Alright, if I meet you on the way and I greet you, then you don’t reply me, I get to realize that this person is not feeling good or he/she is having a problem, because when I meet him or her daily, we always greet each other and talk but now if he or she fails to reply, then there is something disturbing him or her. (Male community leader)

A number of participants also described recognizing the signs and symptoms of poor mental health within themselves. Signs frequently mentioned were “thinking too much”, worrying, headaches and wanting to isolate from others. One female shared that she had once been taken to the hospital for “over-thinking,” which she attributed to the extrinsic stressor of being a single parent. Others mentioned mood swings and feeling chronically upset. In reflecting on their own experiences, participants did not differentiate between suspected underlying MHDs and normal psychological reactions to situational stress and distress (e.g., they did not differentiate between ongoing underlying anxiety and anxiety due to a specific situation or life circumstance):

For my case, I always feel myself when I am suffering from a mental disorder, I always develop [a] headache and it’s always caused when I have a particular issue disturbing me. For other people, you easily notice that there [are] some changes in their way of living, they live in annoyance . . . (Female sex worker)

Less frequently, narratives also emerged regarding symptoms and signs indicative of more severe MHDs. In these instances, participants didn’t describe a change in behavior, but rather a chronic state. Participants described persons who wander aimlessly, don’t make sense, exhibit erratic behavior and engage in extreme intoxication. There was also reference to “madness:”

Such a person can be very quarrelsome, they shout aimlessly, sometimes they are violent and at times, they use obscene words. Then you can tell that such a person is different from others and therefore they need to be counselled. (Male community leader)

Mental Health Literacy, Domain 2: knowledge and beliefs about risk factors and causes.

Participants identified a number of barriers to individuals achieving good mental health, including individual, interpersonal, and socioeconomic factors. Identified underlying causes of poor mental health included poverty, substance abuse, poor social support, chronic diseases, IPV, loss of parent(s), and land evictions. Poverty and financial insecurity were the most frequently mentioned
causes of distress and suspected drivers of MHDs followed by heavy alcohol use and IPV. Some participants attributed poverty to factors within a person’s control (e.g., gambling), but most attributed it to factors beyond a person’s control (e.g., high rates of unemployment). Regardless of the locus of control or cause of financial stress, the strain it created was a recurring theme described as taxing; especially for those seeking to provide for their families:

[People] struggle to survive. Someone wakes up unknowing of what they will eat that day. Some have failed to pay rent. They can’t have a stable state of mind; instead they are worried of being evicted. (Male community member)

Poverty especially among men. If a man lacks money or has no money in his wallet yet he has responsibilities, life at home becomes complicated. For example, his family member might ask for something that is cheap but [for him it is as if it] costs 1 million. (Male community leader)

This inability to provide for one’s family was also described as the primary cause of IPV, which was identified by a number of female participants as an underlying cause of mental distress:

Even some family problems like fighting, quarrelling...when you find a husband beating a wife the lady can’t be with a settled mind. (Female community member)

In Uganda, traditional gender norms dictate that men are responsible for providing for their family. When a man is unable to fulfill his role as the breadwinner, this can lead to stress and arguments between partners. These arguments can then escalate into violence, typically perpetrated by men toward women. It can also lead to individual family members having to fend for themselves in order to find food, which can further exacerbate feelings of distress:

Money brings about happiness in a home. For example, a man having it in mind that his family will maybe need 20,000shs daily and gives it to his family daily without waiting for his family members to ask the money from him, finds a bunch of matooke, a sack of charcoal and brings it home. It is therefore very hard for a wife to quarrel with her husband and vice versa. [..] But in a family where a husband cannot buy sugar at home...for example, if the family members ask for a quarter of kg of sugar yet he also lacks money. The husband just shouts back at the wife. The woman also quarrels back at her husband asking him whether she has to do prostitution to get money hence end up fighting. (Female community member)

Substance abuse emerged as the second most commonly recognized underlying cause of poor mental health. Participants across communities identified alcohol and drug use (e.g., marijuana, kuber1 and aero fuel2) as a major cause of mental health problems. Participants viewed the use of drugs as being more prevalent among the youth and males in particular. Harmful alcohol use and alcoholism were viewed as more widespread problems, cutting across age groups and gender. Participants from the fishing community described heavy drinking as ubiquitous.

