UNDERSTANDING MENTAL HEALTH SERVICES FOR PSYCHOSIS IN UGANDA

A REPORT ON CURRENT CARE, KEY GAPS AND CHALLENGES IN THE MANAGEMENT OF PERSONS WITH PSYCHOSIS IN UGANDA

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EXECUTIVE SUMMARY

This document is specific to the current state of mental health services for psychosis in Uganda. People with primary psychosis are responded to by the Ugandan general population with a deep level of stigma embedded in a cultural/spiritual interpretation of psychosis and other serious mental illnesses. Primary psychosis is perhaps the most stigmatized mental disorder; in contrast to 'secondary' psychosis, which is 'attributable' to other factors such as alcohol and substance use or comorbid health conditions. Primary psychosis stands alone.

People with psychosis and other severe mental illnesses are deeply discriminated against by their community. They suffer serious social and economic disadvantage. Their families are stigmatized and often reject them and leave them homeless or to the whims of the local police, and hospital care, if nearby. Most families would have been to traditional and faith healers before they reach the point of despair in managing psychotic symptoms.

Yet, here is the rub. If primary, and indeed secondary psychosis is to be properly addressed in the community and by the Ugandan health system, then the response to psychosis must be embedded within the range of challenges that face a fragmented health system in a low-income country such as Uganda. This tension is seen throughout this report, and must be acknowledged and held, if psychosis as a severe mental illness in Uganda is not to be of such low impact in the literature, research, community engagement, health system and psychosocial response.

This report tells us that there is a dearth of published and grey literature, and research on mental health services for psychosis in Uganda. But the research as minimal as it is, does highlight the inadequacy of the Ugandan health system to provide evidence based mental health services for those affected by this illness.

Cultural beliefs about psychosis, mental health literacy of individuals and their families, and accessibility to mental health services are seen as the key determinants for help-seeking behavior among people with psychosis in Uganda. And the two major pathways to psychosis care, identified both from the literature and qualitative interviews, include conventional health facility-based services and alternative care practices.

Of particular note in this report is the heavy use of what is called Alternative Care in response to psychosis and other severe mental illnesses. Perhaps such care should be better termed 'Cultural Care,' as traditional and faith healers are embedded in local culture and would be 'the first port of call' for most families with a person with psychotic symptoms. More understanding of the impact of Alternative Care is needed to further explore the depth of cultural understanding and practices in response to psychosis. Perhaps some form of meaningful interaction between conventional care, and alternative care might be the subject of future research. Alternative care providers offer cultural understanding and are accessible; they are considered part of the local community, and can connect people to local support. They speak

the same spiritual and everyday language as the local communities in which they work. There is need to further explore this level of influence and how it impacts on services for psychosis.

The results of the qualitative interviews point particularly to the need for mental health (and psychosis) literacy improvement in the community, the integration of mental health services into the public health system, the training and supervision of health professionals in mental health/psychosis care, an uninterrupted supply of mental health medicines to health facilities, cultural awareness and sensitivity training for health workers.

The Key Informant Interviews provide invaluable insight into psychosis in Uganda, and indicate that there is a small group of people in Uganda with keen insight and understanding of where the health system needs to grow in a proper response to the health and social care of people with psychosis. A person-centered response, within a community context, to the care of people with psychosis is a priority, as well as psychosis care in an integrated health system which is currently lacking, and this report recommends action in these areas. Also, the human rights of people with mental illness must be on the agenda.

Above all, the report indicates the range of gaps and challenges in responding to people with psychosis in Uganda. The range is very wide, but the insights particularly from the qualitative study point the way towards dignity and the fulfillment of rights for people with psychosis in Uganda.

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Acronyms and abbreviations

CBT- Cognitive Behavioural Therapy
FEP- First Episode Psychosis
HC – Health Centre
KII – Key Informant Interview.
MH-Mental Health
MHS-Mental Health Services
MOH – Ministry of Health.
NGO – Non-Government Organisation.
SMI – Severe mental illnesses.
WHO – World Health Organization.
YBU – YouBelong Uganda
PCO – Psychiatric clinical officer

Operational definitions

Psychosis: Psychosis is characterised by the presence of hallucinations, delusions or both. (1) Psychotic features occur in a range of psychiatric, neurological and medical conditions. (1, 2) Psychoses are classified as idiopathic/primary (no identifiable cause) and secondary to medical conditions or toxins such as illicit substances and prescribed medication. (2)

This project will adopt a broad definition of psychosis encompassing idiopathic primary psychoses and psychoses secondary to medical conditions and toxic substances such as prescription and recreational drugs. Thus, for purposes of the Landscape Report, psychosis will be defined as any condition presenting with delusions, hallucinations or both in the presence or absence of disorganized thinking and/or abnormal psychomotor behaviour. (1)

Primary psychotic disorders: These are mental disorders occurring along a spectrum and distinguished from each other by duration, complexity and severity of psychotic symptoms.(1)They include; schizotypal disorder, delusional disorder, brief psychotic disorder, schizophreniform disorder and schizophrenia.(3)

Secondary psychotic disorders are psychoses that occur secondary to neurological, endocrine, metabolic and other medical conditions, toxins, substance use and prescribed medications. (2)

Delusions: Fixed false beliefs held even in the presence of contradictory evidence. (1, 2)

Hallucinations: Sensory experiences in the absence of external stimuli. (1, 2)

Health facility: Any institution that offers health care services in Uganda including health centres and hospitals.

BACKGROUND

Psychosis is a severe mental illness (SMI) characterised by the presence of hallucinations and/or delusions, which are associated with perceptual and cognitive disruption in affected individuals. (1-3) A delusion is a fixed false belief held even in the presence of contradictory evidence. (1, 2) On the other hand a hallucination is a sensory experience in the absence of external stimuli. (1, 2) Whether it manifests as a feature of primary or secondary psychotic disorders, psychosis has negative health, social and economic outcomes for individuals and families. (2)

About 80% of all individuals living with mental disorders reside in Low-and-Middle-Income-Countries (LMICs) such as Uganda. (4) However, mental disorders are not accorded priority in these settings regarding allocation of resources towards health services and research initiatives. (5) Despite the well documented impact of SMIs on the long-term health and well-being of patients, the caring responsibilities and the economic situations of families and communities (6), there is a paucity of data on mental health services for SMIs, particularly psychosis in Uganda. Bridging this knowledge gap will facilitate improvements in the management of psychosis and related mental disorders in Uganda.

YouBelong Uganda (YBU), a Uganda registered Non-Government Organisation (NGO) operating to build capacity of community mental health systems in Uganda, was commissioned by the Psychosis Flagship Programme of Wellcome Trust to conduct a preliminary study describing available mental health services for psychosis in Uganda. Thus, the purpose of this report is to provide an overview of available mental health services for psychosis, challenges experienced by patients and health systems in management of psychosis and opportunities to address key gaps in the patient pathway for psychosis care in Uganda.

Data characterising mental health services for psychosis in Uganda has been collated from review of published and grey literature and a qualitative study involving key informant interviews with various stakeholders. Section 2 provides a detailed description of study methods. Section 3 is a brief summary of results from each method while sections 4 and 5 discuss key findings from all data sources in relation to study objectives. Section six is dedicated to the identification of future research opportunities to address key gaps in the management pathway for psychosis in Uganda.

SECTION 1: INTRODUCTION

1.1 Mental health care in Uganda

Similar to other resource-limited settings, mental health care is not prioritized in Uganda. (4, 7) One of the indicators for the low priority accorded to mental health is the draft mental health policy that was formulated two decades ago in 2000, revised and updated in 2012 and finalized in 2018 but is yet to be fully integrated into practice. (8) Secondly, less than 1% of Uganda's health budget is apportioned to mental health care. (9-11) Key barriers to prioritization of mental health care in Uganda include inadequate funding, limited epidemiological data to quantify the burden of mental disorders, lack of evidence to facilitate development of effective interventions and a plethora of competing health priorities such as malaria, HIV and other infectious diseases. (10, 11)

1.1.1 Organization of mental health services

Uganda's formal health infrastructure consists of a tiered system of health centres II-IV, general, regional referral and national referral hospitals based on the catchment area and services provided. (12) At the lowest level, communities have village health teams consisting of health volunteers tasked with coordinating health promotion activities and linking patients to care. However, the involvement of this latter cadre in the provision of mental health services is limited. Table 1 shows the number of health facilities and cadres of mental health professionals present at each level of the health system.

Mental health services are meant to be provided at HC III, HC IV and hospitals (General, Regional and National Referrals) by mental health professionals or general health workers as shown in Table 1. (13) However, mental health services are not well integrated into the primary health care (PHC) system (14) and are not provided at a majority of health centres. (8, 15, 16) Specialist mental health care is only accessible at two of the five national referral hospitals (Mulago National Referral Hospital and Butabika National Referral Mental Hospital), and regional referral hospitals. The National Referral Mental Hospital at Butabika, is also the lead institution for training, provision and supervision of mental health services in Uganda. (13)

The Butabika National Referral Mental Hospital has a multi-disciplinary team of mental health professionals unlike lower levels that may have none or only one mental health specialist. Regional referral hospitals, which are 13 in number, have 30-40 bed mental health units headed by a specialist mental health clinician (Psychiatrist or Psychiatric Clinical Officer (PCO), and offer both inpatient and outpatient mental health care. Inpatient mental health services are also available at some district hospitals that have 8-20 designated mental health beds and a few HC IVs with mental health specialists (PCO or psychiatric nurse). (14)

Table 1: Cadre of mental health specialist by level of health facility in Uganda

Type of health facility	Number of facilities* (both public and private facilities)	Cadre(s) of mental health professional present
National Referral Hospital	5 (Only 2 provide MHS)	Psychiatrists, clinical psychologists, PCOs, psychiatric nurses, psychiatric social workers, occupational therapists
Regional referral hospitals	13	Psychiatrists, PCOs, psychiatric nurses
District/General hospitals	163	PCOs, psychiatric nurse
Health Center IV (County/Sub district level)	222	PCOs, Psychiatric nurse
Health Center III (sub-county level)	1574	Psychiatric nurse or general/comprehensive nurse
Health Center II (parish level)	3365	Nursing officer
Village Health Teams	N/A	N/A

***MHS**-Mental Health Services, **PCO**-Psychiatric Clinical Officer (clinician with 3-year Diploma training in diagnosis and management of mental illnesses), **N/A**-Not Applicable*

Mental health resources are inequitably distributed in Uganda (8, 17) with much of the mental health funding apportioned to Butabika National Referral Mental Hospital. (9-11) Additionally, trained mental health workers are almost exclusive to urban settings (8) yet 88% of Uganda's population is rural. (9) Even in urban settings, mental health professionals are skewed towards higher level health facilities such as regional and national referral hospitals and are barely found at lower level facilities. (11, 18) Akin to human resources, access to psychotropic drugs is inequitable. Studies conducted across different regions of Uganda reported unreliable supply of psychotropic medication at rural health facilities in Eastern (19), Northern (14) and South-Western Uganda. (20)

1.1.2 Ugandan Government Mental health policy and legislative framework

Mental health policy

The Uganda mental health policy encompasses a range of reforms required to provide adequate mental health services to Uganda's population. These include scaling up of mental health services through integration into primary health care (PHC), development of community-based care and increasing specialized human resources throughout the health system; equitable access to mental health services; intra- and inter-sectoral collaboration for coordinated service delivery; promotion of mental health research initiatives; surveillance of mental illnesses and raising public awareness about mental disorders. (21) A few of the reforms, particularly service decentralization and increasing access to mental health services have been implemented to a limited extent. (19)

Mental health legislation

The previous Mental Health Act of Uganda, enacted in 1964 was overtly non-protective of the human rights of people with mental illness. (7, 22) The Act was plagued with several shortcomings such as the use of stigmatizing language in reference to people with mental

illness, promotion of inhumane handling of patients and a failure to uphold the positive rights of adequate medical management and rehabilitation of persons with mental disorders. (7) Uganda enacted a Persons With Disabilities (PWD) Act in 2006 to protect the rights of all PWDs, including mental disorders and subsequently ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). (23) An updated Mental Health Bill, designed to uphold the rights of persons with mental disorders in line with the CRPD was tabled in parliament in 2014 (23) and passed into law in 2018. The law centers on ensuring adequate treatment, preserving the rights of patients with mental illness and protecting them from torture and all forms of exploitation.

