Health Practitioners’ Perspectives of Treatment of Psychosis in Rwanda: An Exploratory Study

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Abstract/Summary

According to the WHO, over 50% of individuals suffering from schizophrenia and psychosis do not receive the appropriate care for their illness (2014). This study explored the treatment options for psychosis in Rwanda, from the perspective of health care practitioners. To date, there is no existing literature examining this topic available to the public. Twenty-four semi-structured interviews of health care workers all over Rwanda found that while practitioners are well trained and passionate, they lack the human resources and access to adequate treatment options. Psychosis in Rwanda, community understandings, mental health training and treatment options are discussed to create an understanding of the treatment of individuals with psychosis in Rwanda. While this paper opens up dialogue and understanding into the treatment for patients with psychosis in Rwanda, more research is essential to understanding different perspectives and the implications of these findings.
List of Abbreviations and Defining Terms

FGAs - First Generation Antipsychotics
GoR – Government of Rwanda
HICs – High Income Countries
ICD-10 – International
LMICs – Low and Middle Income Countries
MoH – Ministry of Health
PTSD – Post Traumatic Stress Disorder
SGAs - Second Generation Antipsychotics
WHO – World Health Organization

Psychosis: A symptom of psychotic disorders, often presenting as hallucinations or delusions (HSE, 2015).

Hallucination: False perceptions of sensory experiences such hearing, seeing or feeling something that is not there (HSE, 2015).

Delusion: Irrational or untrue beliefs held despite contradictory evidence, and confusion of thought (APA, 2015; HSW, 2015).

Psychotic Disorders: Severe mental health disorders characterized by lack of understanding of reality (APA, 2015). This classification is no longer used in the DSM.

Schizophrenia: A severe mental health disorder characterized by hallucinations, delusions and lack of insight (WHO, 2014).

Psychotropic medication: Medication used to reduce psychotic symptoms.

Insight: The ability to determine the difference between what is symptom and what is reality

Stigma: ‘The negative reaction of people to an individual or group because of some assumed inferiority or source of difference’ (APA, 2015). Culturally known as Akato or Kutisanzura

Positive Symptoms: Symptoms that add to the person’s behavior such as hallucinations or delusions.

Negative Symptoms: Symptoms that reduce one’s personality such as withdrawal, depression, lack of motivation, lack of personal hygiene.
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Introduction
Individuals suffering from psychosis or psychotic illnesses are up to 2.5 times more likely to experience premature death than the general public (WHO, 2014). According to the WHO, over 50% of individuals suffering from schizophrenia and psychosis do not receive the appropriate care for their illness (2014). This lack of treatment or mistreatment increases the likelihood of human rights violations towards those individuals, often due to stigma or lack of understanding (WHO, 2014). Services and treatment of psychosis and psychotic disorders can be difficult to obtain in many areas of the world, and low and middle income countries (LMICs) present with unique and significant barriers. Lack of services, personnel, access and decentralization can all hinder an individual from receiving a diagnosis and treatment. On top of difficulty of access, stigma can play a large role in the experience of individuals with psychosis, as they are at extreme risk as their symptoms can impact the lives of others and can be difficult to understand.

Psychosis, is a symptom or cluster of symptoms which typically refer to decreased functioning and changes in personality which include an impaired of understanding of reality (CAMH, 2015). Psychosis is often the initial diagnosis for an individual exhibiting symptoms such as hallucinations and delusions, while a more advanced diagnosis is being made. On average, men present with psychosis at an earlier age than women, and women typically respond more positively to medication and treatment (CAMH, 2015). The prevalence of psychotic symptoms in the world is between 5%-8% (Kellher, Jenner & Cannon, 2010), while the prevalence of psychotic disorders is around 3.5% (Peral et al., 2007). The most commonly recognized and frequently studied around the world is schizophrenia, which was the common label found in the literature review for this project. Schizophrenia, with a prevalence rate of 0.12% - 1.6% (Peral et al., 2007; CAMH, 2015) is a severe chronic and debilitating mental illness that affects more than 21 million people across the world (WHO, 2014; Olwit, Musisi, Leshabari & Sanyu, 2015; Brooke-Summer et al., 2015). Schizophrenia is associated with changes in personality and perception, frequent relapse, decreased social and occupational functioning and low economic attainment (Olwit et al., 2015; WHO, 2014). The term psychosis will be the predominant label is used for this project due to the changing understanding and belief of these types of symptoms around the world.

Aims of the Study
While considerable research is conducted in Rwanda on mental health status, the treatment of psychosis, if studied, has never been published for public education and consumption. This study examined health care practitioner’s perspectives on treatment of psychosis in Rwanda by beginning with the question: What is the typical treatment for people with psychosis in Rwanda? The understanding, labeling, education and treatment procedures for psychosis will be explored to obtain a culturally relevant understanding of psychosis in Rwanda. Given the lack of existing available and comparable studies on psychosis in Rwanda, this study aimed to build a baseline of information.

Literature Review
Psychosis Overview
Symptoms
Psychosis can broadly be described as lacking the ability to conceptualize reality, with a specific difficulty with spatial and time awareness. Symptoms of psychosis can differ depending on the individual, the circumstances, the reason for psychosis and the illness associated with it. Psychotic symptoms can impact all aspects of an individual’s wellbeing and
functioning, including their thoughts, emotions, communication, awareness and behaviour (WHO, 2016). Symptoms of psychosis can be separated into two categories, positive symptoms and negative symptoms. Positive symptoms can be understood as symptoms that add something to one’s personality or state of being. Positive symptoms include hallucinations, delusions and disorganized speech. Negative symptoms typically remove or reduce from the individual’s personality and being, including catatonic behaviour, reduced energy and motivation, isolation and slowed movement. While psychosis is not an independent diagnosis, it is a cluster of symptoms that are identified in a number of different illnesses including schizophrenia, schizoaffective disorder, bipolar disorder and sometimes depression. Separately from these mental illnesses related to psychosis, these symptoms can also be substance induced or caused by pre-existing physical conditions.

