Perceptions of mental illness among HIV counselors in Uganda:

A qualitative study

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Declaration

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Abstract

The HIV/AIDS pandemic has led to millions of deaths; disability for the sufferers and multiple socio-economic effects on HIV infected and affected individuals. Among the factors affecting people living with HIV/AIDS that may contribute to HIV related disability is mental illness such as HIV related manias and depression. 'HIV counselors' make up part of the team at the forefront of HIV treatment and management in Uganda but little is known about their perceptions of mental illness. This study therefore sought to explore the perceptions of mental illness among HIV counselors in Uganda. A qualitative study was conducted. Ten individual interviews and three focus group discussions were carried out among 31 HIV counselors. They were selected from five HIV treatment centers in Kampala district, Uganda. An interview guide based on Kleinman's explanatory model of illness with case vignettes depicting depression, alcohol abuse, mania, and psychosis were used to facilitate discussion. Data was thematically analyzed. HIV counselors exhibited some knowledge concerning depression among HIV positive clients, with some viewing the symptoms of depression as "understandable sadness" arising from the HIV client's psychosocial reality which is rife with poverty, stigma and lack of social support. Counselors also reported that some of their client's physical symptoms were a result of their emotional problems. Mania and psychosis were attributed to religious beliefs and witchcraft; and in some cases disease progression or HIV drugs. Chronic alcohol abuse, despite continuous counseling was seen as a waste of the counselor's time in face of overwhelming numbers of clients per day. Such clients, along with clients with suicidal ideations were often threatened or ignored. Counselors agreed that they needed training on assessment of mental illness, and how difficult cases could be referred.

Opsomming

Die MIV/VIGS pandemie het al miljoene sterftes tot gevolg gehad; ook ongeskiktheid vir die lyers en veelvuldige sosio-ekonomiese gevolge vir individue met MIV sowel as ander individue wat daardeur geraak word. Van die faktore wat 'n uitwerking op mense het wat leef met MIV/VIGS en wat kan bydra tot HIV ongeskiktheid, is geestesversteurings soos HIV verwante manies en depressie. "MIV-voorligters" is deel van 'n span wat aan die voorpunt staan van die behandeling en bestuur van MIV in Uganda, maar min is bekend oor hulle persepsies van geestesversteuring. In die onderhawige studie is MIV-voorligters in Uganda se persepsies van geestesversteuring ondersoek. 'n Kwalitatiewe studie is onderneem. Tien individuele onderhoude en drie fokusgroepbesprekings is gedoen onder 31 MIV-voorligters. Hulle is geselekteer uit vyf MIV-behandelingsentrums in die Kampala-distrik, Uganda. 'n Onderhoudskedule gebaseer op Kleinman se verklarende siektemodel, bestaande uit karaktersksets-gevallestudies wat depressie, alkoholmisbruik, manie en psigose uitbeeld, is gebruik om die besprekings te fasiliteer. Die data is tematies ontleed. MIV-voorligters het getoon dat hulle in 'n mate oor kennis beskik ten opsigte van depressie by MIV-positiewe kliënte. Sommige voorligters het die simptome van depressie beskou as "verstaanbare droewigheid" wat voortspruit uit die MIV-kliënt se psigososiale werklikheid, bestaande uit armoede, stigma en 'n gebrek aan sosiale ondersteuning. Voorligters het ook gerapporteer dat sommige kliënte se fisiese simptome die gevolg is van emosionele probleme. Manie en psigose is toegeskryf aan godsdienstige oortuigings and toordery; en in sommige gevalle aan progressie van die siekte of MIV-medisyne. As gevolg van die feit dat voorligters daagliks oorlaai word met kliëntgetalle, is kliënte wat kronies alkohol gebruik beskou as 'n vermorsing van voorligters se tyd, ten spyte van voortdurende voorligting. Sulke kliënte, tesame met kliënte wat selfmoordneigings getoon het, is dikwels gedreig of geïgnoreer. Voorligters was dit eens dat hulle opleiding benodig in die assessering van geestessiekte asook leiding oor hoe om moeilike gevalle te verwys.

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Table of Contents

x

List of Tables

Acronyms and Abbreviations

AD- Adjustment Disorder

EM's- Explanatory models

KCCA- Kampala City Council Authority

MOE- Ministry of Education

MOH- Ministry of Health

TASO- The AIDS Support Organisation

PTSD-Post Traumatic Stress Disorder

SCOT- Strengthening HIV counselor Training in Uganda

SSA- Sub Saharan Africa

UCA- Uganda Counseling Association

UNAIDS- Joint United Nations Program on AIDS

Chapter 1

Background

The HIV/AIDS pandemic has led to millions of deaths; disability for the sufferers and multiple socio-economic effects on HIV affected individuals (UNAIDS World AIDS Day Report, 2011). One of the factors inherent in the management of HIV is faster and more efficient ways to reduce HIV related disability and death (UNAIDS World AIDS Day Report, 2011). Mental illness affects many health related outcomes for an HIV positive individual, and the prevalence of anxiety, depression and substance abuse is higher among people living with HIVAIDS than in the general population (Joska, Stein & Flisher, 2008). The HIV virus also directly affects the central nervous system, giving rise to mental illnesses such as manias (Baingana, Alem & Jenkins, 2006).