1.2 Burden of psychosis in Uganda

There is a dearth of literature on national prevalence estimates of mental illnesses in Uganda. (24) A few prevalence studies were conducted between 2002-09 in specific districts or regions (24-27) but none was specific to psychotic disorders. Notably, a few studies with a focus on mental health services, have documented the relatively high prevalence of primary psychotic disorders. A generalizable study that was based on analysis of national health surveillance data reported a prevalence of 160/10,000 persons for all mental and neurological disorders in 2016, with epilepsy accounting for the greatest burden of disease. (28) According to the same study, the prevalence of schizophrenia in 2016 was 11/10,000 persons (28), which is equivalent to 4,158,360 persons of Uganda's current population that is estimated at about 46 million people. The central region bore the brunt of this burden with a prevalence of 26/10,000 persons followed by Western and Northern regions with a prevalence of 7.2 and 4.5 per 10,000 persons respectively. Nonetheless, it is plausible that the concentration of resources in Central Uganda accounts for better reporting of mental disorders in the Health Management Information System (HMIS) and consequently the higher prevalence of disease. Secondly, the figures are only representative of those patients that seek care at health facilities yet majority of individuals with mental illness in Uganda, especially those with psychosis, favour traditional over western medicine. (8, 29) Figure 1 shows the 2016 estimated prevalence of schizophrenia for the four major regions in Uganda - Central, Eastern, Northern and Western regions.

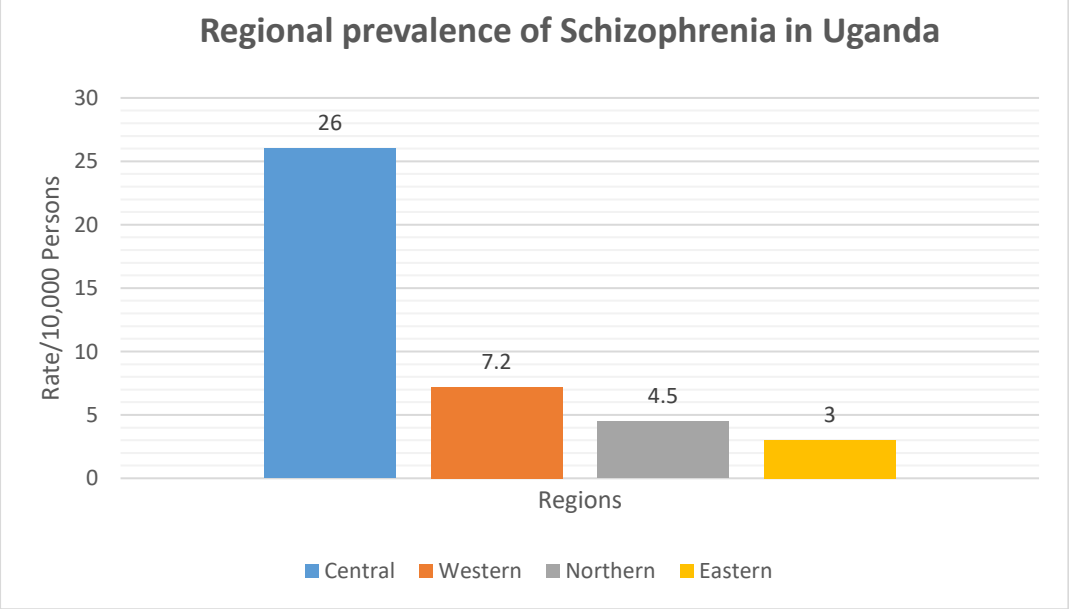

Figure 1: 2016 Regional prevalence of schizophrenia in Uganda, adapted from Alitubera et al (28)

Health facility-based studies also reported a high prevalence of psychotic disorders among persons with mental illness. A 2018 study conducted at Butabika National Referral Mental Hospital found that over 60% of all index patients had a psychosis-related diagnosis with a predominance of schizophrenia spectrum disorders. In fact, 30% of new patients were diagnosed with a non-affective psychotic disorder. (13) The results of this study are comparable to another study conducted across lower level health facilities in two centrally located Districts, Wakiso and Kampala that reported bipolar affective disorder and schizophrenia as the commonest mental disorders managed in these PHC facilities with a prevalence of 36.3% and 33% respectively in the one year period between July 2018 – June 2019. (18)

1.3 Community perceptions of psychosis in Uganda

In the Ugandan context, cultural beliefs largely underpin explanatory models for severe mental illnesses such as psychosis and are an important determinant for help-seeking behaviour. (30, 31) There is a general preference for alternative therapies for psychosis care due to an overriding cultural belief that psychosis is caused by evil spirits, witchcraft or punishment from unappeased ancestors and is thus best treated by traditional and faith healers with the supernatural ability of interposing between the spiritual and physical realms to ward off suffering. (8, 31, 32) These beliefs are equally liable for the high level of stigma endured by patients with severe mental illness, especially those with psychosis. (8)

1.4 Access to technology in Uganda

According to the Uganda Communications Commission (UCC), internet coverage in Uganda increased from 36.8% in 2018 to 37.9% by the end of 2019, which is equivalent to 23 million internet users. (33) These estimates indicate that over half of Uganda's population has access to internet. The increase in internet use is paralleled by an increase in the number of smart phones in Uganda. UCC estimates that over 15 million people access internet using mobile phones. (33) Thus, there is reasonable capacity for uptake of digital interventions within the Ugandan population. Of note, higher social economic status and urban residence are key predictors of internet access and smart phone ownership. (33) Health workers are more than likely to have access to mobile phone technology but access to reliable internet could be a challenge particularly in remote/rural areas.

1.5 Study objectives

Objectives of the psychosis landscape report project are outlined below.

1.5.1 General objective

To describe the current state of mental health services for psychosis in Uganda.

1.5.2 Specific objectives

1. To identify current methods for early detection and diagnosis of psychosis in Uganda.
2. To describe current models of care for psychosis in Uganda.
3. To determine key challenges faced by persons, clinicians and health systems in achieving early diagnosis and functional recovery from psychosis and how these may differ between rural and urban settings.

4. To identify ongoing research studies aimed at overcoming diagnostic and treatment challenges of psychosis in Uganda.
5. To identify key opinion leaders and stakeholders with specific interest in psychosis including clinical and research networks.
6. To identify future research opportunities for improvement of psychosis management in Uganda.

SECTION 2: METHODS

Two methodological approaches were employed to collect data; 1) a review of published and grey literature and 2) a qualitative study involving key informant interviews (KIIs) with policy makers, researchers, health workers and alternative care providers.

2.1 Literature review

2.1.1 Published scientific literature

Four electronic databases including Google Scholar, Psyc-Info, Medline and PubMed were searched using the search strategy in Table 2 below. The key concepts, 'Psychosis,' 'Mental Health Services,' and 'Uganda,' were searched along with related terms as illustrated. Searches were not limited by study design or year of publication. Results from key concept searches were then combined using the Boolean Operator 'AND.'

Table 2:Search Strategy for published scientific literature

Research Question: ***What is the current state of mental health services for psychosis in Uganda?***					
Concept 1	Psychosis	OR	Schizophrenia, schizophreniform disorder, schizoaffective disorder, Schizophrenia spectrum disorders, psychotic disorders, mental disorders, severe mental illness, neuropsychiatric disorders, hallucinations, delusions		
AND					
Concept 2	Mental Health Services	OR	Mental health care/management, Primary Health Care/services, mental health support, mental health recovery	OR	Antipsychotic Agents, Cognitive Behaviour Therapy, Psychotherapy, Psychosocial support, Psychosocial support system
AND					
Concept 3	Uganda	OR	East Africa, Low-and-middle-income-countries, low-resourced settings		

Selection criteria

Retrieved articles were subjected to title/abstract and full-text screening based on the criteria below;

Inclusion criteria

1. Studies conducted to describe available mental health services and models of care for psychosis in Uganda.
2. Studies on methods used for early detection and diagnosis of psychosis in Uganda.

3. Studies about diagnostic and treatment challenges of psychosis faced by patients, clinicians and health systems in Uganda.
4. Research protocols for projects aimed at overcoming diagnostic and treatment challenges of psychosis in Uganda.
5. Studies aimed at identifying gaps and opportunities for improvement of available mental health services for psychosis in Uganda.
6. Studies comparing patient outcomes and access to mental health services for psychosis between rural and urban dwellers in Uganda.
7. Studies on community-based mental health services and post-discharge monitoring and care for patients with psychosis in Uganda.
8. Studies on the use of alternate therapy by patients with psychosis in Uganda.
9. Studies about the level of communication between conventional mental health care providers and alternate care providers for psychosis management in Uganda.

Exclusion criteria

1. Studies on mental health services conducted outside Uganda or LMIC settings.
2. Editorial papers.
3. Opinion pieces.

2.1.2 Grey literature

A desk review of unpublished/grey literature was conducted. Aside from YBU, three other mental health NGOs – Mental Health Uganda, Transcultural Psychosocial Organisation, Health Right International Uganda and the Ministry of Health and three psychiatry training institutions – Makerere University, Mbarara University of Science and Technology and Butabika School of Psychiatric Clinical officers were contacted in search of programme, project or research reports on services for psychosis in Uganda. Of all these organisations, only YBU and Butabika School of Psychiatric Clinical Officers had reports and dissertations relevant to this project. The same selection criteria used for published literature was used to screen YBU research reports and dissertations at psychiatry training institutions. Two research reports from YBU and three dissertations from Butabika School of Clinical Officers met inclusion criteria and were included in this review. A document review guide (see Appendix 1) was used to extract project data.

2.1.3 Analysis of literature review data

A thematic analysis approach was used. Retrieved data from both published and grey literature was synthesized to identify major/emergent themes in line with project objectives. Data was then integrated with key informant perspectives from the qualitative study to generate evidence on available mental health services for psychosis in Uganda.

2.2 Qualitative study

Data for the qualitative study was obtained from Key Informant Interviews (KII) conducted with a range of stakeholders as shown in Table 3 below. Sampling of respondents was purposive, based on their roles and experience in management of psychosis in Uganda. Altogether, 30 interviews were conducted by one of the project supervisors, a project officer and two research assistants using interview guides developed for each stakeholder category (see Appendices 2-5).

Table 3: Study sites, sample size and participant cadres for the qualitative study

Study site	Population & sample size
Ministry of Health	Policy makers (2)
Universities	Researchers (12)
• Makerere University (Dept. of Psychiatry, Mulago Hospital)	• 5 researchers/psychiatrists
• Mbarara University of Science and Technology (Dept. of Psychiatry, Mbarara Hospital)	• 1 psychiatry senior house officer • 2 researchers/psychiatrists
Butabika National Referral Mental Hospital	• 2 researchers/clinical psychologists • 2 psychiatrists/researchers
Health facilities	Health care providers (12)
• Butabika National Referral Mental Hospital	• Psychiatrist • PCO • PNO
• Mbarara Regional Referral Hospital	• 2 PCOs • 1 PNO
• Kasangati HC IV (Nangabo Sub County, Wakiso)	• Nursing officer
• Ndejje HC IV (Wakiso)	• PCO
• Maganjo HC II (Nabweru Sub-County, Wakiso)	• Nursing Officer
• Bukoto HC II (Kampala Central Division)	• Clinical officer
• Kitebi HC III (Kampala)	• Nursing officer
• Kiswa HC III (Nakawa Division)	• Nursing officer
Kampala District	Alternative care providers (2)
	• Faith Healer • Traditional Healer
Wakiso District	Alternative care providers (2)
Wakiso	• Faith Healer • Traditional Healer

***Dept.**-Department of psychiatry, **PCO**-Psychiatric Clinical Officer, **PNO**-Psychiatric Nursing Officer*

2.2.1 Data analysis

A framework analysis of qualitative data was conducted. Audio files were transcribed and imported to NVivo computer software for data coding, generation of sub- and major themes. Key themes were retrieved and discussed in light of the literature review data to generate an integrated evidence base for the current landscape of mental health services for psychosis in Uganda. Salient quotations from interview transcripts relevant to research questions have also been included in this report.