Depending on the culture, these symptoms may also indicate alternative illnesses or have other identified causes. While psychotic symptoms in Kazakhstan may indicate one’s journey to becoming a Shaman (Penkala-Gawecka, 2013), in Ghana the same symptoms are caused by an invasion of evil spirits or supernatural powers needing the help only of traditional healers (Ae-Ngibise, 2010), and in Islamic cultures symptoms of mental illness are understood as the outcome of a weak relationship with God (Angermeyer et al., 2015). While presenting with similar symptoms as found in Western cultures, the understanding, diagnosis and treatment of these symptoms differ across the world.

**Diagnosis**

In Western medical facilities, two distinct nosologies are used to diagnose an individual with any mental illness. In North America, the common tool is the Diagnostical Statistical Manual V (DSM V), published by the American Psychological Association (APA). In Europe, the common diagnostic tool is the ICD-10 published by the World Health Organization (WHO). For both diagnostic manuals, it must be determined that the symptoms are not due to any physical condition or ingested substance or chemical (ICD-10, 2015; DSM-V, 2015). These tools outline strict criteria of symptoms, severity and length of disturbances necessary to decipher the appropriate mental health diagnosis. Both the DSM-V and the ICD-10 are quite similar in symptomology and diagnostic criteria for different psychotic disorders (First, 2007). Both criteria systems require at least one month duration of symptoms to initiate a diagnosis (First, 2007).

Treatment recommended for psychotic illnesses are not listed in the DSM-V, however much research has been conducted to produce the best practices literature and guidelines for treatment of these illnesses. One specific guideline manual is also published by the APA. The ICD is used widely outside of the USA, as it is created in an inclusive process involving all 193 members of the WHO (APA, 2009). Unlike the DSM, created by the APA and for the American population, the ICD is developed as a global tool, striving to be multidisciplinary, multilingual and to aid in the reduction of the burden of mental illness globally (APA, 2009; Martin, 2009).

There is still concern surrounding the cultural relevance of both systems. While the DSM-V has added to the cultural section in the rear of the text, and the ICD is a global effort in development, for many mental illnesses they are not seen as accurate. For psychotic illnesses however, research has shown much consistency in psychotic symptoms over the past 100 years (Sartorius, Shapiro & Jablensky, 1974; Heckers et al., 2013). The core symptoms of
psychosis such as hallucinations, delusions and disorganized thoughts remain consistent, while the themes and topics of hallucinations and delusions may vary across individuals and cultures (Heckers et al., 2013). The diagnosis of these symptoms requires the clinician to evaluate the differences between reality and symptom, and the range of behaviour considered normal for that community. Thus the judgements and conceptualization of these symptoms is undeniably a product of the clinician’s cultural experiences and expectations (Akyeampong, Hill & Keinman, 2015). The severity of these symptoms and their negative impact of daily functioning is also dependent on culture. While in Western countries appearance, communication skills and organization are highly important when understanding the severity of one’s symptoms, in other cultures this is not the case. An example from Ethiopia found that productivity, involvement with family and maintaining social obligations to be important markers of wellness (Habtamu, Alem & Hanlon, 2015). When using either diagnostic manual in differing cultures it is important to understand the local context and insight as well as the clinical understanding. These understandings may include dark magic, spiritual troubles or even poison. Just like the differences in diagnostic systems and understanding symptoms, treatment can vary depending on country and culture as well.

**Treatment for Psychosis in a Western Setting**

Treatment for psychosis in western cultures is very specific, scientific and is based on research evidenced best practices. Medical treatment for the symptoms of psychosis is not independent to individual psychotic illnesses, rather specific to the patient and the symptom clusters they are experiencing. Both medication and psychosocial treatments are recommended for individuals with psychosis and psychotic illnesses.

Much of the treatment of psychosis has been developed around the different models that have been employed to explain psychotic illnesses. Models of schizophrenia and psychotic disorders include but are not limited to Bio-Psycho-Social model, Cognitive Regulatory Model (Bowins, 2011), Cognitive Model of Poor Functioning (Luther et al., 2016), Five Factor Model (Ohi et al., 2016), Hypoglutamate Hypothesis (Kapur & Seeman, 2002) and the Classical Dopamine Hypothesis (Carlsson & Lindqvist, 1963; Laruell & Abi-Dargham, 1999). While the Bio-Psycho-Social model suggests an equal influence in all aspects of an individual’s genetics, upbringing and life, the cognitive models suggest a misfire of normal brain activity that should usually be reserved for sleep or times of survival and distress, and the hypoglutamate and dopamine hypotheses suggest an imbalance in chemicals in the brain which cause the psychotic symptoms. While these models shape the development of treatment, it is the hypoglutamate and dopamine hypotheses which support and are supported by antipsychotic medication. Currently it has been argued that clinicians are leaning too far towards a bio-bio model of illness, where biomedical treatment is the only therapy used and other cultural and social circumstances and therapies are not being utilized (Whitley, 2014).

**Biomedical Treatment**

Biomedical treatment is typically the initial form of treatment a patient receives (Neilson, 2007). Medication can be found in the form of oral tablets or injectable solutions. Antipsychotic medications are used primarily for the treatment of psychosis, with two types of antipsychotics being available: first generation antipsychotics (FGAs) and Second Generation Antipsychotics (SGAs). FGAs commonly used include, Chlorpromazine, Fluphenezine (Prolixin) and
Haloperidol (Haldol). SGAs include but are not limited to Clozapine (Clozaril), Olanzapine (Zyprexa), Quetiapine (Seroquel) and Risperidone (Riserdal). The WHO’s Essential Medication List has named Chlorpormazine, Fluphenazine, Haloperidol and Risperidone as the essential medications for psychotic disorders (2015). Side effects from antipsychotic medication include increased appetite, weight gain, diabetes, sedation, tremors or tics, dizziness and decreased sex drive (CAMH, 2015; Barnes, 2011). These side effects differ depending on the exact medication and quantity being used. While both generations have been found to significantly reduce positive psychotic symptoms, the newer, SGAs, have proven to have fewer harmful side effects (Practice Guidelines: Work Group; Leucht, Corves, Arbter et al., 2009).