The World Bank (2006) report on *"Disease and mortality in Sub Saharan Africa"* shows depression to be significantly higher in sero positive individuals than in the general population in Kenya and Zaire (Sebit, 1995).   HIV is also linked to poorer cognitive development in HIV- infected infants in Uganda (Musisi & Kinyanda, 2009). Studies among individuals enrolled in HIV care and treatment in Cape Town, South Africa, revealed   prevalence rates for depression, Post Traumatic Stress Disorder (PTSD) and Alcohol dependence/abuse to be 14%, 5% and 7% respectively (Myer et al., 2008).

Studies conducted in Uganda detail the mental health aspects of HIV, particularly mental health problems, at various HIV/AIDS disease stages (Musisi & Kinyanda, 2009). HIV related secondary mania (Nakimuli-Mpungu, Musisi, Kiwuwa Mpungu & Katabira , 2008), HIV related Dementia (Kinyanda, 2009; Wong et al., 2007), and HIV psychosis and depression related to HIV infection (Nakasujja et al., 2010) have been reported. Suicidal behavior has been cited as a risk for people diagnosed with HIV (Musisi, 2009), as well as anxiety disorders (Kinyanda, 2009). These studies highlight the magnitude of mental illness among HIV/AIDS patients in Uganda. It is important to note that in spite of these

prevalence figures, the majority of HIV care and treatment centers do not employ a mental health worker or psychiatrist (Uganda Bureau of statistics, 2002).

On a regional level, this study is nested in the drive to improve the provision of mental health care in Uganda, as one of the participating countries in the Program for improvement of Mental Health Care (PRIME) (Lund et al., 2012). This program is premised on the fact that there is a high level of unmet need for mental health care in low and middle income countries (LMCI's) (Kohn, Saxena, Levav, & Saraceno, 2004). The aim of the PRIME project is to improve mental health service provision through non specialized health care settings (Lund et al., 2012) with a focus on mental, neurological and substance abuse disorders (MNS) (Lund et al., 2012). The PRIME project situational analysis reports that although Uganda's health system is poorly equipped to integrate mental health services in general health care, existing care models for HIV provide an opportunity to expand mental health care (Hanlon et al., 2014).

At the forefront of HIV treatment and management in Uganda are medical professionals such as clinicians and nurses, who work hand- in- hand with a group of specialized 'HIV counselors' whose training in counseling is focused on psychosocial factors related to HIV infection (Uganda Ministry of Health, 2005). The counselors have the highest number of contact hours with HIV clients as counseling is often part of routine clinic visits. An HIV counselor may be anyone who has undergone counselor training ranging anywhere from 3 days to 3 years (Senyonyi et al., 2012). In some cases the HIV counselor is in fact an 'expert client', an individual living with HIV/AIDS who informally acts as a community resource for other clients (Kaleeba et al., 1997).

Anecdotal evidence suggests that HIV service providers and HIV counselors in Uganda lack knowledge and skills to recognize and treat mental illness among HIV patients (Uganda Ministry of Health, 2005). Training for HIV counselors in Uganda does not include a module on mental illness (The AIDS Support Organisation (TASO) Uganda, 2012). There is also a paucity of information about this group, due to lack of standardization and monitoring of HIV counseling in Uganda (Senyonyi, 2012). The

HIV counselors' reach in HIV service provision however highlights the importance of exploring their perceptions concerning mental illness.

Chapter 2 Literature review

Introduction

In this section I review the literature relevant to this study and organize it thematically. The themes relevant to this literature review include HIV/AIDS in Uganda, examining the evolution of the epidemic and the Ugandan HIV/AIDS response strategy. The second theme is mental health problems of people with HIV/AIDS in Uganda, including prevalence and recommendations for management. The third theme examines HIV/AIDS care and support, and the evolution of HIV counseling in Uganda. Here I also review literature that describes the level of knowledge that HIV counselors may have concerning mental illness. The final theme is explanatory models of illness in general, and explanatory models of mental illness.

HIV/AIDS in Uganda

In Uganda, the HIV/AIDS epidemic has progressed through three distinct phases: the first phase, (early 1980's-1992) was marked by rapidly increasing prevalence rates, with the highest prevalence in 1992 at 2-30% (MOH, 2006). The second phase (1992-2000) was marked by aggressive public campaigns that saw lower prevalence rates of up to 6.4% (MOH, 2006), although this occurred mainly in urban areas. The third phase (2000 to date) has been marked by a plateau of HIV incidence at about 6.7% (MOH 2006), although evidence from the national surveillance survey points towards an increase in prevalence and incidence currently (Shafer, 2006). At present almost one million people are living with HIV/AIDS - 6.4% of all adults aged between 15-49 years.