SECTION 3: RESULTS

This section provides a summary of results from each data collection method described in Section 2 above.

3.1 Literature review

The database searches for published literature retrieved 224 articles; 52 from Google Scholar, 98 from PubMed, 36 from Medline and 38 from Psyc-Info. 32 duplicates were excluded, and a further 179 articles that did not meet inclusion criteria were excluded following title, abstract and full-text screening. Figure 1 is a flowchart summarizing the search process and results.

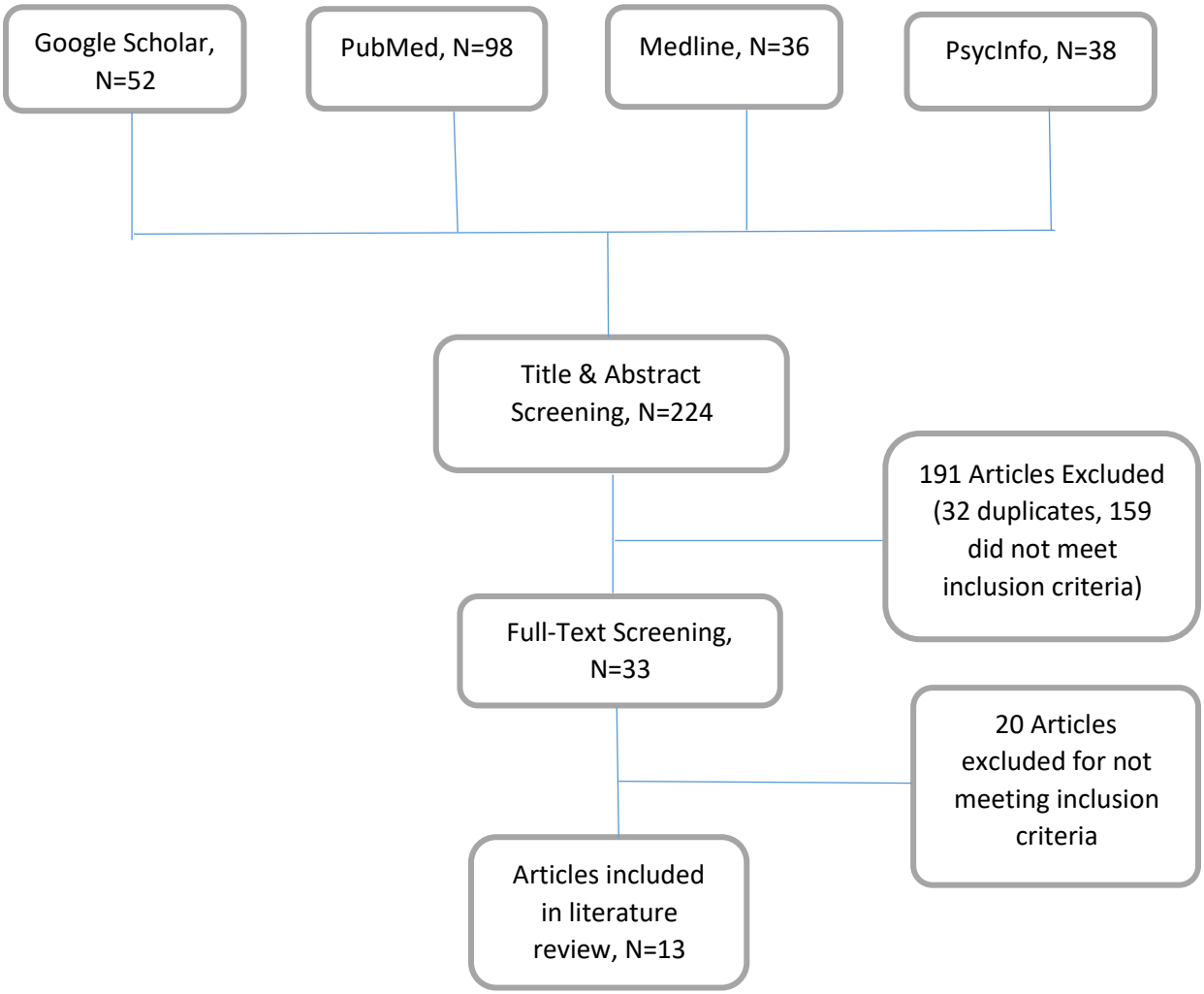

Figure 2: A flowchart of the study selection process

Characteristics of included studies

Literature on mental health services for psychosis in Uganda is scarce. Only 13 studies were included in the published literature review, one of which is a research protocol of a study seeking to identify factors associated with a long duration of untreated psychosis (DUP) with the ultimate goal of developing evidence-based interventions to overcome this major treatment gap for persons with psychosis in Uganda. (29) Of the other 12 studies, there are four cross-sectional studies (7, 19, 34, 35), one of which includes a qualitative component (7); three qualitative studies (31, 36, 37); three literature reviews (22, 38, 39); and two case studies (14, 20), including an evaluation of a mental health programme. (14) All studies are specific to Uganda save for two literature reviews on mental health services for psychosis in Low-and-Middle-Income Countries (LMICs) (39) and Sub-Saharan Africa (SSA). (38)

Similar to published literature, there is a dearth of grey literature on mental health services for psychosis in Uganda. Depression, post-traumatic stress disorder and psychological distress are the conditions of interest for most mental health organisations in Uganda. Predominant roles of mental health NGOs in Uganda include, rehabilitation of patients with substance use disorders, community-based care for depression and psychological distress through counselling, skill development, peer and psychosocial support programmes. (30) There were two relevant NGO research studies whose reports have been included in the literature review. The reports highlighted the determinants of health-seeking behaviour for mental illness, barriers to accessing mental health care (30) and the state of mental health services at lower level health facilities in Kampala and Wakiso Districts. (18) Regarding psychiatry training institutions, majority of dissertations at Makerere and Mbarara University Departments of Psychiatry have focused on depression and anxiety disorders driven by availability of research funding for both mental disorders. Only three dissertations from the Butabika School of Clinical Officers that focused on mental health services (40, 41) and challenges experienced by persons with severe mental illness (42) met the selection criteria for this project and were included in the literature review.

3.2 Key informant perspectives on mental health services for psychosis

Key findings from KIIs with each stakeholder category are summarised in Table 4 below. Questions from all interview guides were combined to determine stakeholder perspectives on pathways to care for persons with psychosis; available mental health services for psychosis management; person with psychosis, clinician and health system challenges/gaps in psychosis care and opportunities to address identified gaps in the person's pathway for psychosis care.

Table 4: Key informant Interview summary responses by key informant category

Interview Questions	**Stakeholder Perspectives**			
	Policy makers	Researchers	Health workers	Alternative care providers
What is the person's pathway for accessing psychosis care in Uganda?	Persons with abnormal behaviours s are taken to PHC facilities by police and care givers especially when they become disruptive to society.	Persons with psychosis symptoms usually seek care from traditional and faith healers first. Conventional MHS are only sought as a last resort, in which case the person attends PHC facilities closest to them or seek care from the national referral hospitals without referral from lower level health centres.	Persons with psychosis symptoms access initial care from alternative care providers or health centres III and IV. In most instances, these persons are referred to the national referral mental hospital without receiving any care at the lower level facilities.	Mental illness is largely attributed to witchcraft or attacks from ancestral spirits so that families favour alternative care providers over mental health services. Dual consultation of both alternative care providers and conventional mental health services is also rampant. Services offered to persons with psychosis by alternative care providers include prayer, counselling, exorcism and catering to the basic social, hygiene and nutritional needs.
What services are available for management of psychosis at different levels of the health system?	MHS are integrated into PHC. General health workers at health centres initiate management of psychosis and refer more complex cases to higher level facilities. Specialised mental health services are available at national and regional referral hospitals throughout the country.	National and regional referral hospitals account for majority of the multi-disciplinary MH workforce. Pharmacotherapy is the mainstay of treatment for psychosis. Due to inadequate human resources and large hospital numbers, psychosocial therapies are only provided to few persons. At lower level facilities, MHS are limited to pharmacotherapy	For health facilities with mental health professionals such as HC IV upwards, diagnosis of psychosis is based on clinical assessment through history taking and where possible, investigations to rule out organic causes of psychosis. At PHC facilities, detection of psychosis and subsequent referral to a higher-level facility is the major service available to patients. Pharmacotherapy is the main form	N/A

		or not provided due to lack of MH professionals and/or psychotropic drugs.	of treatment provided to persons with psychosis.	
What services are available for the person's follow up and rehabilitation in the community?	There are no mainstream services for community follow up of persons with psychosis but they can continue care at lower level health facilities once discharged from specialist care.	Health facilities do not provide community outreach programs due to lack of funding and mental health social workers to facilitate such initiatives.	Community follow up of persons with psychosis is not part of routine care and only happens as part of funded programmes implemented at health facilities including research & MH-NGO projects.	N/A
What challenges do persons face in obtaining early diagnosis and functional recovery from psychosis?	Lack of knowledge about psychosis and available MHS. Cultural beliefs about traditional causes of psychosis that lead persons to seek care from alternative care providers, thereby forfeiting early diagnosis and initiation of treatment.	Delay in accessing MHS due to stigmatisation of psychosis and persons with severe mental illness, tendency to consult with traditional healers first and low capacity of PHC facilities to diagnose and treat psychosis. Unreliable psychotropic drug supply even at national and regional referral hospitals.	Limited access to mental health services due to reduced capacity of PHC facilities to manage psychosis. High costs incurred to transport persons with psychosis to specialised mental health facilities, and purchase psychotropic medication following drug stock-outs. Low mental health literacy hinders access to mental health services for psychosis which in turn deters early diagnosis and functional recovery.	Limited access and high cost of transportation to conventional MHS leads people to seek alternative therapy from traditional and faith healers. Inadequate psychological support and intolerable living conditions due to overcrowding and lack of food at MH facilities also drive people away from conventional MHS for psychosis.
What challenges do clinicians experience in making early diagnosis and providing care for patients with psychosis?	Inadequate HR to adequately manage psychosis in PHC settings. Inadequate training and supervision of general health workers in the management of psychosis and other mental illnesses	Low capacity of general PHC. workers to diagnose and initiate treatment for psychosis. Delay in making a diagnosis of psychosis, especially primary psychotic disorders due to the subjective nature of psychiatric practice. Psychotropic drug stock-outs.	Inadequate mental health workforce to provide holistic patient care. Psychotropic drug stock-outs. Lack of training and supervision to build capacity of PHC workers in the management of psychosis.	N/A
How do patient, clinician and health system challenges differ between rural and urban areas?	Patients in rural areas are more likely to seek alternative care due to limited access to MHS.	MHS for psychosis are inequitably distributed in favour of urban areas although much of the population is rural.	In rural areas, alternative care providers are more accessible and affordable compared to conventional mental health services	N/A

		Patients in urban settings have more access to conventional MHC and are also more likely to afford drugs in case of stock-outs at public health facilities.	leading to delayed diagnosis and recovery for rural patients. Multi-disciplinary mental health services are exclusive to referral hospitals in urban areas and thus unavailable to rural patients unless they are referred.	
What are your thouights on opportunities to address key gaps in the patient pathway for psychosis care?	Harness technological innovations such as mobile applications for improved detection and monitoring of persons with psychosis. Ongoing supervision of general health workers by MH professionals to build PHC capacity for psychosis management. More investment in research to inform mental health policy and service delivery for persons with psychosis.	Utilise information technology in screening, diagnosis and treatment of persons with psychosis. Regular training and supervision of health workers at PHC level in the management of SMI. Develop tools for assessment of persons with primary psychosis in the Ugandan context. Pharmacological and psychosocial intervention research to inform scaling up of EBM of psychosis in Uganda.	Public sensitization about severe mental illness and available mental health services. Training and supervision of general health workers in management of psychosis to increase their confidence in making a diagnosis and initiating treatment. Increased funding to facilitate Psychotropic drug supplies and community-based mental health care for psychosis.	MH workers should explain the causes of psychosis to patients and their families. Hospitals should cater to needs of admitted patients such as food and provide a conducive environment. Follow up patients at home and support them. Recruit more health workers to manage mental disorders in health centres.