While FGAs work by reducing dopaminergic neurotransmission in the brain (CAMH, 2015), these are often found to have more side effects than SGAs, which work by reducing both dopamine and serotonin transmission (SAMH, 2015). The most concerning side effects produced from FGAs are extrapyramidal, such as Parkinsonism, rigidity and tremors (Mayo Clinic, 2016; RCPsych, 2014). Tardive dyskinesia, or the involuntary movements of muscles in the face and extremities is also of concern (RCPsych, 2014). These newer treatments do involve side effects, however much less severe such as changes in appetite, weight gain, fatigue, difficulty concentrating and reduced sexual desire. According to evidence-based guidelines for pharmacological treatment, when taking antipsychotic medication the majority of improvements should be seen in the first month of treatment (Barnes & SCG, 2011). FGAs have also been found to have lower mortality rates, which according to one study can be explained by higher medication adherence (Chen et al., 2015). Typically, FGAs are less expensive to purchase, thus it is expected that these are the most common used in LMICs with lower medication budgets. That is assuming that communities have access to sufficient medications at all, which is often rare (Akyeampong, Hill & Kleinman, 2015). This inequality of access to medications and treatment options is not just found between countries, but also within them. Che et al. (2015) found that individuals living in rural Taiwan were more likely to be prescribed FGAs, while those living in urban areas were prescribed SGAs. This unavailability or inability to afford better medication poses health risks and may create ethical considerations for the healthcare provider. It has been found that many people suffering from mental illness in Africa are prevented from accessing appropriate treatment because of the limited number of psychiatric medicines and the lack of governmental attention and funding given to mental health (Akyeampong, Hill & Kleinman, 2015). While studies have shown that all antipsychotics are effective in varying degrees when treating psychosis, research has shown that SGAs are significantly more effective in treating psychosis than Haloperidol (Darba et al., 2011).

Evidence-Based Treatment
Evidence-based guidelines support the theory that for optimal recovery and functioning, individuals suffering from any psychotic illness should receive both biomedical and psychosocial interventions (Barnes & SCG, 2011; APA, YEAR; WHO, 2001). Specifically, social skills training, psycho education and family intervention are outlined in the evidence-based guidelines (Barnes & SCG, 2011). Involving the family in treatment allows for a greater support network for the patients. While psycho education and social skills training can help patients regain their confidence in re-entering the work/social/family life that their symptoms may have prevented them from accessing in the past. Treating psychosis in its early stages
can prevent the further development of psychotic illnesses and improve the long-term wellbeing of the individual (Reading & Birchwood, 2005). Depending on one’s culture, country, medical access and mental health knowledge, treatments for psychosis and other psychotic illnesses can vary widely (Burns, 2012). Treatment can include biomedical treatment, talk therapy, prayer, herbal remedies, isolation and abuse, to name a few. While understanding the differences between Western and Non-Western treatment strategies for individuals with psychosis, it is important to recognize that research has shown better outcomes and rates of recovery for people with schizophrenia in LMICs than in high income countries (HICs) (Burns, 2012; Whitley, 2014; Sartorius, Shapiro & Jablensky, 1974; Leff, 1992). Research which supports superior outcomes for patients with psychotic illness in LAMICs states community and family cohesiveness, families caring for their members and access to minimally stressful employment as contributors to these outcomes (Habtamu, Alem & Hanlon, 2015). These findings could also prove important in revising our current understanding of psychotic illnesses as a progressively deteriorating condition, which more clinicians believe to be irreversible (Akyeampong, Hill & Kleinman, 2015).

In Western medicine, research on best-practices stresses that a combination of both medicinal and psychosocial treatment should be used to achieve best treatment outcomes (Brooke-Summer et al., 2015; WHO, 2014; Drake, Bondi & Essock, 2009; CAMH, 2015). The psychosocial element to best-practice treatment includes psycho-education, family interventions, intensive case management, cognitive rehabilitation and social skills training (Brooke-Summer et al., 2015). These treatment options can help support the family in caring for the patient as well as teach the patient how to cope with their symptoms in a healthy and productive way. This is also a format of treatment that is able to incorporate both biomedical treatment and cultural treatments for individuals suffering from psychotic illnesses. By incorporating both medicine and cultural therapies the patient will ideally get the most benefit from both avenues. Evidence based treatments for pharmacotherapy typically involve antipsychotic medication discussed above (Drake, Bondi & Essock, 2009; Barnes, 2011).

**Types of mental illness in Africa**

Classifications, understandings and treatment of mental illness differ throughout the world. While there is limited literature on the interpretation of psychosis and psychotic disorders in Rwanda, there is consistent literature explaining these symptoms and behaviours across Africa. Research on the conceptualizations of mental illness in many countries in Africa found that there are often three types of illness classifications: mental, physical, and spiritual illness (Akyeampong, Hill & Kleinman, 2015; Laher, 2014; Edwards, 2011). The first two classifications are similar to the western classifications of mental and physical illness. The third classification, spiritual, is often used for illnesses that have a psychotic element to them (Ae-Ngibise, 2010), and can be further understood in three separate forms: spirit possession, black magic and ill-will (Laher, 2014). In some cultures, individuals who experience certain types of psychosis, which are labeled spiritual illness, are thought of as being called by the ancestors to become a traditional healer (Penkala-Gawecka, 2013).

In a more general term, the symptoms of psychosis are also consistently labeled as ‘madness’, especially by individuals who know no explanation for the bizarre behaviours (Akyeampong, Hill & Kleinman, 2015). Research by Field (1960) found that when referring to a ‘madman’ this
individual is most likely to be exhibiting symptoms of psychosis. This research found the classification of madness to be consistent among West African cultures.

While there is much consistency between the symptoms presented in madness or spiritual illnesses to those of which in the West are labeled psychotic illnesses, there are theories that suggest these symptoms may be in part a product of colonial influences. While patients with psychotic symptoms have been found West Africa for decades, many of these cases have been found in the higher income areas of society, where people would have the most contact with Western influences (Akyeampong, Hill & Kleinman, 2015).