HIV/AIDS Strategy in Uganda

The AIDS Control program (ACP) was created in 1987 as a separate entity under the Uganda Ministry of Health. The government of Uganda took on a multisectoral approach to respond to the

HIV/AIDS pandemic, owing to the fact that HIV/AIDS infection affected more than simply the health of the people. In this strategy however, the mental health aspects of HIV infection were not emphasized (Uganda Ministry of Health, 2005).

In 1987, The AIDS Support Organisation (TASO) was formed to provide medical and psychosocial support for People Living with HIV (PLHIV) (TASO Uganda, 2012). Since then a number of non-governmental organizations (NGO's), private—public partnerships and religious based organizations have been set up with support services for people living with HIV/AIDS.

HIV/AIDS and Mental illness

Mental health significantly impacts health outcomes of people living with HIV/AIDS (Musisi & Kinyanda, 2009) and many patients in HIV care do not receive mental health care (Musisi & Kinyanda, 2009). A study among 85 patients across 3 HIV clinics in the Western Cape, South Africa, showed that a considerable portion of the group were experiencing mental health problems, particularly HIV related PTSD without receiving any mental health treatment (Kagee & Lindi, 2010).

HIV/AIDS and mental illness in Uganda

In this section I will summarize the mental disorders common to HIV/AIDS and the prevalence of each disorder in HIV/AIDS patients in Uganda. The management of each disorder is discussed, with an emphasis on psychological management which is in line with the type of intervention that an HIV counselor in Uganda may be expected to carry out. The mental illnesses reviewed here include suicidal behavior, anxiety, substance (especially alcohol) abuse, psychotic disorders, HIV related mania and dementia.

Suicide rates in HIV positive individuals are similar to those in other medically ill populations, and are as high as 66 times that of the general population (Kinyanda, 2006). Suicidal behavior in HIV is common at initial diagnosis, during periods of deteriorating health and at points of bereavement

(Cooperman & Simoni, 2005, Kinyanda, 2009,). Clinicians and counselors assessing HIV patients need to routinely evaluate them for suicide risk, (Kinyanda, 2009; Rihmer, 2007).

Episodes of anxiety are common among HIV/AIDS victims (Kinyanda, 2009). Musisi and Kinyanda (2009) have reported prevalence rates for depression as high as 41% in HIV positive people. In Uganda, a high prevalence and severity of depression has been reported in association with HIV/AIDS, with symptoms including high sense of failure, dissatisfaction with life, guilt and loss of libido (Musisi, Nakasujja & Zziwa, 2006). Depressive symptoms are more common in later HIV clinical stages than in the earlier stages (Kinyanda, 1998) which implies that loss of health may be responsible for the onset of depression. Depression is also as a result of stigma that is associated with HIV infection (Musisi & Ashaba, 2005). However, the diagnosis of depression is often difficult because the symptoms are often obscured by the symptoms of HIV itself (Musisi & Akena, 2009), or perceived as understandable sadness or grief reaction to the effects of being HIV positive (Musisi & Akena, 2009).

There is also a two way relationship between HIV infection and substance (alcohol) abuse. People that are susceptible to alcohol abuse are at high risk for HIV infection (Kinyanda, 2009; Mbulaiteye et al., 2000). Alcohol abuse leads to reduced inhibitions and impairments in judgment which may increase HIV infection risk (Kinyanda, 2009; Weinhardt, Carey, Carey, Maisto, & Gordon, 2001). In addition, patients diagnosed with HIV/AIDS may take to alcohol abuse as they try to cope with the physical and psychological pain related to HIV infection (Kinyanda, 2009; Mbulaiteye et al., 2000).Counseling has been determined as efficacious in reducing alcohol consumption (Enoch & Goldman, 2002; Kinyanda, 2009).

Psychotic disorders that occur due to HIV infection are referred to as secondary (Maling, 2009) and may be due to an opportunistic infection, HIV encephalopathy or related to HIV medications (Maling, 2009). HIV infection is closely related to new onset psychosis (Maling, Grosskurth & Musisi, 2005). In Uganda, a study carried out in Butabika Psychiatric hospital revealed that almost 15% of

patients with psychotic disorders were HIV positive (Maling et al., 2002). Intervention for new onset psychosis or existing psychosis in HIV/AIDS requires both pharmacological intervention and psychosocial intervention (Maling et al., 2005).

Mania is also related to HIV infection. HIV related mania was responsible for almost 7% of admissions over a six month period in Butabika National Refferal Psychiatric Hospital in Uganda (Nakimuli-Mpungu, Musisi, Kiwuwa-Mpungu & Katabira, 2006). Nakimuli-Mpungu et al. (2006) notes that on the whole, HIV related mania presents differently from primary mania (this occurs as one phase of bi-polar affective disorder). Patients are more cognitively impaired and have more paranoid delusions and hallucinations (Nakimuli-Mpungu et al., 2006). Therapy for mania is mainly pharmacological, although psychological intervention may be required to help the person manage adherence and the double stigma related to having both HIV/AIDS and a mental illness (Musisi & Ashaba, 2005).