[... First of all, here at the lake shores we have a lot of school dropouts and because of that many resort to drug abuse, alcoholism, early marriages and hence all this raises the mental health issue here. (Male community member)

Other underlying causes of poor mental health, such as chronic diseases were mentioned with less frequency. Several participants indicated that individuals diagnosed with HIV and cancer are prone to depression due to the incurable nature of these conditions. This is consistent with prior work throughout SSA showing higher levels of depression among persons living with HIV, attributable to many factors including the difficulty of coping with one’s diagnosis, internalized stigma, social rejection, disease and treatment symptoms, and comorbidities (Abas et al., 2014).

[...] HIV cannot be cured; therefore, that alone fills this person with a lot of thoughts. For example, such people always think that they are going to be sick of HIV forever ‘til they die since HIV does not cure. That also causes mental health problems. (Male community leader)

Mental Health Literacy, Domains 3 and 4: knowledge and beliefs about self-help interventions and knowledge and beliefs about professional help available

Social support and reaching out when one is struggling are important resources for individuals experiencing poor mental health. Participants, especially community leaders, described poor social relationships as a barrier to seeking advice and support among individuals facing hardships. This may lead to isolation and general poor mental health:

What can stop a person from having good mental health is not having a good relationship within the community. For example, I may not have a good relationship with someone, yet this person can have a piece of advice for me towards any serious problem or challenge I may be facing. But if I had a good relationship with this person, he or she could easily advise me on how to overcome the problem I am facing. Therefore, having poor relationships with people within the community leads to bad mental health. (Male community leader)

A few of the younger participants also described the emotional burden and grief surrounding the death of loved
ones and how challenging life can be in the absence of a familial psychosocial support system. Child-led households are not uncommon in SSA, a continent that has been deeply impacted by the HIV epidemic; Uganda is home to 800,000 children orphaned by HIV/AIDS, who are either cared for by extended family or support themselves (Satzinger et al., 2012). Prior research in South Africa, found persistent and worsening mental health problems among AIDS orphaned children over time (Cluver et al., 2012).

The other issue is being an orphan whereby you miss that parental love and care, this also affects many people including myself, life without parents is so stressing and hard. (Female community member)

Participants were not explicitly asked if mental health services and resources existed in their community and no available resources were mentioned. However, a couple of participants described self-employed coping mechanisms to deal with poor mental health. One female participant described getting heart palpitations when stressed, which she normally overcame with prayer. One male participant personally acknowledged using alcohol to cope with and manage his stress, while a few others described alcohol as a coping mechanism anecdotally.

People use alcohol which they wouldn’t have used due to mental disorders. This is so because they think when they take alcohol, they will forget some of their worries. (Female community member)

Substance use being mentioned as both an underlying cause of poor mental health as well as a self-employed coping mechanism speaks to a bidirectional relationship between substance use and mental health in this setting, with each mutually serving as a risk factor for the other.

Mental Health Literacy, Domains 5 and 6: attitudes which facilitate recognition and appropriate help seeking and knowledge of how to seek mental health information

Stigma, shame and negative societal attitudes toward persons experiencing MHDs can reduce an individual’s willingness to seek care. Some participants from Wakiso district described the culture in Uganda as one where people are extremely private about their personal problems and where there is a general lack of emotional support among neighbors. These participants perceived both of these characteristics to be barriers to seeking support among persons struggling with their mental health:

Participant: [. . . ] in this community everyone minds their business, they never want to associate with people’s problems so in most cases when you get a challenge no one will support you or even give you advice on how to finish the problem. This is because here everyone works away from their home so you only get to see people who stay next to you in the evening, at night or over the weekend and here everyone is busy with their family so we have less time to talk to people. (Female community member)

There were two instances where a participant indicated stigma and resentment toward persons in their community experiencing MHDs, suggesting not only a lack of social acceptability, but also a lack of tolerance and compassion. Both occurred during the FGD with drug users in Wakiso. One male participant expressed his frustration at the lack of punitive action available:

For me I put all the blame on [the] government [. . . ] local council members take ages to call a village meeting. There is no law in which you can start punishing someone. For example, there is no law that if someone uses vulgar language in the community, he/she will be punished like this. Our country [. . . ] has become undemocratic. (Male drug user)

Another male participant, in the same FGD described forced bathing of persons in the community suffering from severe MHDs that were no longer maintaining personal hygiene:

Some of them we actually bath[e] them. Sometimes we may be there in a group and then you smell that bad odor coming from that person and we decide to buy a jerry can of water and basin and we bath[e] him (laughter). (Male drug user)

The only openly expressed stigma toward persons dealing with MHDs came from the FGD with drug users, another highly stigmatized population. These participants were frustrated that persons with severe MHDs were disruptive to their community by exhibiting many of the same behaviors frequently seen in intoxicated persons, such as using vulgar language. They also called for punitive action when they themselves engage in illegal behavior in the form of illicit drug use. It is possible and even likely that some of the persons they recognize as experiencing severe MHDs also struggle with a substance use disorder, which frequently co-occur with severe MHDs.

Discussion

In our study sample of 62 men and women residing in 5 communities across Hoima and Wakiso districts, 5 main themes emerged (a) Mental distress and MHDs were perceived as widespread, (b) external factors were considered to be the primary drivers of poor mental health, (c) changes in appearance and behavior were the most widely recognized symptoms of MHDs, (d) limited healthy coping mechanisms for mental distress were currently being utilized, and (e) knowledge and attitude related barriers to
self-help and professional health for mental distress and MHDs exist. The high burden of MHDs in this setting, coupled with a paucity of relevant education and therapeutic resources underscores the criticality of gauging and fostering mental health literacy among community members. Identifying gaps in mental health literacy from the present study and the existing evidence base and recognizing how they impede or facilitate public mental health efforts provides a road map for future research needs.

**Domain 1: The Ability to Recognize Different Disorders and Different Types of Psychological Distress**

The ability to recognize specific MHDs requires knowledge of their symptomology, in order to identify symptoms as signs of psychological distress. Accurate recognition and communication of MHD symptomology is significant because it facilitates effective and explicit communication between patient and provider, which increases both the likelihood a patient will discuss symptoms they are experiencing as well as the likelihood a provider will detect a problem and pursue a diagnosis (Jacob et al., 1998; Jorm, 2000). In our study, many respondents recognized changes in one’s appearance, (e.g. disheveled or unclean clothing), and behavior (e.g., social withdrawal or boundless behavior) as signs of psychological distress. Participants also described symptoms they had personally experienced as a result of psychological distress including, “thinking too much,” feelings of anxiety and headache.

“Thinking too much” is a commonly used idiom of distress in some regions of the world (including SSA) and The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) actually includes “thinking too much” as a causal explanation for distress in some cultural contexts Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013). A recent qualitative study in South Africa explored the meaning of “thinking too much” among the Khwe, a San bushman tribe (den Hertog et al., 2016). The Khwe have terms in the local language that translate to “thinking too much” which they label as a distinct practice from “normal thinking” that involves deep rumination on personal and interpersonal problems. They feel that one engaged in this type of deep thinking can be visibly distinguished by their body language and that “thinking too much” can lead to behavior changes such as social withdrawal. This is consistent with narratives around “thinking too much” in our own study sample. The Khwe are a socially and economically marginalized population and the consequences of this marginalization are frequently attributed causes of “thinking too much.” While there are similarities between narratives from the Khwe and those of our participants, den Hertog et al (2016), caution against generalizing the meaning of “thinking too much” across cultural settings, arguing instead that the meaning of this idiom should be explored at the individual, interpersonal, communal and socio-political dimensions within a given culture in order to contextualize its local meaning (den Hertog et al., 2016).