**Treatment for Psychosis in East Africa**

In rural areas around the world, especially in many African countries individuals first seek treatment from spiritual and traditional healers (Burns, 2012; Ae-Ngibise, 2010; Akyeampong, Hill & Kleinman, 2015). This non-western option can be for belief or resource limited reasons. In all parts of the world, religious beliefs and faith based healing practices are seen for the treatment of many illnesses, including psychosis. Laher (2014) found that biomedical treatments used by spiritual and traditional healers included traditional medicines made from plants, coal, animal fat and other naturally found substances. These treatments can be ingested, applied to the skin or smoked. Some healing prayer or ceremonies may also take place for individuals experiencing mental illness. Individuals experiencing spiritual illness are often treated with prayer or rituals, including (but not limited to) exorcism (Abbo, 2003; Laher, 2014). Furthermore, research from Uganda found that traditional healers also deal with social and familial problems, marital and sexual problems, in addition to cultural and spiritual concerns (Abbo, 2003; Akyeampong, Hill & Kleinman, 2015).

Smolak et al., (2013) explain the benefits of community based traditional and faith treatment for individuals with psychosis as being a positive tool for building coping strategies and engaging patients in treatment. For many collectivistic cultures, this type of treatment is of increased benefit because it allows the family and the community to participate in the treatment and support of the individual suffering. This religious healing has been associated with increased levels of well-being as well as improved quality of life for individuals suffering from psychosis and other mental illnesses (Smolak et al., 2013).

Western style biomedical and psychosocial treatments are also available in most African countries, however the accessibility and affordability is not guaranteed. Due to lack of funding in many countries, mental health services tend to get the least amount of financial support out of all areas of health care. While the doctors, nurses and social workers employed in the country may have adequate training and experience, there are often very few of them for a large population (Akyeampong, Hill & Kleinman, 2015). For example in 2011 Rwanda had approximately 5.5 psychiatrists for a population of 11.14 million (WHO, 2011). Similarly, during the course of this study Rwanda had approximately 7 practicing psychiatrists for a population of approximately 12 million.

**Barriers to Treatment**

The staggeringly low numbers of mental health practitioners and limited availability of medications is an indisputable barrier to treatment in LMICs. While in Rwanda there are
Currently approximately 7 psychiatrists, the majority of these doctors practice in large cities, mainly Kigali. Patients who are in small communities in rural areas often have to travel great distances to get support and/or diagnosis. This lack of human resources in rural communities prevents patients from receiving follow up treatment and thus many patients lose touch with their doctors and treatment plans (Akyeampong, Hill & Kleinman, 2015).

A universal barrier, is maintaining patients on their medication. Consistent medication is a major factor in preventing patients with psychosis from relapsing (Teferra, Hanlon, Beyeo, Jacobson & Shibire, 2013; Kelleher, Jenner & Cannon, 2010; Ndetei et al., 2007; Brooke-Summer et al., 2015), however it can also be one of the most difficult factors to control. Depending on the type of medication patients are taking, their difficulty to remain on the treatment will vary. In poorer regions of the world, the reliability of access to medications can be a primary barrier to medication adherence. In this setting access refers to both the availability of the medication in the community as well as the affordability of the medication for the individual, family or hospital (Akyeampong, Hill & Kleinman, 2015). A common reason for non-adherence is that some patients just do not remember to take their medication, or do not have access to enough tablets for the prescribed amount of time. One resolution to this can be injectable antipsychotics (Barnes, 2012). Injection medication does not have more or less side effects, but they are easier to remember to take because a local nurse can administer the shot approximately every four weeks as prescribed.

Some side effects create unique difficulties when experienced in LMICs and other low-income settings. As discussed above, many side effects are externally visible and can cause additional discomfort and stigma to the patient. The severity of these side effects can cause patients to stop taking their medications (DiBonaventura et al., 2012). Increased appetite and thirst can put stress on food and fresh water supplies of a family. Individuals who are already having difficulty feeding their family, or themselves, will likely not want to be taking a medication that makes them feel even hungrier (Teferra et al., 2013). Patients may not want to be seen in a psychiatric hospital, taking medication, or talking to mental health professionals (Teferra et al., 2013). This stigma may even be present in the patient’s relationship with their health worker, damaging the relationship between the patient and his/her doctor and reducing the likelihood of positive treatment adherence (Teferra et al., 2013). Since SGAs are often known to have fewer or more tolerable side effects, national investment in the newer drugs may be one way to improve medication adherence across the world.

Finally, cultural differences and variations in understanding of mental illness can be a significant barrier to treatment of psychosis or any psychotic illness (Laher, 2014; Teferra et al., 2013). A lack of understanding how their illness responds to the medication may cause patients to misunderstand the need for treatment, including the expectations of treatment. Teferra et al., (2013) explain that some patients believe that medication will work as a cure, and there is no need for long-term treatment for their psychosis. Without this explanation of medications and how they work on symptoms patients may not only choose to discontinue medication, but can also undermine the patient’s beliefs in western medication when the ‘cure’ is not successful. Psycho-education for patients, families and communities can reduce the stigma surrounding medication and illness, as well as inform individuals of the importance for long term and consistent treatment for individuals with psychosis or psychotic disorders.
Conclusion
While there is a significant amount of literature to be found on the mental health status and effects in Rwanda post genocide, it is mainly focused on depression, anxiety and post-traumatic stress disorder. The literature specific to psychosis in Rwanda however, is scarce. There is a small amount of research found on psychosis and psychotic illnesses in other countries in Africa, with a focus on East and Western Africa, and these reports will be used as examples and basic knowledge for this project moving forward. The lack of Rwanda specific literature also supports the necessity of this research and the contribution it will make to the knowledge of mental health in Rwanda. Literature on the understanding of traditional healers and cultural understanding of illness will also be used, as up to 90% of individuals seek support from traditional healers before they approach western style clinicians or hospitals (Lahr, 2014).

Materials and Methods
Using a deductive exploratory methodology, this qualitative study explored the treatment practices and accessibility for psychosis in Rwanda. This deductive approach sought to generate and identify links across a number of themes through the systematic use of interviews with key stakeholders. The data collected from these observations and interviews will ideally be used as foundation for further in depth research and the generation of theories into the phenomenon of psychosis in Rwanda. Data for this project included both primary and secondary data.