HIV associated dementia (HAD) is also common in HIV, and is most common in the late stages of HIV infection (Nakasujja, 2009). It is recognized by the American Academy of Neurology as a distinct category of dementia (American Academy of Neurology AIDS task force, 1991). The prevalence of HIV associated dementia in Uganda is 31% (Sacktor, Wong, Nakasujja, & Musisi, 2005) and HIV related dementia is one of the commonest forms of Dementia affecting young adults (Nakasujja, 2009).

Given the high prevalence and implications of various mental disorders amongst people living with HIV in Uganda, integrating mental health care into HIV care has the potential to positively impact the lives of people living with HIV/AIDS.

HIV/AIDS Care and Support in Uganda

At the forefront of HIV treatment and management in Uganda are medical professionals such as clinicians and nurses, who work hand-in-hand with a group of specialized 'HIV counselors' (Uganda Ministry of Health, 2005). They are called HIV counselors because their training in counseling is focused

on psychosocial factors related to HIV infection (TASO Uganda, 2012). HIV counselors are often trained

by specific HIV treatment centers such as TASO Uganda and the Mild May center which provide training

modules specifically for HIV counseling (TASO Uganda, 2012). The counselors are employed by HIV

service care centers countrywide, and HIV departments at all national health centers (MOH, 2005). This

group of service providers usually have a minimum of a Diploma in a health science related field and

receive an additional six month's training on the basic tenets of HIV/AIDS, including pre- and post test

counseling, supportive counseling and positive living (which entails activities of daily living necessary

for an HIV positive person). The counselors have the highest number of contact hours with HIV clients as

counseling is often part of routine clinic visits. Counselors also attend to clients on issues such as

adherence, handling HIV related stigma, safe sex practices, and they often carry out health talks on clinic

days (TASO Uganda, 2012).

The HIV counselor is also expected to provide home based care for those clients that may be too

weak to attend the clinic (TASO Uganda, 2012). HIV counselors also liaise with families to support the

client (TASO Uganda, 2012). The HIV counselor is a team leader in community outreach efforts that

usually focus on a number of HIV related topics like prevention, HIV testing and living positively with

HIV. Such community campaigns have been successful in Uganda in promoting public health concerns

like prevention and combating stigma (TASO Uganda, 2012; MOH, 2005).

Evolution of HIV counseling in Uganda

Counseling in Uganda has its roots in the traditional lore and culture of Ugandan people, it was

promote with guidance in schools, finally being popularized in the HIV/AIDS prevention and control

strategies (Senyonyi, Ochieng & Sells, 2012). The non-formal traditional counseling system is

responsible for providing guidance to an individual at key events in life such as child birth, marriage,

death, and generally guiding an individual through life (Senyonyi et al., 2012). This system may ensure

that individuals have views on key life events that are firmly based in their cultural beliefs. Religious

institutions also play an important role in counseling, and the major religions in Uganda are Christianity (85%) and Islam (12%) (Uganda Bureau of Statistics, 2011).

Today, HIV treatment centers offer counseling services to mitigate the effect of HIV/AIDS on the family, workplace and community (Senyonyi et al., 2012). Organizations providing HIV/AIDS care and treatment often train their own counselors (Senyonyi et al., 2012), and these trainees are termed "HIV Counselors" (Senyonyi et al., 2012). These organizations have also taken on community-based counseling as an attempt to add depth to HIV/AIDS counseling (Balmer, Seeley, & Bachengana, 1996; Kaleeba, Kalibala & Kaseje, 1997).

The system of HIV counseling

During HIV counseling individuals or couples undergo HIV pre-test counseling followed by a rapid HIV test. Post-test HIV prevention counseling is conducted when an individual is found to be HIV negative; while referral for medical and support services takes place when an individual is HIV positive (Irungu, Varkey, Cha, & Patterson, 2008). This step wise HIV counseling process may provide opportunities for disseminating information concerning mental health issues in HIV. Furthermore, there has been a shift from facility based Voluntary Counseling and testing (VCT) (Mulogo, Abdulaziz, Guerra & Baine, 2011) to a community wide VCT (Mulogo et al., 2011) approach which increases the opportunity to reach more people with information concerning HIV and mental health.

The HIV counselor. This may be anyone who has undergone counselor training ranging anywhere from 3 days to 3 years (Senyonyi et al., 2012). In some cases the HIV counselor is in fact an 'expert client', an individual living with HIV/AIDS who informally acts as a community resource for other clients (Kaleeba et al., 1997). The Uganda Counseling association has made some headway in defining counselors, in order to differentiate between professional counselors and individuals that have been equipped with a few basic skills to target a particular problem (Uganda Counseling Association [UCA], 2007). The first among these categories is the para-counselors, who are all individuals assisting

with the psycho-social problems within society and HIV counselors fall within this category (Senyonyi et al., 2012). HIV counselor training has been needs based, and continues to grow and evolve to cover emerging issues in HIV support. Mental health, however, is not part of the training approach within the HIV training and testing toolkit (Uganda Ministry of Health, 2005).