Some of our participants also described observing members of their community in chronic states of psychological distress, including psychotic episodes, indicating an ability to recognize more severe conditions. A study in East Uganda among the Basoga people explored community members’ ability to recognize symptoms of specific severe MHDs, such as schizophrenia, mania, and psychotic depression, using vignettes (Abbo et al., 2008). The vignettes were widely recognized and identified with local names. In this cultural context, “thinking too much” was recognized as a cause of psychotic depression, where a surplus of thoughts “confuse one’s brain.” In a separate study, caregivers of chronically ill patients in Uganda identified “thinking too much” as a way to describe depressive illness among their patients; in this population, thinking too much was driven by loneliness, chronic pain, and a sense of impending death and reported alongside other depressive symptoms such as loss of appetite and altered sleep patterns (Muhwezi et al., 2008). These examples demonstrate variations in meaning that this idiom can have and underscore the importance of avoiding generalizations regarding this concept. Additional qualitative work is needed in order to contextualize the meaning of this idiom within our study communities.

Harmful substance use, foremost alcohol consumption, emerged as a major community problem in several IDIs and FGDs. However, heavy alcohol and other substance use were not recognized by participants as MHDs themselves. This is consistent with prior research in Uganda describing alcohol use as a major public health concern, but finding low awareness of addiction and alcohol dependency as MHDs (Ssebunnya et al., 2020).

**Domain 2: Knowledge and Beliefs About Risk Factors and Causes**

Environmental and societal stressors are often perceived by the public as the most important contributing risk factors for and causes of MHDs, while health care professionals typically emphasize the underlying biological pathways and genetic factors (Link et al., 1999). Our participants focused exclusively on external stressors with no mention of underlying genetic or biological factors. This resembles prior research from Uganda, which found that mild to moderate psychological distress and emotional difficulties were typically viewed as arising from
difficult living circumstances as opposed to underlying health problems (Kirmayer, 2001; Quinn & Knifton, 2014). Poverty and financial strain were identified as the leading causes of psychological distress and MHDs, followed by substance use, IPV, and poor family/community relationships. One type of underlying cause of MHDs mentioned in prior research in Uganda but noticeably absent in our study was supernatural causes (Abbo et al., 2008; Okello & Musisi, 2006). In contrast to previous studies, clan issues, breaking of traditional rules, and witchcraft were not mentioned by any of our participants as root causes of psychological distress or MHDs.

A robust evidence base suggests that the causal pathways between poverty and MHDs are cyclical and mutually reinforcing; poverty increases the risk of experiencing MHDs (through social exclusion, heightened stress, and higher rates of experienced violence and trauma) and persons living with MHDs are more likely to remain in poverty (due to reduced productivity, health expenses, and stigma) (Flisher et al., 2007; Lund et al., 2010; Patel et al., 2010). Our study participants also felt that poverty was associated with poor mental health through its association with IPV. Many of the underlying causes of poor mental health identified by our participants frequently co-occur and are often mutually reinforcing, with each other, as well as mental health. Prior longitudinal work in South Africa found that women who experienced IPV were more likely to develop depression, alcohol abuse, and suicidal ideation over a 2-year period than women who did not experience violence (Jewkes, 2013). A robust body of literature suggests that persons living with HIV are disproportionately burdened by MHDs, including substance use disorders and women living with HIV in SSA are more likely to experience IPV than HIV negative women (Campbell et al., 2008; Remien et al., 2019). Merrill Singer (1994), first noted the synergistic relationship between substance abuse, violence and HIV/AIDS (SAVA) among poor women of color in the United States in the mid-1990s, coining the term SAVA syndemic.

A syndemic is a confluence of two or more health issues that not only co-occur but exacerbate one another. More recent work has added depression to the SAVA syndemic framework (Sullivan et al., 2015). Recognizing the interrelated nature of these issues is important for intervention development and calls for a syndemic approach to mental health prevention as opposed to targeting individual risk factors. Addressing the intersection of these issues with mental health could also facilitate the integration of mental health interventions into existing health care infrastructure. For example, the development of an intervention to address mental health, substance use and IPV could be integrated into existing HIV care and treatment services. Utilizing existing HIV care infrastructure could increase the feasibility and sustainability of the intervention. Furthermore, if members of the community recognize that HIV, IPV, and substance use are all related to mental health, the idea of an integrated intervention may also be acceptable.