***PHC**-Primary Health Care, **MHS**-Mental Health Services, **MH**-Mental Health, **NGO**-Non Government Organisation, **HR**-Human Resources, **MHC**-Mental Health Care, **EBM**-Evidence-Based Management*

3.3 Key opinion leaders and stakeholders in Uganda with specific interest in psychosis

Key stakeholders identified from KIIs with an interest in management of psychosis in Uganda include;

1. Ministry of Health Uganda, specifically the mental health division, which is headed by the assistant commissioner of mental health.
2. District Health Officers.
3. Mental health professionals including psychiatrists, psychiatric clinical officers, clinical psychologists and psychiatric nurses.
4. Training Institutions including Makerere and Mbarara Universities, Butabika School of Psychiatric Clinical Officers.
5. Alternative care providers including traditional and faith healers.
6. Mental health NGOs; YBU, Mental Health Uganda, Health Right International Uganda.
7. Research organisations, particularly Medical Research Council.

3.4 Psychosis research programs in Uganda.

This sub-section presents a summary of ongoing and completed research programs with a focus on psychosis and/or improved mental health service delivery in Uganda. Studies cut across management of other neuropsychiatric illnesses including epilepsy, depression and anxiety disorders and are thus not specific to primary psychosis.

3.4.1 Ongoing Research Programs

Table 5: Ongoing research programs of interest

Organisation	Research study summary & URL
Mbarara University of Science and Technology, Department of Psychiatry	Study to determine the impact of HIV comorbidity with depression, bipolar affective disorder and schizophrenia on patient quality of life.
Makerere University, Department of Psychiatry	NeuroGAP-Psychosis is 4-year study (2018-22) to investigate genetic and environmental risk factors for patients with neuropsychiatric disorders in Africa. https://bmjopen.bmj.com/content/9/2/e025469.full
	Longitudinal study to determine the incidence rate and predictors of relapse among patients with FEP. Participant recruitment is ongoing, patients to be followed up for 4 years.
	A pilot community-based intervention study to assess the feasibility of engaging lay community health workers to provide psychoeducation and counselling support to patients with FEP.
Butabika National Referral Mental Hospital	DIALOG+ study to test three psychosocial interventions for mental health care including patient-clinician meetings, multi-family group meetings and community support for patients with mental disorders through befriending schemes with volunteers. https://bmcpsychiatry.biomedcentral.com/articles/10.1186/s12888-019-2148-x
	Evaluation study of Brain Gain II peer support programme to investigate the impact of access to a peer support worker on rehospitalisation of frequent users of psychiatric inpatient care services at Butabika Hospital. https://link.springer.com/article/10.1186/s12888-019-2360-8
	UPSIDES is a 5-year (2018-22) RCT to evaluate impact of peer support on the mental health outcomes of health and social functioning, hope, recovery and empowerment of patients with mental illnesses and assessing the cost-effectiveness of a peer support model in MHC. www.upsides.org, https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-020-4177-7

NeuroGAP-Psychosis*-Neuropsychiatric Genetics of African Populations-Psychosis,* ***FEP****-First Episode Psychosis,* ***UPSIDES****-Using Peer Support in Developing Empowering mental health services,* ***RCT****-Randomised controlled trial*

3.4.2 Completed research programs

Table 6: Completed research programmes of interest

PROGRAM	SUMMARY/URL	IMPACT/MAIN FINDINGS
PRIME (Ethiopia, India, Nepal, South Africa, Uganda)	The PRIME study developed and implemented a mental health care plan that delivered various interventions at community, health facility and health service organisation levels in Kamuli District, located in Eastern Uganda. Programme activities were conducted between 2013-17. The programme involved raising awareness about mental disorders in the community and building capacity for increased detection and management of mental disorders by general PHC workers. https://link.springer.com/article/10.1186/s13033-019-0319-2	PRIME demonstrated the efficacy of integrating mental health services into PHC. Detection of mental disorders by general health workers improved at the 3-month mark but was not evident at 12 months in spite of initial training and 3-monthly supervision of general health workers by mental health specialists.
AFFIRM (Ethiopia Ghana, Malawi, Uganda, Zimbabwe)	5-year program (2012-16) with the aim of improving delivery of cost-effective interventions in SSA through development and evaluation of MH interventions in South Africa and Ethiopia, and building MH research capacity in 5 partner countries including Uganda. http://www.affirm.uct.ac.za/affirm/about	Five students sponsored and mentored in MH intervention research through MPhil programme of Public Mental Health at UCT & University of Stellenbosch.
mhBEF (Uganda, Nepal, Liberia)	Project implemented a comprehensive community MH package to improve identification, management and rehabilitation support for PWSMDE and reduce stigmatisation of mental illness in Lira District Uganda. General health workers at HC II & III were trained on mhGAP guidelines for enhanced management of SMD and epilepsy. https://doi.org/10.1080/09540261.2019.1566116	Trained health workers demonstrated positive changes in knowledge, competence and attitude towards SMD.
EMERALD (Ethiopia, India, Nepal, Nigeria, South Africa, Uganda)	5-year project (2012-17) that aimed to identify health system barriers to adequate provision of mental health services in LMICs and corresponding solutions to strengthen mental health systems in participating countries. https://cordis.europa.eu/project/id/305968/reporting	Findings: integration of MHS within PHC improves access to MHC in LMICs thus reducing negative economic impacts of mental illness on families, social health insurance models are key to sustained MH resourcing, integrated care at PHC level should involve training and supervision of health workers and overall health systems strengthening.
CHaRISMA	15-month study with 3 elements: risk score study to profile patients with the greatest risk of rehospitalisation at Butabika National Referral Mental Hospital, action research to define the YBU intervention, Delphi study component to seek opinions from key opinion leaders about the components of a community mental health intervention. Research activities completed, currently conducting data analysis	N/A
SMILE study	Longitudinal study conducted in central and South Western Uganda to investigate factors associated with HIV/SMI comorbidity in order to elucidate the direction of causality between HIV and SMI in the Ugandan context. It also involved a sub-study to investigate the	Prevalence of physical and psychiatric co-morbidity at the two study sites was 13.1%. Childhood and adulthood sexual and physical abuse were associated with increased risk of

	feasibility and acceptability of undertaking clinical trials among persons with SMI/HIV comorbidity. 10.1080/09540121.2020.1717419	having comorbid physical and psychiatric comorbidity.

***PRIME**-Programme for Improved Mental Health Care, **AFFIRM**-Africa Focus on Intervention Research for Mental Health, **SSA**-sub-Saharan Africa, **MH**-Mental health, **MPhil**-Master of Philosophy, **UCT**-University of Cape Town, **mhBEF**-Mental Health Beyond Facilities, **PWSMDE**-People with Severe Mental Disorders and Epilepsy, **mhGAP**-mental health Gap Action Programme, **SMD**-Severe Mental Disorders, **EMERALD** – Emerging mental health systems in low-and-middle –income countries, **MHC**-Mental Health Care, **CHaRISMA**-Curtailing Hospital Readmissions of Persons with severe Mental Illness in Africa, **YBU**-YouBelong Uganda, SMILE-Studies among patients with severe mental illness in HIV endemic Uganda, **SMI**-Severe Mental Illness, HIV-Human Immunodeficiency Virus.*

SECTION 4: CURRENT STATE OF CARE AND SERVICE PROVISION FOR PERSONS WITH PSYCHOSIS IN UGANDA.

There is a dearth of literature on the models of care for persons with psychosis in Uganda. However, the available literature consistently highlights the inadequacy of Uganda's health system to provide evidence-based care to persons with psychosis. (7, 14, 20, 22, 35) The mental health system barely provides the full range of essential evidence-based services known to improve patient outcomes for psychosis such as ready access to antipsychotics and psychological interventions, skills training, family psychoeducation, patient rehabilitation and reintegration into their communities following discharge from hospital. (18, 19, 30, 35) Where these services are available, they are of poor quality and only availed to miniscule proportions of persons with psychosis. (35, 37) This is in keeping with the evidence base from other low resourced settings. (43)

Much of the data on available mental health services for psychosis was obtained from key informant interviews, which also indicated major gaps in both health services provision and research. This section presents key themes from the literature and qualitative study characterising mental health services for psychosis in Uganda. Cultural beliefs about mental illnesses, mental health literacy and accessibility to mental health services are the key determinants for help-seeking behaviour among persons with psychosis in Uganda. (30, 37) The two major pathways to psychosis care identified from both the literature and qualitative interviews include conventional hospital-based mental health services (18, 34, 35) and alternative therapies provided by traditional and faith healers. (30, 37, 42)

4.1 Services for early detection and diagnosis of psychosis in Uganda

Several stakeholders, especially health workers and researchers revealed that persons with psychosis are usually taken to health facilities by immediate family members, care takers or the police when they become disruptive to society. There are no tools used routinely in the diagnosis of psychosis. A policy maker disclosed that although some general health workers were trained in the use of mental health Gap Action Program (mhGAP) manuals for diagnosis and management of mental disorders, the guidelines have only been disseminated to regional and national referral hospitals and are yet to be fully integrated into practice. (Policy maker, MOH) According to health workers, diagnosis of psychosis is based on clinical assessment including history taking, mental state exam and laboratory investigations to rule out physical illnesses such as HIV and malaria. Once a diagnosis of psychosis is made, patients are initiated on antipsychotic medications as outpatients or inpatients, depending on symptom severity. Nonetheless, various respondents asserted that the absence of trained health workers and accessible community-based health services, which are necessary for early detection of persons with psychosis coupled with low mental health literacy, hinder early detection and diagnosis of psychosis by the conventional mental health system.

> "we don't go to the community to look for patients. And in the community, they can't bring someone who has just got abnormal behaviour and is continuing with normal activities, they have to wait until he has done something regrettable" *[Hospital Nurse]*

> "…they don't know that there is a problem going on early enough to warrant going to seek medical care so that is affecting early detection at family level" *[HC Nurse]*

Within the conventional mental health system in Uganda, mental health services for persons with psychosis are rarely provided at lower level health facilities including HC III, IV and general hospitals, which usually initiate 'informal' referral to regional referral and national referral hospitals. (13) Interview respondents also acknowledged that in line with Uganda's primary health care model, persons with psychosis should ideally receive initial care from lower level health facilities. However, it was revealed that the majority of PHC facilities do not have mental health professionals and the general health workers lack the requisite expertise to diagnose and initiate treatment for psychosis, which further delays access to evidence-based care.