Mental health knowledge among HIV Counselors and community workers

HIV counselors and community workers have the highest number of contact hours with HIV patients; but training for HIV counselors in Uganda does not include a module on mental illness (Uganda Ministry of Health, 2005). HIV counselors may therefore lack knowledge and skills to recognize and treat mental illness among HIV patients. Lack of knowledge and skills to manage mental disorders is common among low level health service providers (Atkin, Holmes & Martin, 2005; Hansen, Fink, Frydenberg & Oxhoj, 2001). A study by Atkin et al. (2005) among nurses working with the aged in a general hospital setting revealed that the nurses would suspect that a patient had a mental health problem, but would not know what it was. The nurses revealed that their training was insufficient to detect and manage mental illness. Another study by Hansen et al. (2001) revealed that only about half of mental illness cases were detected and referred by nurses among internal medical inpatients.

One potential reason for the low rate of detection of mental illness is that healthcare providers, including HIV counselors have varying cultural views of mental illness. Cultural views and explanations about mental illness may play an important role in the way HIV counselors may understand and explain mental illness. These views may not be entirely eliminated by formal training and may continue to affect the way an individual offers services to patients and clients (Lobban et al., 2003). However, at the present time very little is known about their perceptions of mental health and an exploration of HIV counselors cultural views of mental health is warranted.

Culture & Mental Health

In cross-cultural psychiatric research there are predominantly two schools of thought, the universalistic and relativistic positions, which view and operationalize the importance of culture in different ways (Kleinman & Good, 1985). The universalistic view posits that psychiatric disorders are universal and have specific symptoms that cluster into universal patterns (Canino & Alegria, 2008, Canino, Lewis-Fernandez, & Bravo, 1997). According to this view, what could vary across cultures or sub-groups within a culture is the symptomatic manifestation of the disorder or the threshold of what is considered pathological versus normal behavior (Canino et al., 1997). The relativistic view on the other hand posits that culture can shape on one hand the manifestation and content of symptoms of mental illness, but also the development of a symptom cluster (Canino & Alegria, 2008).

Both these perspectives have their strengths and limitations. Research premised on the universalistic (etic) approach emphasizes impartiality on the part of the researcher (Kottak, 2006) but tends to exclude people that are mentally ill but do not fit the predetermined diagnostic criteria (Patel, 2005). On the other hand, while research that is premised on the relativistic/ emic approach respects the uniqueness of the context being studied, and increases the chances of uncovering unexpected findings (Headland, Pike & Harris, 1990) the emic approach also presents difficulty in making comparisons across cultures (Patel, 2005).

There are a number of other research studies that that have shown an integration of both etic and emic approaches in cross-cultural psychiatry. One example is by investigating the explanatory models of healthcare providers, including HIV counselors. The next section explores this in more detail.

Explanatory models of mental illness

For this study, HIV counselors' perceptions of mental illness are explored through the explanatory models of illness framework. This refers to the way an individual thinks about illness and its

treatment (Kleinman, 1980). Explanatory models that individuals hold include their ideas on the causes of illness, how the illness progresses and how it can be treated (Ghane, Kolk & Emmelkamp, 2012). Originally, Kleinman (1978) presented the explanatory model of illness as a method to understand how patients view their conditions and their expectations of a cure. The aim was to help clinicians improve patient care by helping them appreciate their patient's conceptualization of illness as it was affected by their social or cultural background (Kleinman, 1978). However, the ways in which people think about illness has been associated with behavior and emotional reactions among patients, carers and professionals (Lobban, Barrowclough & Jones, 2003). This suggests that explanatory models need to be understood, not only from the point of the view of the patient but also the service provider, in this case the HIV counselor.

Explanations that are inconsistent with an individual's explanatory framework: (1) may not be considered, (2) may seem implausible, and (3) may be seen as less satisfactory than those which are consistent with it (Lynch & Medin, 2006). This also highlights the importance of understanding individual explanatory models of illness. Understanding individual explanatory models of illness is perhaps even more important when dealing with health service providers because beliefs held by professionals may affect the treatment offered to the client (Lobban et al., 2003). In essence, the patient will be offered only that treatment that the service provider deems necessary as per their understanding or explanatory model of the patient's illness. In some instances therefore, a patient's illness may be misdiagnosed or not properly treated.