**Domains 3 and 4: Knowledge and Beliefs**

**About Self-Help Interventions and Knowledge and Beliefs About Professional Help Available**

Self-help interventions for MHDs are not only preferable to many individuals over professional intervention, they can also mitigate barriers presented by the lack of formal mental health care currently available in Uganda. While there is limited evidence of the effectiveness of self-help interventions, there is some evidence that social support/connectedness can reduce depression and stress. A global study among adolescents conducted in five cities (Johannesburg, South Africa; Ibadan, Nigeria; Shanghai, China; Baltimore, Maryland; New Delhi, India) found that having a supportive female caregiver in the household and positive relationships with neighbors was associated with lower levels of depression and post-traumatic stress (Cheng et al., 2014). A study in Uganda looking at perceived social support among children and adolescents who lost their parents to HIV/AIDS saw an inverse association between perceived social support and depression (Nyoni et al., 2019). Similarly, a study conducted with undergraduate students in Ghana found that levels of stress and depression were significantly predicted by the level of social support available from friends, family, and significant others (Kugbey et al., 2015).

By extension, comprehensive knowledge around self-help for MHDs can also benefit loved ones. Individuals empowered with knowledge regarding how to help themselves may be better equipped to approach and support friends and family as well. Our interviews did not include direct questions on help-seeking behaviors and participants rarely mentioned these spontaneously. A few coping mechanisms for mental illness mentioned in interviews included drinking alcohol, prayer, and improving familial relationships. A recurrent theme in Wakiso district was that mental health issues were kept private, with immediate family and friends being important sources for help. Concerns regarding MHDs were not viewed as a topic that could be broached by neighbors, colleagues, or other community members.

Other studies in Uganda have stressed the family’s central role in the management of MHDs partly due to perceived stigma toward people with MHDs (Quinn & Knifton, 2014). Taboos around discussing mental health beyond the immediate family presents a barrier to a broader network and safety net of social support. By restricting discussion of mental health and distress to the immediate family it reduces the ability to share lived
experiences within the community and learn about resources and effective coping mechanisms from other community members.

**Domains 5 and 6: Attitudes Which Facilitate Recognition and Appropriate Help-Seeking and Knowledge of How to Seek Mental Health Information**

Stigma and negative perceptions of MHDs can adversely influence help-seeking behavior (Corrigan et al., 2014). This stigma can be external (e.g., from community members or health care providers) or internal, as a result of the way through which MHDs and treatment of MHDs are portrayed in society (e.g., the media). Our FGD with drug users found some participants holding intolerant and stigmatizing views toward persons living with MHDs. These perspectives do nothing to reduce stigma and improve trends of accepting mental health as a public health problem that merits acknowledgment and treatment. Furthermore, they can actively discourage individuals from seeking help. While prior work in Uganda suggests that stigma toward persons with MHDs occurs on many social levels (interpersonal, community, institutional) (Quinn & Knifton, 2014), a recent review of mental health coverage in two prominent Ugandan newspapers found that the voices of persons living with mental illness were more prominently featured than in western media, allowing those with mental illness some agency over the narrative around mental health in their community (A. N. Miller et al., 2019). Still, coverage of mental health in the media is limited and favorable coverage in these two papers is not necessarily indicative of destigmatized views in our study communities. Community sensitization efforts exclusively directed at educating the community about MHDs could help to reduce stigma and improve willingness to disclose mental health struggles with loved ones and providers.

A lack of knowledge of existing mental health resources and eligibility for accessing them can also impede care seeking efforts even among those willing to seek it. Among Ugandans, in-patient mental health clinics are perceived as places reserved for the seriously mentally ill (those experiencing “madness”) and there is a reluctance to seek professional care until a condition is sufficiently severe (e.g., a suicide attempt has been made or a person is embarrassed by their behavior and feels no choice other than to seek support) (Johnson et al., 2009). Although not explicitly addressed in our interviews, generally, there is a shortage of mental health services available in Uganda despite high demand. An estimated 35% of Ugandan’s are affected by MHDs, 15% of which are in need of treatment (Ndyanabangi et al., 2004). With only 4% of its health care budget set aside for mental health service delivery (Ssebunnya et al., 2010) and a single 500 bed psychiatric hospital there is often overcrowding among those receiving inpatient treatment (Molodynski et al., 2017). There are 28 outpatient mental health facilities throughout the country but none have specialized services for adolescents and children and nearly half of the facilities do not have sufficient therapeutics in stock (Kigozi et al., 2010). In order to reach the many Ugandans in need of mental health services, a scaled up decentralized approach is needed.