> "And then also when you go to the health care centres like wherever you go you may not meet a specialist for the very first time, sometimes you may meet a general practitioner whose knowledge in making a diagnosis maybe a challenge" *[Hospital based Psychiatrist]*

> "The patients usually make first contact with general hospitals but many of the health workers in those hospitals are not well versed with mental health issues, patients sometimes get mishandled, they are not diagnosed immediately which delays the access to proper care." *[University Psychiatrist/Researcher]*

> "Most people who present with psychosis, it is a bit not so easy to come up with the diagnosis especially at the lower levels, there is a confusion, most mental illnesses can just be lumped into one thing at lower levels, to come up with diagnosis and the care they receive that will help them, it takes quite some time." *[Policy maker]*

The evidence points to a referral system that is largely non-functional in which primary health workers do not formerly refer patients to higher level facilities. A study conducted to analyse utilisation of mental health services at lower level facilities in Kampala and Wakiso reported that verbal referral of persons with mental disorders to the national referral mental hospital without accompanying documentation was a common finding. (18) The literature also indicated that patients are aware of the gaps in mental health services at the PHC level and are thus likely to bypass this level in favour of the National Referral Mental Hospital, resulting in an overwhelmed facility. (30)

On the other hand, evidence from the literature and qualitative interviews indicates that early detection and cultural diagnosis of psychosis occurs primarily within the alternative care pathway that is preferred by patients due to accessibility of traditionalists and the prevalent cultural explanatory models for psychosis. (37, 44). Traditional healers use spiritualism and cultural regalia such as shells, bones and stones to diagnose psychosis (44), which are more in keeping with the patients' and family's beliefs about psychosis, and therefore more acceptable than diagnostic procedure by conventional care providers. The quote below from a traditional healer in Wakiso District serves to explain:

> "Our spirits inform them the cause of their mental illness and the way forward, if the cause of mental illness is due to the cultural rituals that were not performed 100 to 200 years ago by the grand parents who passed on, the spirits inform them and tell them what to do so that the person can recover fully" *[Traditional healer, Wakiso]*

Interview respondents also revealed that although some alternative care providers may refer patients for conventional mental health services, this is more of an exception than the rule. There is hardly any referral from conventional to alternative care providers, hence no formal communication/engagement between the two pathways of care exists to allow for timely referral of patients by traditional healers for early initiation of evidence-based care within the

conventional mental health system (44) and vice versa. Alternative providers echoed the lack of collaboration with mental health workers although they spoke of referring persons with psychosis and comorbid HIV or substance use to conventional mental health services.

> "Patients who have psychosis that is due to substance use are referred to hospital because they need to take medicine to dilute the chemicals in their bodies, and specialised counselling" *[Faith healer, Wakiso]*

> "If a person is brought here and from the spirits assessment I realise that the cause of psychosis is not ancestral spirits, demons or witchcraft, I send them to health centres for treatment… The referrals I make for people with psychosis that is because of HIV or drugs not ancestral spirits or witch craft." *[Traditional healer, Wakiso]*

4.2 Treatment for Psychosis

4.2.1 Pharmacotherapy

According to the literature (18, 38) and qualitative study, hospital-based biomedical management in which patients are prescribed antipsychotic drugs is the predominant model of care for persons with psychosis in Uganda. In addition, respondents from regional and national referral hospitals reported that electroconvulsive therapy is provided to patients with poor response to pharmacotherapy. However, similar to literature findings (34), numerous interview respondents, specifically health workers and researchers, highlighted the limited range of available antipsychotic drugs in Uganda, with prescriptions dictated more by drug availability than clinician preference. Both the qualitative study and literature review revealed that first generation antipsychotics are the mainstay of pharmacotherapy for psychosis management in Uganda. (34, 35)

A 2012 study conducted at Butabika National Referral Mental Hospital and Mulago National Referral Hospital to describe prescription patterns for hospitalised persons with psychosis found that chlorpromazine, haloperidol, trifluoperazine and fluphenazine are the commonest drugs administered to persons with psychosis. Other commonly prescribed drugs were carbamazepine, the antidepressants fluoxetine and amitriptyline, and trihexyphenidyl for management of antipsychotic medication side effects. (34) A more recent study (2018) conducted at PHC facilities in Kampala and Wakiso also reported chlorpromazine and haloperidol as the commonest drugs administered to persons with psychosis. (18) This is in line with the essential drugs prescription guidelines recommended by the Ministry of Health in Uganda, which to a large extent are informed by the available resource package (cost effectiveness) and not necessarily efficacy of medications.

4.2.2 Alternative therapy

In addition to allopathic remedies, traditional and faith healers are an important source of care for persons with psychosis in Uganda. The overriding belief that mental illnesses such as psychosis are caused by evil spirits leads patients to seek care from traditional healers believed to possess supernatural power that wards off suffering. (31, 32) In a study conducted in two Ugandan districts to determine prevalence of mental disorders handled by traditional healers, Abbo et al (25) found that over 60% of patrons had a diagnosable mental disorder of which psychosis (29.7%) was the commonest.

Low access to conventional mental health services is another factor that leads patients to seek alternative therapies first. Unlike conventional mental health services, alternative care providers are community-based and readily accessible to persons with psychosis. This was aptly stated by a hospital based researcher;

> "because there are gaps at the community level, the psychiatrist, clinical psychologists, psychiatric nurses are not community based, they are hospital-based. So that becomes a problem, when a local person gets a problem, they have to first think about the nearest person who can offer support and usually these are traditional healers and religious fundamentalists, they are within their communities so they are able to say, no, we can handle this, you don't need to worry,"

In the management of psychosis, traditional healers offer supportive counselling, herbal remedies and traditional/spiritual therapies to their clients.

> "We give them our medicine and they recover as instructed by the sprits. We get our medicine from herbs" *[Traditional healer, Kampala]*

> "Our sprits that we use for treatment calms down the demons and ancestral sprits that has caused psychosis to that individual. This happens when and only the person with mental illness/family members of the family members do what the spirits have told him to do" *[Traditional healer, Wakiso]*

In some instances, traditional healers have been known to utilise tranquilisers and sedatives such as benzodiazepines and chlorpromazine in the herbal concoctions that are offered to patients. (45)

Faith healers reported that they provide prayer and counselling services in addition to social support and catering to the basic needs of patients with psychosis.

> "We encourage them to keep hopeful about their mental health recovery, future goals like getting a job, marriage. The time they spend at church, we pray and counsel them" *[Faith healer, Kampala]*

> "The patient we have here currently with psychosis we make sure he takes his medicine in time, we share everything together with him, encourage him to bathe, wash clothes and involve him in domestic activities, provide them with accommodation, food, water" *[Faith healer, Kampala]*

4.3 Psychosocial and community-based interventions for psychosis

Evidence from published and grey literature suggests that resource-limited countries like Uganda barely provide other essential aspects of mental health care for psychosis outside of the biomedical model. (5, 38, 39) Indeed, several stakeholders affirmed this narrative. Even at higher level facilities such as the National Referral Mental Hospital, psychosocial interventions are provided to very few patients. (35) For instance, a recent study at Butabika Hospital found that of the enrolled 156 patients managed for first episode psychosis (FEP) in 2018, 84% received antipsychotics while only 2% and 13% respectively received a vocational plan and multifamily group psychoeducation. (35) Nearly all studied essential psychosocial services for FEP were of low quality owing to the miniscule proportions of patients receiving them. (35)

Qualitative interviews highlighted key barriers to a multi-disciplinary approach in the care of persons with psychosis including, limited funding, inadequate mental health specialists and inequitable distribution of available mental health resources between rural and urban settings; PHC and referral health facilities. Some of the respondents reported that psychoeducation and counselling are sometimes offered to patients. However, this is not routine and services are of questionable quality as they are not rendered by professionals. A nurse at a HC II explained;

> "We can do some counselling on a lesser extent given the fact that we don't have a number of them accessing our facility here. Where some people have come in with even mild forms of psychosis some counselling is always extended to them" *[Nurse, HCII]*

Similarly, respondents mentioned the near absence of community-based services for persons with psychosis to support rehabilitation and functional recovery. Community-based services are usually limited to research and intervention programs that typically have definite timelines and operate at select health facilities. Some of the programs that embedded a community care component for patients with mental illness include the 'mental health Beyond Facilities' (mhBEF) project (37), the ongoing Brain Gain peer support programme (46), Dialogue+ (47) and the YBU Home program. (48) Refer to Table 5 for specific program details.

While conventional mental health services seem to predominantly work from a biomedical model, as they have little available time to offer psychosocial support, alternative care providers appear to be particularly attuned to the psychosocial needs of persons with psychosis. In addition to providing herbal/traditional remedies and prayer, they routinely engage with families to explain the cause of psychosis from a cultural perspective, offer supportive counselling support and cater to other social needs of persons with psychosis. (44) While enumerating services offered to patients with psychosis, a traditional healer explained;

> "Health workers don't do a thorough assessment regarding the cause of psychosis like us the traditional doctors, health workers just gamble, and what the person or family members want is to know exactly the cause of mental illness. Our sprits inform them the cause of their mental illness and the way forward" *[Traditional healer, Wakiso]*

He further elaborated;

> The care we give to our patients is of a good standard; we provide them with good accommodation, clothes, enough food and water, and we talk to them in a calm way. In your facilities like Butabika, you focus on giving them medicine. You don't talk to them in a good way; calm and nicely *[Traditional healer, Wakiso]*

A faith healer also explained;

> People with psychosis come here when they have lost hope…We encourage them to keep hopeful about their mental health recovery, future goals like getting a job, marriage..." *[Faith healer, Kampala]*

SECTION 5: KEY GAPS AND CHALLENGES IN PROVIDING MENTAL HEALTH SERVICES TO PERSONS WITH PSYCHOSIS IN UGANDA AND GAPS IN PSYCHOSIS RESEARCH

Psychosis in Uganda remains understudied, largely undiagnosed and untreated in its early stages resulting in poor treatment outcomes for those who eventually access specialist care. (29) Findings from this study indicate consensus from all data sources on the conspicuous gaps and challenges along the pathway to care for persons with psychosis in Uganda, as is also the case for other mental illnesses.

Lack of awareness about psychosis and available mental health services, scarcity and inequity of mental health resources were cited by interview respondents as the most important barriers to provision of evidence-based care for psychosis in Uganda. Similar to other LMICs, mental health resources/services for psychosis are disproportionately directed towards the biomedical management of severe mental illnesses in health facilities at the expense of psychosocial interventions and community-based care (7, 38, 49), which is contrary to mounting evidence in support of more integrated care that addresses the vast range of psychosocial needs for persons with psychosis. (39, 48) Nonetheless, the retrieved literature and qualitative interviews unveiled a myriad of gaps in the biomedical model. Ultimately, the key challenges plaguing Uganda's mental health system point to inadequate investment in mental health services which undermines the health system's capacity to scale up evidence-based care for patients with psychosis and other mental illnesses. Key gaps and challenges along the patient pathway for psychosis care in Uganda are discussed below. For specific patient, clinician and health system challenges, refer to Table 4.

5.1 Low mental health literacy and cultural explanations of psychosis

Much of the reviewed literature highlighted the lack of community awareness and sensitization about the causes of severe mental illnesses and available health services. (14, 20, 22, 36) Similarly, there were phrases scattered throughout the interviews asserting that "people have no knowledge about psychosis," "people are not aware of mental illness" and "people don't know about mental health services." Lack of awareness about psychosis results in delays to access conventional mental health services and initiate treatment, which translates into poor patient outcomes such as longer time to remission of symptoms, higher relapse rates and progression to more severe/chronic phases of psychosis. (2, 29) While commenting on the consequences of low mental health literacy, a psychiatrist and researcher at Mbarara Hospital explained;

> "many of them by the time they come they have been with the illness for a longer time and of course that affects their recovery. Because the longer you stay without seeking care, the longer it takes for you to recover."

A psychiatrist at Butabika Hospital also shared the view that patients are usually taken to hospital only when they develop disruptive symptoms – another indicator for the community lack of awareness about psychosis.