Illness explanatory frameworks tend to lie along two broad categories. There is a distinction between those explanatory frameworks which attribute illness to physical causes and those which attribute illness to psycho-social factors (Foster, 1976; Kleinman, Eisenberg & Good, 1978; Kleinman & Gale, 1982; Kleinman & Sung, 1979; Murdock, 1980; Shweder, Much, Mahapatra, & Park, 1997). The most common physical explanatory model of illness attributes illness to bio-medical causes (Lynch & Medin, 2006). These propose that illness comes about as a result of disruptions or breakdown in one's

bodily or physiological processes (Lynch & Medin, 2006). On the other hand, psycho-social explanatory frameworks attribute illness to thoughts or emotions, which usually result from social factors (Lynch & Medin, 2006). The psycho-social explanation of illness is quite common since illness is attributed to psycho-social causes in many cultures (Evans-Pritchard, 1937; Murdock, 1980). Another form of psycho-social explanation of illness comes from alternative medicine practitioners who attribute illness to negative thinking or harmful thoughts (Baer, 2001), or negative belief patterns and unresolved stress (Myss, 1996).

Some individuals integrate both psycho-social and physical causes into a single model (Comaroff, 1978; Evans-Pritchard, 1937). Here, the individual does not deny that there is a physical agent responsible for causing the illness, for example, a virus, bacteria, or parasite. However, the individual also upholds that there must be a social agent, in particular an individual or a spirit, (Evans-Pritchard, 1937) responsible for sending the disease pathogen.

Conceptualizations of mental illnesses have been documented among the Baganda, which is the majority tribe in the Lake Victoria region in Uganda. The Baganda classify mental illness into four parts; these include *Eddalu*, which closely resembles Western psychotic features with violent tendencies. The second category is *Ensimbu* which translates as epilepsy (Patel, 1995). Category three is *Obusiru*, best translated as foolishness (Patel, 1995). Finally, there is *Kantooloze* or dizziness (Patel, 1995). This category may be a somatic representation that may be related to a wide range of symptoms from delirium, pressure of thoughts or a subjective feeling of being confused (Patel, 1995). Two neurotic conditions are also recognized, which include *emmeeme etyemuka* or pounding of the heart with fright and *emmeeme egwa,* which is general body weakness and loss of appetite that may be common in depression (Patel, 2005).

The Baganda also categorize mental illness based on aetiology, categories include those that come by themselves, and those caused by witchcraft, the strong mental illnesses and the weak, and finally

the Kiganda (caused by ancestral spirits) and the non-Kiganda (those more related to Western medicine) (Patel, 1995). In addition, psychotic illness in Sub Saharan Africa is often recognized as 'madness' while neurotic presentations are often more somatically defined and often not considered mental disorders at all (Patel, 1995). However, the Baganda do not have direct translations for common psychiatric disorders, which poses a challenge in assessment and psychological counseling (Senyonyi et al., 2012).

There are significant similarities in traditional views concerning mental illness in Sub Saharan Africa (Patel, 1995). One significant attribution for mental illness, widespread in African culture is the idea that mental illness is caused by spirits (Patel, 1995). Mental illness is also often attributed to witchcraft, and when it becomes chronic and perceived to be incurable, it is said to be in God's hands (Aidoo & Harpham, 2001; Good, 1987). Lay people often relate mental illness to religious beliefs and it may be seen as the will of God; recovery can therefore only be achieved through prayer and higher commitment to religious practices (Schnittker et al., 2000). Beliefs in witchcraft and religious attributions for mental illness may not be held by lay people alone; professionals may also endorse such beliefs because of their own cultural and religious backgrounds. On the other hand, professionals may not spontaneously offer cultural and religious explanations for mental illness, but rather tolerate them, knowing the value that such beliefs hold in society (Aidoo & Harpham, 2001).

Some non professionals may endorse a biological cause such as heredity or chemical imbalance in the brain as some of the natural causes for mental illness (Schnittker et al., 2000). This is because lay explanations of mental illness may be influenced by interactions with medical professionals (Aidoo & Harpham, 2001). In the same way, the media also often influences lay models of mental illness (Schnittker et al., 2000). It is therefore plausible that HIV counselors may have biological/medical explanations for mental illness, given that they work on close proximity with medical professionals.

Vignettes to Investigate Explanatory Models of Mental Illness

Most of the research investigating explanatory models of mental disorders has been conducted on patients living with a mental disorder, using a modified version of either the Explanatory Model Interview Catalogue (EMIC) or the Short Explanatory Model Interview (SEMI) (Alem, Jacobsson, Araya, Kebede, & Kullgren, 1999; Muga & Jenkins, 2008; Okello, 2006; Patel, Gwanzura, Simunyu, Mann & Lloyd, 1995). Few studies have investigated explanatory models among healthcare providers (Patel et al., 1995). Patel et al. (1995) carried out qualitative interviews among 76 care givers including community workers, traditional healers, relatives of patients and psychiatric nurses to elicit concepts of mental illness in Zimbabwe. Results indicated that participants identified a mentally ill patient by their behaviors such as wandering away from home, eating or smearing themselves with fecal matter, inappropriate laughter, impaired self-care and eating dirty food. Three case vignettes were used that described cases of non-psychotic disorders including: (1) a depressed woman, (2) a man with agoraphobia and panic attacks, and (3) and a woman with medically unexplained somatic symptoms. Although the description of the patient was recognized by all care givers, most said that the descriptions provided did not reflect an illness, but a psychological problem that resulted from external factors such as poverty, alcoholism, or poor marital relations. The participants in the study rarely regarded non-psychotic disorders as a medical problem and are almost never referred to them as mental illnesses.