Participants and Sampling
Non-probability was used to identify interview participants, including availability sampling and snowball sampling. Inclusion and exclusion criteria were in effect for the selection of participants. Twenty-four healthcare professionals were interviewed, all with varied levels of mental health experience, as outlined in Table A. Participants were from eight hospitals around Rwanda, the University of Rwanda and the Ministry of Health.

Secondary Data Analysis
Secondary data was obtained in the form of patient and illness statistics from Ndera Neuropsychiatric Hospital, Icyizere Center (Psychological Trauma Center) and Caraes Butare (Ndera branch in Butare). This data was released to the research team by the hospital director directly. Data was broken down into the number of patients admitted per year and what
general diagnostic category they were admitted under. Data was divided amongst hospitals, as well as overall general numbers. All data were in the form of basic tallies with no identifying information contained in the document.

**Study Tools and Development**
The duration of interviews was 10 – 80 minutes, consisting of structured open-ended and probing questions. All but one interview were recorded, with refusal being due to her involvement in the military. Interview structure questions were developed through existing literature on treatment and conceptions of psychosis in African countries. The interview schedule was developed to provoke discussion about the topic of psychosis in four main areas; Community and cultural understanding of psychotic symptoms; The role of traditional and faith healers in treating patients with psychotic symptoms; Typical treatment options for patients presenting with psychotic symptoms in hospitals; and The health care professional’s opinion of the treatment options available for their patients.

**Ethical Consideration**
Ethical approval for this study was granted by the CGH/HPM Ethical Review Committee, Trinity College Dublin and by the Rwanda Ministry of Education. All ethical guidelines, including informed consent and confidentiality were followed strictly.

**Data Analysis**
This study used a thematic framework analysis. Themes were derived using a deductive approach, where major themes emerging from the literature review were used to formulate the interview schedule for the key informant interviews. As the interviews were semi-structured there was also information gathered that was not provoked from literature information. As the primary data is collected from healthcare providers, it is important to acknowledge the implications to the data that their education and employment may have. These individuals all had Western biomedical training and thus while working in a LMIC their medical practice and understanding is that of a Western professional. Through revision of interview transcripts, subthemes were identified and explored.

**Reliability and Validity**
Using the explanation of reliability and validity in qualitative research by Golafshani at the University of Toronto, Canada, this research was evaluated in regards to credibility, transferability, dependability and confirmability (2003). It is believed that this research accomplishes high degrees of all four areas. This research accomplished credibility because respondents consistently discussed the same or similar topics, and thus participants would not be surprised by any of the discussions below. Transferability/generalizability was attained by having a variety of participants from different types of institutions from all over Rwanda. Dependability is _____ because the research methods and tools are easily replicated. Finally, confirmability was attained by having much of the findings supported by existing research in the field.
Results and Discussion

Analysis of Secondary Data

The most current health centre statistics revealed that an average of 54% of patients seen in the three major mental health treatment facilities in Rwanda were seen for psychosis or other related psychotic disorders in the last five years. This equates to an average of 14,744 patients per year. For the only psychiatric hospital, Ndera in Kigali, this means an average of 9,243 patients seeking treatment for psychosis or psychotic disorders each year. This secondary data provides a context to the volume of psychosis patients seen in hospitals throughout the country, to gain a better picture of the impacts of the primary data. The significant number of patients seen with psychosis supports the need for this and further research into this area of care in Rwanda.

Data Themes

Four major theme categories were identified in the literature and were also present in the data: Psychosis as an illness, Community beliefs of psychotic symptoms, Practitioner mental health training and Treatment options for psychosis. Further analysis of the data further revealed several sub themes, and sub-sub themes, under each of these five themes. Traditional and spiritual healing practices, themes which are heavily represented in the existing literature, were also commonly mentioned, and are discussed under the themes of Treatment and Community beliefs. It is an important distinction that traditional and spiritual healers are two separate entities in this data. Traditional healers being community members who provide traditional healing remedies and practices. Spiritual healers are religious leaders or patrons who practice prayer and spiritual practices to heal individuals of their ailments. Stigma was also a significant topic in existing literature and this data, and is discussed across all five major themes in this paper.

Psychosis as an Illness

When discussing psychosis and the various symptoms included in this label, participants were asked for a description of how psychosis presented in Rwanda. Specifically ‘what does it look like?’ The presentation of the illness was described similarly as those symptoms used in the medical literature, separated into positive and negative symptoms. Hallucinations, delusions and lack of time or spatial awareness were the most common symptoms discussed. One participant discussed psychotic symptoms as follows:

> In positive symptoms with psychosis they present hallucination, delusions and disorganized thought. Even disorganized behaviour. That is the positive symptom. The negative symptom you see sometimes they present a little bit strange, show little emotion, seem to be unable to do anything, they have also poor social function. (88811, Female Psychologist)

Another participant had a very similar response:

> Sometime they are very dirty. Clothes, their hygiene is poor. And they are thinking their mind are not on are not normal. They are incoherent, they are some of them they don’t speak they are they have inhibition, if I can say they don’t speak. Yea they stay in the same isolated area... (8888, Male Psychiatric Nurse)

The discussion of positive symptoms was more common in interviews than that of negative symptoms. This may be because positive symptoms create more difficulties for families and communities than negative symptoms do. Positive symptoms were also more frequently associated with stigma,
community disruption and difficulty with medication adherence. Consistent understanding and explanations of psychosis is an illness were found across all 24 participants. This consistency is potentially due to the fact that all participants were healthcare providers trained in biomedical medicine. While understandings of psychosis were consistent among participants it is important to note that these understandings may differ greatly from those of patients or community members. The understanding of participants was clearly different than that of the community in regards to psychotic symptoms. This difference in community understanding is supported frequently in the literature by Laher, 2014 and Teferra et al., 2013, while similar research indicates this is the reason that Traditional and Spiritual healers are often the first point of contact for patients (Bur, 2012; Ae-Ngibse, 2010 & Akyeampong, Hill & Kleinman, 2015). This literature supported the consistent answers by participants about the reliance on traditional and spiritual healers for treatment of psychosis. According to the majority of practitioners interviewed, patients often seek assistance from a traditional healer as their first point of care for their psychosis. One participant who works in decentralising mental health treatment in one province discussed the slow change that is happening in the first point of treatment for patients with psychosis:

When people used to get sick in the community their first impression was that this person is being poisoned or they can say this is a demonic attack. So those are the first thing they will thing and their first pray for them or get to the traditional healer and get then medication. (88812, Female Psychologist)

When asked if there was any relationship between traditional and Western medicine the consistent answer was ‘no’. However it was often thought by participants that building a relationship between the two health providers would improve patient treatment and build more trust in the Western medical system while also allowing patients to continue participating in their beliefs and rituals with the traditional healer. When asked about any potent traditional methods of treating psychosis, participant 88825 discussed the benefit that could come from modern and Western treatment options being combined. He states, ‘I think it would be the benefits would be positive on both sides. Because the person who is sick will continue to take medicine and will continue to pray to god’ (88825, Female Psychiatric Nurse). She continued by suggesting, ‘We can call the pastor and talk to him, not to judge him or to say you did wrong things, you could bring the patient here immediately, we are trying to discuss and uh to give him the knowledge in order to help others’ (88825, Female Psychiatric Nurse).

This suggestion, would allow patients to participate in both forms of treatment without judgment from either side. It would also allow patients to actively participate in their beliefs, traditions or religions without putting themselves in danger by avoiding hospital care. This idea was thought to be a very difficult scenario to accomplish due to the lack of trust and relationship between traditional/spiritual healers and hospitals. Such a pattern in attending traditional or spiritual healing prior to medical attention is consistent with the existing literature (Burns, 2012; Ae-Ngibse, 2010; Akyeampong, Hill & Kleinman, 2015). Furthermore, Smolack et al. (2013) suggested significant patient benefits in combining traditional and modern medical support to increase engagement, treatment adherence and to provide extra social and coping skills. The overwhelming support to integrate or work with traditional or spiritual healers from hospital was unique and not encountered in previous literature for this project. A representative from the MoH discussed a current programme that aims to give traditional healers a certification of practice, after completing some formal health and mental health education. Part of this education would be knowing when to refer patients to hospital:

We try to initiate collaboration between our modern facility and traditional healers because we started to educate them... So that as every community they can recognise they can understand the meaning and symptoms and if they can know what they can do and what they can’t cannot do. So they can send the patient in in the hospital... The collaboration, it will be better for the patient (8883, Male Psychiatric Nurse MoH).
Community Understanding of Psychotics Symptoms
This data found that psychotic symptoms can have a variety of different explanations amongst the Rwandan population, which was consistent with the literature, and similar to the understanding in other East and West African countries (Akyeampong, Hill & Kleinman, 2015; Laher, 2014; Edwards, 2011). Some individuals see psychotic symptoms as spirits communicating through the living, demons or the devil invading the body, a sign of negative wishes of a neighbor or the sign of a future healer. The most common community understandings discussed in this study was the invasion of the individual by an angry spirit or demon. The differences in understanding of psychosis is best exemplified through participant 8881’s answer, having been asked what psychosis looked like in Rwanda:

In fact when we talk about psychosis in Rwanda we look at it as academic but it is different from those other people who didn’t get this course because its taken as matter of culture whether they can have misinterpretation. So that some people can think someone is suffering from if I can say demon if I can say from some bad spirit so that now a days they can be transferred to the hospital. But some people are still thinking that a traditional practitioner with their tradition they can help them. (8881, Male Psychologist)

The belief that the family or community can do something spiritually to benefit the individual with psychotic symptoms was common, ‘If we do not offer sacrifices to them the those spirit come and they are harmful’ (8882, Male Psychologist). This understanding that psychotic symptoms come from spirits and can be cured through prayer and sacrifice could increase stigma in communities. Literature from Laher (2014) and Ae-Ngibise (2010) reinforced these findings, finding that the understanding of evil spirits causing psychotic symptoms is common. If communities do not understand psychosis as a medical illness, which needs medication from hospital to treat, the stigma of negative spirits and being cursed will likely continue. Increasing community understanding of the bio-medical explanation of psychosis may reduce stigma related to negative spirits and increase the chances of a family bringing their loved one to hospital for treatment.

Mental Health Training for Healthcare Practitioners
Frequently the research team was faced with hospital medical staff who were unable to provide information or direction to the mental health department or staff member of their hospital. This observation was consistent over seven of the eight hospitals visited for this project. This shows the lack of priority and lack of interest in mental health, even by medical professionals. This attitude is detrimental to moving forward to increasing laymen awareness as well as increasing attention from the MoH and other government officials.

Attempting to contact and meet with mental health staff across various hospitals highlighted the severe dearth of human resources for mental health. One major hospital in Kigali only had one mental health trained individual, who only worked one day a week. For this reason this hospital was not used for this project as their single mental health professional was unable to find time to meet with the research team.

The extreme lack of psychiatrists in the country (at the time of this research it was 7 practicing psychiatrists for a population of 11.78 million) might be understood by the lack of psychiatric training available in the country. It could also be a result of a lack of student demand for such areas of study due to stigma and unawareness. All the psychiatrists that were interviewed had to gain their training in another country in order to get their qualifications. While there is currently a program for psychiatric
nursing at the University of Rwanda, the general training and mental health education available is extremely limited.

During this topic of discussion it was a surprise to the research team when two psychiatrists agreed that one reason there may be very few psychiatrists and other mental health staff is because there is great professional stigma. A very interesting conversation ensued:

Yea even us. We are marginalized. (88821, Male Psychiatrist)
Yea I was saying even intellectuals. Even if you say, yea I’m in psychiatry they say what? (88822, Male Psychiatrist)
Say how you go there? We knew you when we were in medicine, you are brilliant. And you choose psychiatry? You couldn’t find another domain to choose? (88821, Male Psychiatrist)

There are likely a number of different reasons for the lack of mental health professionals other than stigma, which effect the low human resources in hospitals and community health centres. Lack of interest or lack of awareness of the area of work is amongst them. If professionals are exposed to such stigma and inaccurate beliefs (for example beliefs that mental illness is contagious) one can only imagine the stigma faced by patients in the community. The professional stigma is a large indication on the misbeliefs of other medical staff. This could also have a negative implications for how non-mental health staff treat mental health patients who come into their care.