> "usually before someone develops overt psychosis there are what we call prodromal symptoms, most people are not aware of those prodromal symptoms. For patients who present with symptoms which are not so disrupting to others - someone isolates themselves, someone is talking to themselves… people will not see it as something necessary to take someone to the hospital. So by the time they bring out that person their symptoms will be so bad." *[Psychiatrist, Butabika Hospital]*

Another key factor at play in the delay to access mental health services is the alternative explanatory model for psychosis in Uganda. Due to pervasive sociocultural beliefs that attribute the cause of psychosis and other SMIs to witchcraft and evil spirits, patients commonly opt for alternative care provided by traditional and faith healers first and only turn to conventional mental health services as a last resort. (31, 40, 42) These mostly negative beliefs also lead to stigmatisation of mental illnesses, which further prevents timely access to mental health services due to fear of social alienation following diagnosis. (22, 36) The notion of attributing psychosis and other severe mental illnesses to traditional causes was emphatically echoed by all stakeholder categories of the qualitative study. As one psychiatrist at Mbarara Regional Referral Hospital explained,

> "when it comes to mental health care in Uganda and maybe most African countries by the time the patients get to the hospital they have been through a lot, reason being that in Africa people don't believe that you can have a mental health problem. When you have a mental health problem they think something is happening. You are possessed, you are cursed, you are bewitched, a lot of thoughts from the cultural backgrounds. So people first go and seek a lot of alternatives of care"

Beliefs about psychosis and other SMIs are deeply ingrained within local Ugandan culture so that they cannot be simply set aside, but must be accommodated alongside evidence-based policy and services. However, some respondents spoke of the health system's failure to render culturally sensitive services to patients and their families. A psychologist/researcher at Mulago Hospital commented while talking about the disparate perspectives about mental illness that drive patients to seek alternative care;

> "they will continue seeing the faith healers because they speak the same language, they are on the same page, you know this is what she's grown up listening to, so it is, kind of disturbing…. I think it is still going to be hard to come by until the professionals can speak the same language. Speaking the same language doesn't mean that you are going to go traditional, speaking the same language means that you are better at communicating, it means that you speak, you use the language that the caregiver is going to understand"

The failure of the conventional mental health system to provide patient-centred care that is responsive to the sociocultural aspects of mental illness and the lack of collaboration with alternative care providers is a major gap and opportunity for both research and interventions to improve care for patients with psychosis in Uganda. (44)

5.2 Inequitable distribution of mental health services/resources

Inequitable distribution of mental health services between rural and urban areas is yet another barrier to timely access to evidence-based care for psychosis. (14, 22) Mental health resources are skewed towards urban areas and in most cases, are geographically inaccessible to rural residents who must incur high costs and have to travel long distances to access care. (7, 20, 37) In contrast, traditional healers are readily accessible to communities and are perceived as a more favourable care option for severe mental illnesses such as psychosis. (37) Furthermore, the few mental health specialists in Uganda are concentrated at the national and regional referral hospitals, such that majority of the lower level health facilities such as HC II, III and IV lack capacity to adequately manage severe mental illnesses. (7, 19, 37)

Numerous interview respondents emphasized the fact that the inequity of mental health resources between rural and urban settings unfairly disadvantages vulnerable populations in rural areas that are already grappling with poverty and limited access to other social services such as education and better infrastructure that are more accessible to urban residents. This was

most succinctly captured by a psychiatrist and researcher at Mbarara Hospital while commenting on the weighty impact of inequity on patients from rural communities;

> "the other challenge is, the patient coming to the hospital and going back it requires money. Those families are poverty stricken, they just can't afford. They may have to sell a piece of land, that means, you cannot sell land all the time to treat somebody, the land will get finished. Eventually they just give up. They will come once, twice, thrice and then they give up"

5.3 Low capacity for detection and management of mental disorders at primary health care facilities

Mental health services are not well integrated into the primary health care system. Lower level health facilities lack capacity to manage patients with psychosis due to lack of trained mental health specialists and shortage of antipsychotic medications. (19, 50) Over 80% of Uganda's population is rural, with PHC facilities including HC II-IV providing the bulk of health services to the population. (8, 9) However, Uganda has a limited mental health workforce that is concentrated at urban health facilities, leaving generalist PHC workers who are inadequately trained to manage mental disorders, as the first point of contact for patients with mental illnesses in rural areas. (7, 14, 20, 22) For instance, a 2014 situational analysis of mental health services in a rural district in Eastern Uganda with a population of 750,000 found only two specialist mental health workers; a psychiatric clinical officer and psychiatric nurse. The study also unveiled the district-wide absence of inpatient mental health services and psychosocial interventions and the very limited mental health care at PHC level mainly involving identification and referral of patients with severe mental illness. (19)

Respondents from the lower level health facilities reported that they rely on the basic mental health knowledge acquired during their primary training and do not receive subsequent training and supervision from mental health specialists to enable them manage severe mental illnesses such as psychosis. Additionally, there was unanimous agreement among the interviewed mental health specialists that there is a poor attitude towards mental illnesses and stigmatisation of psychosis by general health workers at public lower level facilities and private hospitals that negatively impacts on the management of mental illnesses in those settings. A psychiatrist at Mulago Hospital explained;

> "Health workers have stigma attached to mental health, many people don't want to associate with them, many of them don't want to manage them, many are scared that they may become violent and they will hurt me, so it is surprising but many health workers don't want to care for these people"

Similarly, while commenting on the reluctance of private hospitals to care for persons with psychosis, another hospital-based psychiatrist and researcher remarked;

> "They will allow to keep depressed patients, anxiety patients, substance use patients but they will never ever allow to keep the psychotic patients. I think it an issue of perception and that goes back to stigma… the moment you have a psychotic disorder and you move into a private facility, they sedate you and refer you."

As discussed in subsection 4.1, the lack of skills/capabilities among general health workers across the health system highlights the gaps in early detection and appropriate management of psychosis in Uganda. This was a major finding from both the literature review and qualitative studies. In fact, service users are aware of the gaps in mental health services at PHC facilities, which results in direct 'self-referral' to specialist mental health services especially the National Referral Mental Hospital. (30)

5.4 Unreliable supply of psychotropic drugs

Psychotropic drug stock-outs are common at Uganda's health facilities including at district and specialist/referral hospitals. (8) A situational analysis (19) and two case studies (14, 20) conducted across different regions in the country, all reported erratic supply of psychotropic medication. Comments about the unreliable supply of antipsychotic medications were ubiquitous across all stakeholder categories of the qualitative study. Drug stock-outs were reported to be more rampant at lower level facilities although respondents from regional and national referral hospitals also reported unreliable drug supply as a major barrier to adequate management of persons with psychosis.

> "You find that they supply drugs but there are no anti psychotics or if they are there, they are very few or if they are there most of them are lacking" *[nurse, HC III]*

> "The medicines are usually there, but it's not regular, it is normal for you to go to Mulago and you don't even find medicines for a week plus, when you are lucky, you will find haloperidol, you will find stelazine, you will find chlorpromazine, but you will find most of the times those medicines are out of stock." *[Psychiatrist/researcher]*

Clinicians reported that due to drug stock-outs, they are forced to alter patient treatment in line with available drugs or ask patients to buy drugs from private pharmacies, which constrains adherence to treatment as majority of patients cannot afford to buy drugs. Secondly, there is a limited range of drugs available for management of psychosis, which hinders clinicians from adjusting pharmacotherapy to suit patient needs. For instance, one psychiatrist at Mbarara Hospital explained;

> "we rely more on the old medications, they call them, first generation, typical anti psychotics, which are good, they also work but then there are certain patients where they don't work, where they need second generation and then you don't have, or they needed to use long acting it is easier for compliance to the patient but then they are not available and then the patients cannot afford."

5.5 Lack of holistic patient care

Essential psychosocial interventions such as Cognitive Behavioural Therapy (CBT), patient/family psycho-education and occupational therapy are either absent or minimally provided to persons with mental illnesses at the majority of health facilities in Uganda including the National Referral Mental Hospital. (7, 35) In addition, community-based mental health services to ensure early detection of psychosis and linkage to care, continuity of care post-discharge from mental health units and reintegration of patients into their families and communities, are not part of mainstream psychosis care in Uganda. (22) This stems from the limited funding allotted to mental health care (22, 51) and an inadequate multi-disciplinary workforce to provide holistic patient care. (19) Consequently, services for psychosis are in a sense operating in a type of crisis management model, dealing with mostly severe illnesses that present late to under resourced health facilities. A holistic approach to health care for psychosis within an integrated model remains out of the reach of the majority of patients and families affected by psychosis. Interview respondents frequently expressed the belief that available funding and human resources for mental health are too inadequate to cater for the psychosocial needs of persons with psychosis.

> "Then we are supposed also to go for outreach to go to near where they live and we are supposed to be meeting them but also those outreaches they are not sponsored by government you find that they are just initiated on those well-wishers and those charities and what like churches and what. So we find also that sometimes they are also not reliable…" *[Hospital based Nurse]*

> "when it comes to psychosocial care, when you look at the ratio of the psychologists we have and the patients we have really it is so, so, big. Not every patient will get psychosocial services as we require them to get. So we find that, we know the ideal what is required of them but because of so many constraints they end up not getting the ideal." *[Hospital based Psychiatrist and researcher]*

The fragmented mental health care provided to persons with psychosis is ill-equipped to promote patient wellbeing and functional recovery. (7) This was clearly articulated by a hospital based clinical psychologist/researcher;

> "very commonly patients with psychosis will not access psychosocial interventions, they will get the psychiatric care and that's it and yet you realise that there is such a big need, a dire need to have the care givers on board, to even have the patients on board… even when you are giving the medicines in psychosis, in schizophrenia there are those residual symptoms that will not go even when you administer whichever drug, and they are just resistant to treatment but if we had psychosocial services that are adequate, we can actually teach the patient to live with the residual symptoms and we can do behavioural modifications and you know they will stop being bothered by these problems and they will be able to move on…"

5.6 Absence of rehabilitation /post admission recovery services

The absence of mainstream rehabilitation services to help persons with psychosis and other mental illnesses to reintegrate as active participants into their communities following discharge from hospital remains a major gap in mental health services for psychosis in Uganda. (22) In response to the lack of community-based mental health care, some programs have been implemented or trailed to inform potential scale up of services for persons with mental illnesses. (See Table 5) However, evidence from the literature indicates that program sustainability is often limited by inadequate resources including government funding and allied health workers to deliver community-based mental health care. (14, 20)

Multiple interview respondents also identified inadequate funding and human resources as key barriers to community follow-up of persons with psychosis after discharge from hospital.

> "There is no other team that follows up patients after discharge, the Butabika community recovery team is not well facilitated to carry out follow up visits" *[Hospital based PCO]*

> "…because of the funding and the nature of the work and the nature of staff that we have, we are not able to follow up cases in communities" *[Hospital based PCO]*

Box 1: A note on rural versus urban challenges

Some of the gaps in mental health services for psychosis are more pronounced in rural settings.

- **Access to mental health services/inequitable distribution**: as previously highlighted, the concentration of mental health services in urban areas limits access to psychosis care by rural residents. Patients in rural areas are thus more likely to consult traditional healers that are within their communities.
- **Mental health literacy**: rural communities are less likely to be aware about psychosis and available mental health services than their urban counterparts who live in closer proximity to services.
- **Socioeconomic challenges**: patients from rural areas tend to be more economically disadvantaged and less likely to afford transport costs to mental health services or drug purchases in case of stock-outs at public hospitals.
- **Integration of mental health services into PHC**: although most lower level facilities lack capacity to manage psychosis, PHC facilities in rural areas are especially ill-equipped due to shortage of trained mental health specialists and psychotropic drugs

Source: qualitative interviews.

Figure 3: Rural versus urban challenges in the management of psychosis in Uganda

5.7 Gaps in psychosis research

Literature on the current state of mental health services for psychosis in Uganda is scarce. This may be due to the absence of specialised clinics for psychosis at both PHC level and national referral hospitals. (35) Secondly, much of the retrieved literature focussed on the key challenges of scarcity and inequity of mental health resources/services and not on available services per se. (7, 19, 30, 31, 36, 37, 41) Available studies are also limited in terms of rigor and design. For instance, in this literature review, there are no longitudinal studies providing evidence on patient management through the course of illness from diagnosis to functional recovery. Indeed, much of the data characterising the patient pathway along the continuum of care for psychosis from early detection to functional recovery was obtained from KIIs.