According to the few studies conducted in Africa investigating the explanatory models (EMs) of mental illness, there appears to be a distinction between those of psychotic (e.g. schizophrenia and bipolar disorder) and non-psychotic disorders (Aidoo & Harpham, 2001; Patel et al., 1995, 1996). Patel (1996) hypothesizes that many Africans do not distinguish between non-psychotic and psychotic disorders, mainly because they are unable to identify non-psychotic disorders as being related to mental illness. However there is insufficient data to support this view since only a few studies have been conducted addressing this issue, none of them recent, and few outside Zimbabwe.

Effect of explanatory models of mental illness on service provision

As earlier noted, the ways in which people think about mental illness has effects on patients, carers and professionals alike (Patel, 1995). Beliefs about the cause of mental illness have been related to the treatment options that service providers offer patients (Cape, Antebi, Standen & Glazebrook, 1994). When the provider views the cause of a mental illness as having a psychosocial cause, then they are less likely to emphasize pharmacotherapy in the treatment plan and instead recommend psychotherapy or social support (Cape et al., 1994).

Mental illness such as anxiety and depression may sometimes be seen as a natural part of syndromes such as HIV/AIDS and may be viewed as expected, following a diagnosis of HIV/AIDS (Aidoo & Harpham, 2001; Musisi & Akena, 2009). In this case the client's low mood may be erroneously viewed as "understandable sadness" (Musisi & Akena, 2009). Musisi and Akena (2009) point out that symptomatic and non symptomatic HIV positive individuals do not differ on depression prevalence, therefore HIV patients that complain of fatigue or insomnia should routinely be assessed for depression.

Symptoms of depression may also be attributed to relational problems or socio-economic situations of the patient, as a study in rural Zambia revealed (Aidoo & Harpham, 2001). Such a "normalizing" perspective may obscure the correct underlying diagnosis and result in failure to recommend potentially effective treatments (Kurian, Abraham, Kathryn & Connor, 2004). In addition, patients with depression and anxiety often present with somatic complaints, and the underlying mental illness may go undiagnosed by the unskilled health service provider (Aidoo & Harpham, 2001). This may well be the case with HIV counselors. In practice, the terms "stress and depression" may be used interchangeably to explain the clients symptoms (Aidoo & Harpham, 2001), but perhaps without a clear understanding of the clinical significance of the term 'depression'.

Provider's beliefs about the measure of control that patients have over their symptoms also affect the patient-provider relationship (Lobban et al., 2003). When service providers perceive that patients have more control over their symptom related behavior; they tend to be less positive and accepting (Lobban et

al., 2003). An attribution of controllability results in less helpful behavior by service providers (Weiner, 1988, 1990). This situation is worsened if the counselor does not recognize that the individual's behavior is due to mental illness.

Beliefs about the efficacy of treatment in controlling symptoms have also been explored (Lobban et al., 2003. Some links have been reported between professionals' beliefs that client symptoms can be alleviated by certain kinds of treatment and treatment plans, increasing the chance that these treatments will be recommended or offered (Caldwell & Jorm, 2001; Jorm, Angermeyer& Katschnig, 2000). The implication of this is that the HIV counselor may only refer the client to those treatments they believe will help the client. The referral process however is undermined by lack of information on the client's problem (being unable to recognize mental illness) and the available therapeutic interventions. However, the link between how beliefs impact on actual practice has not been established (Lobbban et al., 2005).

Given the key role of the HIV counselor in the care and treatment for HIV positive people, who may often face mental health challenges as has been explained in the literature; it is important to explore the HIV counselors' perceptions of mental illness. However, a review of literature on HIV counselors in Uganda reveals no published information on their perceptions concerning mental illness (Uganda Ministry of Health, 2005). As previously mentioned, HIV counselors in Uganda do not receive routine mental health training. This section therefore focuses on lay perceptions of mental illness. These perceptions, depending on the social, political and or cultural contexts may differ or be comparable to those of professional mental health service providers (Schnittker, Freese & Powell, 2000). Some research however has been done elsewhere on perceptions of mental illness among health service providers, by using vignettes to investigate explanatory models of these service providers.

Conclusion

As can be seen from the review of literature above, there is paucity of literature concerning HIV counselors in Uganda in general, and their understanding and handling of mental illness specifically. This study will therefore provide information on the knowledge and explanatory models of mental illness among HIV counselors.