However limited the services and mental health professionals were, this research found that the mental health practitioners available were all well trained and passionate about their work. This is a similar finding to that of Akyeampong, Hill and Kleinman (2015) who discuss high skill level and training of available personnel, however a severe lack of trained professionals existing in LMICs. Nearly every participant mentioned the use of the ICD-10 or the DSM-V, and consistent explanations of symptoms and presentation of psychosis. When asked if there was a guideline used in diagnosing psychosis one participant said, ‘We use the DSM. The DSM criteria, which is enough to diagnose the psychosis. And any mental disorder you can use the DSM and now we are at DSM-V’ (Participant 8883, Male Psychiatric Nurse MoH).

When the same participant was asked if nurses and social workers are trained in the DSM the same as the doctors they replied,

Everybody can should be able to when is dealing with patient should have the same understanding and should be familiar with that DSM. Especially for the medical doctors and then nurses. But for social workers it is not necessary because they are not involved in the diagnosis and treatment (Participant 8883, Male Psychiatric Nurse MoH).

**Treatment options for psychosis**

Within the major theme of treatment options for psychosis, four sub themes were identified in the data; medication, therapy, traditional and spiritual healers and modern medicine relations. Most participants acknowledged the community belief that treatment for such ailments are available from traditional healers, however are not successful in treating psychosis if not combined with medication and hospital care. One participant, a psychologist and pastor, believed that spiritual healers were capable of healing psychosis in some cases. This participant indicated that a spiritual healer near his community has the ability to heal some people, and there is no explanation for it.

For example at Ruhango we have a catholic priest. Every second Sunday of each month there are many many thousand of Rwandan who went there. And with different kind of. Yea we have
also others but he is the most popular... But coming back to the healing, he is guided by god and uh this you see in this are there is no there is no um scientific proof but there is a result of people who are healed. He pray and miracles we call it miracles. (8882, Male Psychologist)

The ability for a trained PhD psychologist, with European training to still state that certain prayer can heal psychosis and other medical illnesses, speaks to the religious and cultural understanding and faith that some Rwandans have. Having trained professionals with this belief in spiritual healing powers could impact the community education progress of getting people more comfortable with seeking assistance at hospitals.

Approximately half of participants mentioned a treatment approach that included alternatives to medication, while few mentioned the actual implementation of such holistic options. Often this was said to be due to lack of resources, monetary, time and personnel. When asked about the treatment available to patients with psychotic symptoms, one participant said this:

…We don’t straight away go to the medication part of it unless we see the extreme part of the patient... Mostly the principal is counseling then we will try to see what are the causes that surround this psychosis and delusions and then to actually reduce them ... we look for the family who can be uh caretaker who can accept to take that person in the community... So basically we don’t really do much because within our capacity framework and as a hospital set up we do not have all those things that the psychotic patient might need to come back into a stable state. But we try our best. And also we consider medication as a last resort (8884, Male Doctor).

The above exemplifies the complex and holistic knowledge that these practitioners have about the treatment options and best practices for patients with psychosis, combined with the barriers they face with providing and maintaining such treatment. For this specific participant, his hospital is unable to provide the appropriate treatment as outlined by their practice policies because of lack of structure and human resources. This lack of human resources leads to healthcare professionals relying on mainly medication therapy and less on psychotherapy and non-drug related therapies. Unfortunately this prevents patients from getting a well-rounded treatment plan that can realistically be carried out by his/her healthcare team. This finding was supported by previous research done by Akyeampong, Hill and Kleinman (2015) who attribute the lack of psychosocial treatments available to the lack of available trained professionals.

While psychotherapeutic treatments were discussed in many of the interviews for this project, all of these discussions mentioned the lack of psychotherapy and talk therapy available to patients. This lack of access to this form of therapy was even discussed by a representative from the MoH, Honestly I can’t say the psychosocial treatment available. But we try to use the available resources in order to do what we can call reintegration of the patient... But uh we have few specialists in that area. (8883, Male).

Under the sub-theme of medication, two sub-sub themes were identified: First, patients are being deprived of what are considered first-line medications in high income countries, and second, side effects from medications are proving harmful for patients. Most participants stated that even if their patients were prescribed SGAs it would be very difficult for them to purchase them. There is a shortage of SGAs in pharmacies. This means that if someone is using a SGA they may have treatment interruptions due to lack of access. When asked to elaborate about the difficulty with medications in pharmacies in smaller communities one participant stated:
So we have a problem of new antipsychotics for their cost. For the cost and our community didn’t have money for buying those medication and access to those medication isn’t here. Because even if we have pharmacy they call they couldn’t buy them because they know no one will buy them. So maybe when the company who which do production of these new antipsychotic could reduce the cost, could be helpful in treating psychotic patient (88819, Male Nurse)

The common use of FGAs in low-income environments was also supported in the literature, both due to personal cost and due to lack of funding from governing bodies (Akyeampong, Hill & Kleinman, 2015; Che et al., 2015). Due to the lower cost of the medication, FGAs are often more accessible to individuals with limited income. For example, hospitals are more likely to prescribe FGAs to their inpatients because these drugs are at a reduced cost in comparison to SGAs.

When asked about general treatment for psychosis patients, more than half of participants discussed a lack of general drugs and specifically a lack of SGA medication. The data showed that the use of Haloperidol in hospitals and health centers for treatment of psychosis was more dominant than any other medication or therapy used by participants. While Haloperidol does show significant benefits for patients with psychosis, it is known for its extreme, and obvious side effects and can permanently hinder an individual if taken long term (Darba et al., 2011; Mayo Clinic, 2016). Participants identified multiple side effects as a result of the medication given to their patients, some of whom identified these side effects as the reason patients stop or refuse further treatment:

These drugs they have side effects and side effects are one of the reason for stopping treatment. When you are like this in society it is a problem. He is not moving like others. And the patient knows that it is because of the treatment that he is walking like that or having issues. And he says ok I have to stop this treatment its not good. (88822, Male Psychiatrist).