Researchers highlighted the near absence of research about psychosis. For instance, a researcher from Makerere University remarked;

> "whatever you think of in psychosis has not been done, whether it is neuroscience, clinical psychiatry, psychosocial care, health system, health financing..."

Some researchers attributed the lack of research on primary psychosis to the impracticality of focusing on psychosis as a single diagnosis in Uganda yet it commonly presents alongside other co-morbidities such as HIV and substance use disorders. A psychiatrist and researcher at Mbarara Hospital explained thus;

> "I must say no research has focused on psychosis per se we all tend to do research that is cross cutting. Probably I am looking at HIV and psychosis maybe I am looking at schizophrenia and substance use. So no one is really focusing on primary psychosis we are all looking at cross cutting challenges like say you have psychosis and then you have substance use disorders how does that affect your recovery and your long term outcome and things like that."

Accordingly, researchers explained that much of the available mental health research has focused on clusters of mental illnesses and how to improve their care.

> "I am not going to separate and say I am focusing on schizophrenia, I am really focusing that I have these people and they all need care. It has never crossed my mind that I am going to study schizophrenia in isolation. I am looking at all people with mental health problems." *[Psychiatrist, Mbarara Hospital]*

> "Studies have been done but most have been epidemiological not intervention. Most studies have considered clusters, there are few that considered specific disorders." *[Clinical Psychologist and researcher, Butabika Hospital]*

Other reasons that were cited by respondents for the scarcity of psychosis research were inadequate funding and prioritisation of the more prevalent mental disorders such as depression and anxiety.

Key research gaps that were identified by respondents include,

1. Disease profiling to understand key correlates of psychosis including presenting features, common organic causes and co-morbidities in the Ugandan setting as articulated by a psychiatrist and researcher at Mulago Hospital;

   > "Psychosis is not the same across the world, actually there are a number of studies that show that the clinical presentation of psychosis may differ, their expression of symptoms, their perception, but also response to medications may differ because of genetic factors and many other things, so the research should initially first focus on simply just typing those clinical features and then the explanatory models of psychosis"

   A psychiatrist and researcher at Mbarara Hospital also recommended;

   > "if we can do a profile of the common organic causes of psychosis because they are more treatable…. when we are treating patients we have it at the back of our mind and say in Uganda for any patient who has first time psychosis we need to test for HIV first before we do anything else."

2. Intervention studies to understand the efficacy of pharmacological and psychosocial therapies for persons with psychosis in Uganda. Respondents agreed that there is need to investigate which drugs are most efficacious in our setting instead of overly relying on literature from the Western countries.

   > "I think we use a lot of drugs that are used elsewhere but we don't know which drugs are more effective in our group of patients" *[Psychiatrist and researcher, Butabika Hospital]*

   > "we still have very limited research in the area of non-pharmacological treatment, I think there is a need for research in that area of non-pharmacological treatment of psychosis" *[Researcher and psychiatrist, Mulago Hospital]*

3. Community engagement studies to investigate the level of mental health literacy, increase awareness about psychosis and reduce stigma. There were ubiquitous calls for community-based research to understand explanatory models for psychosis, develop

and evaluate interventions to increase mental health literacy and improve community-based mental health care.

> "first of all, we should focus on the challenges in the general population which hinder them to access mental health services and then we also we need to go to the community and investigate how much they know about mental illness." *[Psychiatrist, Butabika Hospital]*

> "we need to understand, how can you help the community to manage psychosis either in terms of support and things like that which is culturally acceptable so that when we take patients back home, we also utilize what they would want to do to help the patient." *[Psychiatrist and researcher, Mbarara Hospital]*

SECTION 6: FUTURE RESEARCH OPPORTUNITIES TO ADDRESS KEY GAPS IN THE CARE PATHWAY FOR PERSONS WITH PSYCHOSIS IN UGANDA

Future research opportunities that are identified in this section are premised on major findings from the literature review and KIIs.

1. ***Early detection and diagnosis of psychosis requires a) a social determinant of mental health approach and b) culturally appropriate, evidence-based and meaningful collaboration between alternative and conventional care providers.***

   A more in-depth understanding of the care pathway is necessary to inform interventions for early detection and diagnosis of psychosis in Uganda. Alternative care (traditional and faith healers) remains the preferred first choice of care for the majority of persons affected by primary and other forms of psychosis versus conventional care. The cultural, socioeconomic and health reasons for this pattern of help seeking behaviour demands further study to understand a) local/cultural understanding of psychosis and related disorders, b) alternative care practices that can allow for early detection of psychotic symptoms and c) collaboration with conventional care to facilitate formal referral or shared care pathways. (7, 14, 20)

   Specific to conventional care, it would be worthwhile to profile the symptoms/different presentations of psychosis in the Uganda context, beyond textbook definitions, to inform early intervention protocols on detection and diagnosis of psychosis by community, primary and specialist mental health workers. There is need for more genetic, ethnographic, case review and case control studies to understand local predisposing, precipitating and protective factors for psychosis.

   A key determinant in making a diagnosis of psychosis in the Uganda context is the skill set of the health worker; in this regard, the question of what are the most effective methods of imparting diagnostic skills to non-specialist health workers remains. To address the lack of mental health specialists in low resourced health systems like Uganda's, the global evidence recommends integration of mental health services into primary health care. (52, 53) In Uganda, different implementation research initiatives including PRIME, mhBEF, etc., have studied the integration of mental health services in primary care through training of non-specialist workers (54) however, a persisting gap is the divide between knowledge transfer and actual health worker diagnostic and treatment skills after training. (55)

   This calls for a different approach to training and/or skill transfer within the paradigm of task sharing in the management of psychosis. Competency based approaches to training have shown good outcomes (56) and research on how these approaches can improve diagnosis of psychosis within the health system in Uganda should be undertaken.

   In addition, telemedicine and other technological interventions have been advocated as novel interventions to increase supervision of primary and community health workers by specialist mental health professionals in the management of severe mental illnesses (39) but evidence for their feasibility and cost effectiveness, specifically for psychosis in the Uganda context, is not well established.

Another area for further research is how conventional/mainstream health services can be more culturally responsive/attuned to facilitate early diagnosis of psychosis. (44) Findings from our study highlighted the low mental health literacy/awareness that impacts on early detection of psychosis, and help seeking behaviour at primary health facilities. This also speaks to the need for mainstream health services to adapt culturally sensitive messages /communication in raising community awareness and reducing stigma associated with psychosis and other mental disorders.

Whereas all the above research opportunities have a focus on early detection and diagnosis of 'prodromal or early' symptoms of psychosis, there remains a gap in access to care and treatment for persons with chronic Schizophrenia whose debilitating symptoms make them homeless and vulnerable to a range of human rights violations. Context specific research should be undertaken to determine how best to improve access and keep this category of patients in care, and support their recovery/rehabilitation.

2. *A holistic (bio-psychosocial-cultural) model of care is required to improve outcomes of persons and families affected by psychosis.*

Current treatment for psychosis in Uganda is predominantly biomedical in approach, with limited psychosocial interventions across the continuum of care. A major reason for seeking conventional care in Uganda is access to pharmacotherapy given the chronic nature of psychotic disorders and treatment recommendations for long term use of medicines.

The psychotropic medicines supply chain management in Uganda requires increased efficiency leading to improved treatment outcomes for patients and families affected by psychosis. There is need for health services research to determine how a cost-effective and sustainable mental health medicines supply chain can be instituted. In line with pharmacological treatment options, there is also need for research on treatment outcomes for patients receiving first generation versus second generation antipsychotics and, those receiving conventional and/or alternate treatment regimens.

Determining what psychosocial services are feasible, acceptable, appropriate and (cost) effective for individuals and their families affected by psychosis will go a long way in filling a major treatment gap for psychosis. This should also include research questions on what psychosocial interventions are effective at facility level and at community level, to support recovery of patients and families affected by psychosis.

3. *A health systems approach is required to conduct research and improve services for Psychosis (and other SMIs) in Uganda.*

Uganda's (mental) health system remains grossly under resourced with a lack of basic health care, let alone mental health care and services for patients with psychosis. In addition, the available human resources for health care, with few mental health specialists, means that 1) primary psychosis cannot be easily delineated from other psychotic disorders, and 2) psychotic disorders cannot routinely be handled separate from other SMIs within an integrated system approach. Therefore, addressing the health service needs for patients with psychosis has to be in tandem with mental health service needs across the spectrum of mental, neurological and substance use disorders (MNS)

disorders, and other health conditions. For instance, the impact of current COVID-19 pandemic on persons living with psychosis and other SMI in Uganda is increased rates of relapse. (57)

This calls for a multi-sectoral agenda that involves different government sectors including health, gender, justice, finance, security, education and local government, and the private sector. Such an agenda should also have a socio-development perspective that allows the following key questions to be answered:

a) What collaborative care model for psychosis care is effective and sustainable within the health and socio-cultural system in Uganda?

b) How can mental health services for psychosis be mainstreamed into government service delivery beyond policy and legislative documents?

c) What interventions for early detection and referral are appropriate, feasible and effective at community level, including schools and religious/cultural institutions?

d) Which mobile applications and digital technologies are feasible and cost-effective in improving screening, detection, diagnosis and monitoring of patients with psychosis and, in the delivery of psychosocial interventions following discharge from hospital/facility-based care?

e) What is the current and future impact of COVID-19 on individual mental health and the attendant (mental) health care services?

CONCLUSION

This study shows that psychosis in Uganda, particularly primary psychosis is in need of much attention from the mental health research and health systems fields.

High stigma associated with psychosis in Uganda, is devastating to individuals, families, and local communities. And stigma is a major barrier for health-support seeking behaviour for people and families who fear discrimination and ostracism by their village community. Poorly defined pathways to care for people with psychosis in Uganda add to the barriers to a fulfilling and meaningful life for the individual and their family.

Although one can make the same argument for other mental illnesses, consensus from the collated evidence and key stakeholder perspectives highlights major gaps specific to services for psychosis including: a lack of awareness about psychosis and available mental health services across different strata of the population, a fragmented health system with a biomedical bias, scarcity and inequity of mental health resources and a lack of cultural sensitivity in mainstream health services. The cultural context for psychosis in Uganda, must be clearly understood and analysed in future research. The integration of alternative care, through traditional and faith healers, in culture and community life is pervasive. This requires significant reflection as to what dynamics are occurring in this particular pathway of care for psychosis in Uganda, that can be of assistance in the further development of evidence-based models of psychosis care.

A human rights and person-centered response, within an integrated health system is extremely important in order to improve the care of people with psychosis. Notably, study findings reveal that Uganda has local mental health expertise, albeit in small numbers, with keen insights and understanding of how the health and social care of people with psychosis can be improved. This creates the necessary platform on which to implement the recommended actions vis a vis delivery of evidence based mental health services for persons affected by psychosis in Uganda

Psychosis is a very important area for future research. Biomedical, social determinants, human rights, stigma, cultural determinants and practices, and health systems and integrative services, are all crucial areas for the research community. And above all, recognizing the autonomy and the ‘voice’ of persons with psychosis, in the development and implementation of their health plan, must be at the center of future mental health services for people with psychosis in Uganda.

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APPENDICES

Appendix 1: Document review guide for program and research reports

ITEM	DATA
Key stakeholders with interest in psychosis	
Assessment process of patients with psychosis including early detection and diagnosis	
Current treatment and care practices for patients with psychosis in Uganda	
Diagnostic and treatment challenges of psychosis in Uganda	
Health system gaps in psychosis management	
Opportunities for improvement of mental health services for psychosis	

Appendix 2: Interview guide for policy makers at Ministry of Health

Mental health services for patients with psychosis

1. How would you describe the current models of care for patients with psychosis in Uganda from diagnosis to recovery?
2. What challenges are experienced by patients in accessing early diagnosis and treatment for psychosis in Uganda?
3. What challenges do clinicians face in early detection, diagnosis and treatment of patients with psychosis?
4. What are the differences in these challenges between rural and urban settings?
5. What policies and guidelines are in place to guide the management of patients with psychosis in Uganda?
6. To what extent are mental health policies, other health policies and guidelines integrated into current management practices of patients with psychosis?