Uganda was one of four countries where the Mental Health and Poverty Project (MHaPP), was conducted with the aim of drafting and implementing a mental health policy (Flisher et al., 2007; Kigozi et al., 2010). In Uganda, the focus was on task shifting from specialized mental health providers and psychiatric centers (which are limited) to primary care settings. The study was implemented through a collaborative multi-modal approach which included training general health care providers at primary health care facilities and community health workers, sensitization projects with district management, and the establishment of community support groups for persons suffering from severe MHDs and their caregivers. Post-intervention interviews with participants found that the support groups led to a reduction in stigma and increased social inclusion; health care providers reported that the trainings reduced stigma among providers as well (Petersen et al., 2011). A key finding from the MHaPP study in South Africa was that improved mental health literacy increased demand for mental health services and community health workers were a valuable resource in strengthening mental health literacy. Both of these approaches to decentralizing mental health services should be explored in our study setting.

As a qualitative study, although the data yielded was rich and informative, this work does not allow us to estimate the prevalence of specific MHDs in this setting. Another limitation of this work was the scope of questions asked. As one of many health issues explored, we were limited in the number of questions and amount of time that could be devoted to mental health in each data collection session. Finally, as part of a community-based study nested inside of a cohort study, we were unable to capture the perspectives of health care providers, which would have been a complementary addition to our study sample. Despite these limitations, the present study adds to a limited but growing evidence base aimed at understanding how mental health is perceived in Uganda among people in the general population.

**Public Health Impact and Recommendations**

Mental health is an essential component of public health and the mental health literacy framework is a useful tool
for identifying areas to target for intervention. A robust understanding of community mental health literacy is critical to determining mental health educational needs, inform service delivery and improve overall mental health and this study highlights what is and is not well understood by community members in Hoima and Wakiso districts. While a number of studies in Uganda have quantified the disease burden of MHDs, the qualitative evidence base is more limited; many studies have focused exclusively on opinions of stakeholders such as community leaders, traditional healers and health care professionals, with only a handful of seeking to understand perceptions of the general community members themselves.

The most prominently identified risk factors for poor mental health (poverty, substance use, IPV, HIV) in our study sample were consistent with findings from elsewhere in Uganda and more broadly in SSA. Tying our results into the larger evidence base, which highlights the interrelated and synergistic nature of the relationship of many of these risk factors with mental health, we advocate for an integrated approach to addressing mental health that addresses multiple risk factors simultaneously. We also suggest that intervention efforts leverage existing health infrastructure such as primary care settings and HIV care settings for integrated service delivery.

In order to develop such an intervention in our study setting, additional qualitative work is needed to identify care seeking preferences and potential barriers to care. Qualitative work should also be conducted with providers to inform their training needs. An audit of existing mental health resources and educational materials in each community is also warranted. This coupled with community level assessments of the prevalence of common MHDs, such as depression will assist in quantifying the current need for mental health services. These data can then be triangulated to develop targeted mental health services and educational resources.

Conclusion

This study adds the voice and perspective of community members in Uganda to the sparse evidence base on perspectives of mental health in Uganda. Our participants were aware of MHDs and mental distress in their community and within themselves. Most could describe observed and experienced symptoms as well as risk factors for MHDs, but there was a lack of recognition of biological and genetic risk factors. Participants reported many of the same symptoms and underlying causes of poor mental health observed in prior work in SSA but there were also divergences in our findings, such as the absence of witchcraft and clan issues as causes of MHDs. Stigma, anticipated stigma, and taboos around discussing personal issues outside of the household may be barriers to help seeking, social inclusion, and sharing of healthy coping mechanisms. Prior to intervention development, additional formative work is needed.

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Notes

1. Kuber is a highly addictive tobacco product that is rich in nicotine and typically sold as dry leaves. It can be added to tea or licked. It is not illegal to purchase kuber in Uganda despite the fact it is a class A drug.
2. Sniffing aerofuel (jet or aviation fuel) is common in Uganda as well as other countries such as Ukraine and Russia. Similar to other inhalants such as glue, the effects are short-term intoxication and euphoria.

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