Side effects can be so severe that the individual either stops taking medication and thus relapses, or is very clearly identifiable to the community, which causes stigma. When asked what were some of the reasons for patients to stop treatment one participant said: ‘And these drugs they have side effects and side effects are one of the reason for stopping treatment.’ (88822 Male Psychiatrist)

While these concerns regarding medication side effects are not a problem unique to the Rwandan context, it is a significant challenge to treating these patients. Lack of adherence to medication can also be a significant barrier to improving the quality of life for patients with psychosis.

The majority of participants mentioned Haldol as being the first medication used for patients with psychosis, with the research team interested in knowing if there were differences between treatment options across different service points. One participant had worked both in the community and in a major hospital (Ndera Psychiatric Hospital). When asked if treatment for psychosis is similar at Ndera psychiatric hospital when compared to the district hospitals the participant explained:

Somehow similar because you know we are now most of the time using old antipsychotic. You know, Haloperidol, all those old. They are most common because they are cheap and anyone can afford. But like at Ndera hospital and Sehashika as referral hospital begin to have some
second generation... but it is really prescribed for people who have means to afford. It is not for everyone (8885, Female Psychiatric Nurse).

Literature has also supported this pattern of old outdated medications being used for the most financially vulnerable populations. The same pattern is seen with other disease treatments such as TB and HIV. This repetition of second line medication being given to the world’s poorest and most vulnerable is ethically questionable at best. It is a pattern that is in grave need of attention. This pattern has been found not only between countries but within them, with rich and poor imbalances as well as urban and rural imbalances in access (Che et al., 2015). This also poses a unique difficulty for healthcare providers who are aware that they are not prescribing the best medication to their patients, but have no accessible alternative. The discrepancy between practitioners optimal treatment for psychosis and the available treatment can open some interesting ethical debates. What is a practitioner to do when he/she believes that the treatment prescribed is the only option, but may also cause harm to the patient?

When asked how each participant would improve the treatment of psychosis in Rwanda, most people had multiple suggestions. One participant described the ideal type of infrastructure for improving treatment in the community:

I would really get proper infrastructure because you know psychotic patients need really a safe house where they can’t break and just move around. And sometimes you know they can become violent. I would look at the human resource by employing well trained nurses who don’t do any other thing. I would also to minimize transfers and what I would not really employ because it is hard to employ a neuropsychiatrist or someone who ill well trained in psychiatry but I would at least be able to pay on regular visits by psychiatrists from Kigali to come and do consults here maybe once or twice a week. (8884, Male Doctor)

Participant 8886 suggested improved medications as the ideal situation for Rwanda moving forward in treating patients with psychosis, linking poor medications directly with non-adherence to treatment, ‘First of all it would be the ideal situation to get good medication without side effect. It is an idea. Because side effects are the one of the causes of stopping medication.’ Participant 8888 further corroborated the need for better medication:

What I can suggest is maybe we can we can use those treatment who don’t cause more side effect can be helpful. Only if they find some medication which don’t cause some side effect it can be helpful for the patient for their improvement for their working activity, it can be helpful in different domain if in the social economic domain, the degree to decrease the stigma and discrimination… (8888, Male Psychiatric Nurse)

As predicted, there was also considerable mention of needing more access and more resources, especially in non-central location and communities. These additional resources also included the need for more governmental support:

It would be very helpful if the ministry of health would think of supporting people with mental problems. They don’t work during the weekend. That means Saturday and Sunday patients have no care. I don’t blame the hospital because in order to have someone who would work during weekend it requires them more money to pay them. (88814, Female Psychiatric Nurse)

We have to the government has to sponsor this domain and make available these drugs with a low price. Available for our patient, with a holistic approach in those places. With psychologists social workers and everything. (88821, Male Psychiatrist)
Participants also made a number of other suggestions. Many participants directly suggested improvement to medication for patients with psychosis would be their ideal for the future,

> You know this century we use typical neuroleptics [that] were used in 1950s, we are in 2015. I travel, and I saw in other countries they don’t use these drugs that we use here in our country. (88822 Male Urban psychiatrist)

In the same conversation, another psychiatrist suggested a change in government practice: ‘We have to [ask] the government to sponsor this domain and make available these drugs with a low price. Available for our patient.’ (88821 Male Urban psychiatrist).

All the suggestions for the future are supported by the strengths and weaknesses identified in all categories of these interviews. In an attempt to improve quality of life, support family and community, and maintain cultural and spiritual needs, this data shows that the majority of mental health practitioners are in agreement. These suggestions are also consistent with existing literature stating need for combined biomedical and therapeutic methods of treatment (Brooke-Summer et al., 2015; Drake, Bundi & Essock, 2009), and the need for access to more effective medications with less severe side effects (Mayo Clinic, 2016; Darba et al., 2011). The unity among participants, the support of the literature and the findings of this data show that some improvements need to be made for treatment of psychosis in Rwanda.

**Future Implications**

The greatest limitations of this study only including healthcare practitioners leave ample room for future research. Due to the lack of existing research on psychosis or treatment of psychosis in Rwanda, this research was ethically unable to involve patients and their families. Different findings may have been produced had patients, family members or other community members been interviewed on the topic of treatment for psychosis. As such, future research into the phenomenon of psychosis in Rwanda should involve patients and their families, as advocated for by groups such as ‘the Hearing Voices Network’.

**Conclusion**

This study is the first of its kind on psychosis in Rwanda, as far as extensive literature review has demonstrated. It was found that while health care practitioners working with psychosis have knowledge of and desire to have access to first line treatments, these are often not available. It was also made clear that this lack of first line treatment, both medication and non-medical treatment options, is at the detriment of their patients. Stigma, alternative understandings of psychosis, lack of both personal and governmental financial resources and a lack of trained personnel are all of concern in regards to patient treatment. It is important that these concerns have been highlighted as they are consistent and congruent with WHO mental health improvement guidelines. WHO has published goals to increase mental health services across the world, specifically in hard to reach and low-income areas. Improving treatment in LMICs includes training primary health workers, providing access to the necessary medications, supporting families and communities in outreach care and educating the public to reduce stigma and discrimination (WHO, 2014).
References