Recommendations

1. Who are the key opinion leaders and stakeholders with interest in psychosis?
2. What recommendations do you have for new technologies and interventions for detection, diagnosis, treatment and monitoring of patients with psychosis?

Appendix 3: Interview guide for researchers

Mental health services for psychosis

1. How would you describe the current models of care for patients with psychosis in Uganda from diagnosis to recovery?
2. What challenges are experienced by patients in achieving early diagnosis and functional recovery from psychosis?
3. What challenges are experienced by clinicians and the health system in achieving early diagnosis and recovery from psychosis?
4. How do the above challenges differ between rural and urban settings?

Systems-focused research

1. What current research programs are you engaged in or aware of that are focused on diagnosis and/or treatment of psychosis in Uganda?
2. What are the key gaps for research initiatives needed to improve management of psychosis in Uganda?

Recommendations

1. Who are the key opinion leaders and stakeholders with interest in the management of psychosis in Uganda?
2. What are the specific gaps in the health system where new technologies or interventions could be useful in detection, diagnosis, treatment and monitoring of patients with psychosis?

Appendix 4: Interview guide for health workers

Management of psychosis

1. What is the capacity of health workers at this facility to detect and diagnose psychosis?
2. What services are available at this facility for early detection and diagnosis of psychosis?
3. What treatments, if any, are available for management of psychosis at this health facility?
4. What services are available for follow up and rehabilitation of patients with psychosis that are discharged from your care into the community?
5. Where do you commonly refer patients with psychosis?

Challenges in the management of psychosis

1. What challenges do patients experience in obtaining early diagnosis and accessing care for psychosis?
2. What are the differences in the diagnosis and treatment of patients with psychosis in rural and urban settings?
3. What challenges do clinicians experience in making an early diagnosis and providing treatment for patients with psychosis? ensuring early diagnosis and functional recovery for patients with psychosis?
4. What current research programs if any, are being conducted at this health facility on psychosis and its management?

Recommendations

1. To what extent do primary health care providers receive training and other technical support for management and referral of patients with psychosis?
2. What are your recommendations for new interventions or technologies that could be useful in diagnosis, treatment and monitoring of patients with psychosis?

Appendix 5: Interview guide for alternative care providers

Mental health services for psychosis

1. What services do you and similar practitioners provide to patients who present with psychosis?
2. What challenges are faced by patients with psychosis in accessing treatment?
3. What reasons do patients commonly cite for not utilising conventional mental health services for psychosis?
4. To what extent do you interact with conventional mental health care providers to treat, refer and follow up patients with psychosis?
5. What are your recommendations for improving care for people with psychosis in Uganda?

Appendix 6: Characteristics of research studies included in the published literature review

Author, year (site)	Study design	Objective	Participants and data collection methods	Key themes	Analysis of results/ Main findings
Mwesiga et al, 2019	Mixed methods study protocol	To determine the prevalence and factors associated with DUP & ACT use in Uganda.	18-60 yr olds presenting with FEP at Butabika Hospital	A proposed research study to overcome treatment challenges of psychosis in Uganda	The goal of the authors is to close the research gap for factors underpinning the long DUP in SSA and thus facilitate development of effective interventions aimed at reducing DUP and ensuring better patient outcomes in Uganda.
Rukat et al, 2014 (Mulago and Butabika National Referral Hospitals)	Cross-sectional quantitative survey	To describe the prescription patterns of hospitalised patients with psychosis.	All inpatients at the two referral hospitals were included in the study. Data were collected on one day in march 2012. The patients were grouped in one of 4 categories: schizophrenia, bipolar, depression and unspecified psychosis.	Models of care for patients with psychosis: pharmacological management.	**Psychosis management**: First generation antipsychotics including chlorpromazine, Haldol, trifluoperazine and fluphenazine are the treatment of choice for nearly 90% of patients diagnosed with psychosis. Others include carbamazepine and antidepressant. 64.8% of all patients were treated for psychosis, 25.7% had schizophrenia
Sessions et, 2017 (Bwindi)	Qualitative study	To evaluate perceptions of mental health stakeholders about the benefits and challenges of developing a community based mental health programme	13 semi-structured interviews and 6 FGDs were carried out with community members and other mental health stakeholders.	Challenges experienced by patients in accessing care for mental illness including early diagnosis, treatment, rehabilitation and community integration.	**Barriers to access of mental health services**: stigma, low mental health literacy. **Barriers to community-based care for patients with mental illness**: high implementation costs, inadequate human resource, community preference for institutionalisation of patients with mental illness.
Bailey J, 2014	Literature review	To identify challenges of development and delivery of improved mental health services in Uganda.	This is a narrative literature review presenting the main issues impacting on delivery of adequate and quality mental health services. Published and grey literature was reviewed.	Challenges faced by patients, clinicians and health systems in achieving early diagnosis and treatment of mental illness. Gaps and opportunities for improvement of mental health services. Inequitable distribution of mental health services between urban and rural settings.	**Identified challenges**: limited numbers of trained health workers, pervasive stigma in the community and within the health care system, low mental health literacy, lack of services in rural areas. **Opportunities for improvement of mental health service**s: situating psychiatry training institutions in rural areas, establishing and strengthening collaboration between all stakeholders including health providers, communities and allied health workers to reduce stigma and provide holistic care to patients.
Baingana et al, 2011 (Gulu, Kitgum & Pader Districts)	Qualitative evaluation study	To evaluate a programme developed to integrate mental health services into PHC in war-affected communities of	Review of project documents and qualitative methods of observation, key informant interviews and FGDs with patients, project administrators and village health teams were conducted to evaluate the	Opportunities to improve early detection of mental illness and access to mental health services. Gaps in available mental health services	**Identified barriers to care**: inequitable distribution of mental health services, lack of drugs for patients with mental illness, low mental health literacy within the community. **Opportunities for service improvement**: build capacity for increased detection and treatment of

		Northern Uganda.	successes and challenges of the programme.	Barriers to accessing mental health services	mental illnesses at both the community and PHC levels, strengthen working relations between government and NGOs, increase availability of mental health drugs.
Byaruhanga et al, 2008 (rural South-western Uganda: Mbarara District)	Case study	To describe the delivery and challenges of a mental health outreach programme in rural Mbarara	The program lasted three years 2002-4. It included capacity building of rural primary health care workers to detect, diagnose and manage common mental disorders, training of community health workers and community/public sensitisation about mental illnesses.	Gaps in mental health services Opportunities for improvement of mental health services Challenges faced by patients and health care systems in delivery of mental health services.	**Challenges**: inequitable distribution of mental health services between urban and rural areas, poor community understanding of mental illness and where to seek treatment, inadequate/unreliable psychotropic drug supply **Gaps**: low capacity to detect and manage mental disorders in rural primary health facilities, mental health services are not well integrated into PHC, few mental health specialists, no continuity of care of patients with mental disorders in the community. **Opportunities for service improvement**: decentralise mental health services and integrate them into PHC through ongoing training and supervision of primary health workers, establish community-based care through increased sensitisation and training of community health workers to identify, refer and follow up patients in the community, collaboration with alternative care providers, NGOs to facilitate holistic patient management and increase early detection and diagnosis of mental illnesses.
Cooper et al, 2010 (one central metropolitan district and a rural district in Eastern Uganda)	Mixed method (quantitative and qualitative)	To analyse Uganda's mental health system through a human rights lens.	Surveys/questionnaires given to several respondents at universities, MOH and NGOs. Qualitative study: Interviews, FGDs conducted with service users, health workers and other stakeholders.	Gaps in available mental health services	**Gaps**: inequitable distribution of mental health services, poor quality mental health services due to inadequate resources, overemphasis on curative/biomedical therapy with no provision for psychosocial support and rehabilitation services, Lack of multisector collaboration to address social determinants of mental health and enable functional recovery of patients
Kisa et al, 2016 (Uganda: Lira District, Nepal and Liberia)	Qualitative study	To assess pathways to care for patients with severe mental illness.	6 in-depth interviews, 27 FGDs and 77 key informant interviews with health workers, service users, care takers and policy makers were conducted across the three countries.	Available health care services for patients with severe mental disorders. Challenges faced by patients in accessing care for severe mental illness	**Access to care**: In Uganda, traditional healers come second to hospitals as a care option for patients with severe mental illness. others include witch doctors and places of worship. **Challenges**: (systemic, familial, community and individual)lack of drugs and mental health specialists, negative attitudes of health workers towards mental illness, family and community barriers, overcrowding at health facilities, better rates and services provided by traditional healers, lack of social support and patient follow up, geographical inaccessibility to mental health services.
Chidarikire et al, 2018 (SSA)	Adapted realist review approach	To identify available treatment and interventions for	Databases searched; 40 studies were identified to describe available interventions for	Current models of care for psychosis	**Available treatments:** antipsychotics, ECT and psychosocial interventions mostly provided at large urban facilities.

		patients with schizophrenia in SSA	schizophrenia in SSA, two of which were from Uganda.	Gaps in mental health services for psychosis	**Gaps**: inequitable distribution of services with most found at large urban centers, lack trained personnel, over reliance on alternative care providers, lack of drugs and other therapies for schizophrenia.
Mwesiga et al, 2020 (Butabika Hospital)	Cross-sectional study	To assess the quality of individual and group level interventions for first episode psychosis at Butabika Hospital.	Retrospective chart reviews of patients managed for first episode psychosis between January 2018 and January 2019 were performed to identify quality of essential components of psychosis treatment.	Models of care for patients with psychosis in Uganda Gaps in mental health services for psychosis	**Available care**: Essential evidence-based services for FEP are available at Butabika Hospital including antipsychotic treatment, individual and family psychoeducation, employment support, and patient monitoring but are of low quality and not always provided to patients **Gaps**: erratic provision of evidence-based mental health services for FEP, inadequate human resource to provide holistic patient care, lack of funding to institute all essential elements of care for FEP, no specialised clinic for psychosis at the facility
Nsereko et al 2011 (Nationwide)	Qualitative study	To examine help-seeking behaviour and associated factors among patients with mental illness	Conducted interviews with stakeholders from health, education, law and justice, gender and social welfare departments, politicians, media and NGOS. FGDs were conducted with nurses and teachers from a mix of rural and urban districts.	Challenges faced by patients in achieving early diagnosis and functional recovery from mental illness. Differences in challenges between rural and urban settings.	**Challenges**: Sociocultural beliefs influence help-seeking behaviour such that patients with mental illness are more likely to consult traditional healers first and only turn to health facilities as a last resort, high cost and inaccessibility of mental health services, tendency to bypass PHC services in favour of regional and national referral facilities, lack of public awareness about available mental health services.
Patel 2016	Literature review	To discuss the barriers and interventions for scaling up of essential services for schizophrenia in LMICs	N/A	Gaps and opportunities for improvement of mental health services for primary psychosis	**Opportunities for service improvement**: adopt a collaborative care model to increase access to evidence-based management of schizophrenia including both antipsychotic medications and psychosocial interventions. Empower PHC providers and community workers to deliver mental health services. Increase supervision of lower level health and community workers by psychiatrists through telemedicine and other technological advancements, political commitment to increasing finances and to achieving progressive increase in service coverage with respect to range of services and area of coverage.
Hanlon et al, 2014 (Uganda: Kamuli District, Ethiopia, India, Nepal, South Africa)	Cross-sectional situational analysis	To compare context, challenges and opportunities for integration of mental health services into primary health care in 5 LMICS (South Africa, India, Ethiopia, Uganda and Nepal)	Data obtained from health facilities, surveillance data, research publications, government and NGO reports and communication with service coordinators	Gaps in mental health services at District level.	**Gaps:** inadequate mental health workforce including trained specialists and other multi-disciplinary workers such as social workers, psychologists, unreliable supply of psychotropic medications, PHC workers inadequately trained to manage mental illnesses.

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