Study Rationale

HIV counselors have a wide coverage, meet HIV clients within the clinic setting and have access to the clients' family and the community at large. In this study I explore the extent to which HIV counselors can identify mental health problems and the extent to which they believe these problems affect the lives of their clients. Perceptions of mental illness among HIV counselors need to be understood because they may affect referral and service provision. If for example, the counselor believes that the individual's mental health problem, such as depression, originates from a problem beyond their control such as poverty; or that a problem such as psychosis is due to ancestral spirits, this may affect the extent to which the counselor may offer otherwise efficacious psychological intervention or referral for psycho-pharmacological treatment. In addition, counselors may hold negative and potentially stigmatizing views concerning mental illness which portray people with mental illness as dangerous (Schnittker et al., 2000), and this may have a detrimental effect on the counselor-client interaction. Data from this study could form a basis for training HIV counselors to recognize and appropriately refer cases of mental illness among HIV positive clients.

Aim

The aim of this study is to explore perceptions of mental illness among HIV counselors in Uganda.

Research questions

1. What is the knowledge about mental illness amongst HIV counselors?

2. How do HIV counselors explain mental illness among their clients, including the causes and overall effects of mental illness on life outcomes?

3. How do HIV counselors perceive their role in addressing mental illness in HIV positive people?

Chapter 3 Methods

Introduction

In this section I outline the study design, setting, population and sampling. Data collection and analysis are included. Finally, I describe the ethical considerations for the study.

Study design

An exploratory qualitative study design was used. Qualitative research designs enable the researcher to answer the questions of "*what*", "*how*" and "*why*" things happen the way that they do in the social world (Hancock, 2002; Moriarty, 2001; Patton & Cochran, 2002), as compared to quantitative research which seeks to answer questions such as "*how much*", "*how often*" and "*how many*" (Patton & Cochran, 2002). The rationale for using a qualitative research design was to obtain a rich description and a deeper understanding of the HIV counselors' perceptions of mental illness (Patton & Cochran, 2002).

Setting

The study was carried out in Kampala, the capital city of Uganda. Kampala city is located in central Uganda, on the shores of Lake Victoria. The city has a population of approximately 1,659, 600 people (Uganda Bureau of Statistics, 2011). The main languages spoken in Kampala are Luganda and Swahili, although the official national language is English. Kampala is the center of HIV services in Uganda and many HIV service centers have their headquarters in and around Kampala. Activities under these HIV service provision centers include HIV counseling and testing, treatment, ongoing supportive counseling for HIV positive clients and their families, home-based care and various community outreach activities.

Study Population

The study participants were HIV counselors in Kampala district. Kampala district was chosen because, as earlier mentioned, it is the hub of HIV service provision in Uganda, and serves clients from various regions of the country. The participants were recruited from five HIV treatment centers within Kampala district, including:

- Mild May Uganda

- The AIDS Support Organisation (TASO)

- Kampala City Counsel Clinic, Kawempe

- Nsambya Hospital Home Care

- Mengo Hospital Home Care

These centers were chosen because they are all established HIV treatment centers in Kampala district and provide HIV counseling and treatment services, and therefore have full time HIV counselors. The centers were also accessible in terms of distance. The original plan was to interview counselors from seven HIV care and support centers within Kampala. However, this was not possible because the institutional procedures from two centers could not be fulfilled.

Sample size and sampling methods

Using a purposive sampling approach, a sample of 31 HIV counselors was obtained from a population of counselors in the five centers. Recruitment was undertaken with the assistance of the counseling co-ordinators who provided the necessary introductions at each site. Appointments were made to engage the counselors at these centers in individual interviews and focus group discussions. The selection of counselors was based on the following inclusion and exclusion criteria:

Inclusion Criteria: minimum of two years experience working as an HIV counselor at one of the stipulated HIV care and counseling centers. Two years working as an HIV counselors was

assumed to be sufficient experience with the dynamics surrounding HIV patients to allow the counselor contribute to the discussions.

Exclusion Criteria: professional training in any mental health related field. Since HIV counselors are not routinely trained in mental health in mental health care, contributions from a an HIV counselor with mental health training would have potentially biased the results and not give a true depiction of the Ugandan HIV counselor

Measures and instruments

Initially, seven case vignettes were developed based on mental illnesses reported among HIV patients in Uganda including depression (with suicidal ideations), anxiety, substance abuse, PTSD, psychosis, mania and dementia. A senior psychiatrist reviewed the vignettes to ensure that they met DSM-IV criteria (See Appendix 1). An interview guide based on Kleinman's explanatory model of illness was also used to facilitate the discussions. Questions on the interview guide included; "which of the conditions was familiar to the respondent" "the name given to the condition", "the causes of the condition" and "how the counselor felt this client could be helped". One question was added; "*How do you think you can be helped in your work to handle that person better*". This was to elicit counselors' perceptions on the possible factors that would make it easier for them to deal with cases of mental illness within their work settings (see Appendix 2).

Data Collection

Individual interviews and focus group discussions were carried out at the selected centers. The interviews and focus group discussions were conducted in English as all HIV counselors have a minimum of A' Level English grade before recruitment.

Individual interviews were conducted first. Interviews were carried out in the counselors' consultation rooms. At the start of each interview, each respondent was provided with a participant

information sheet and an informed consent form. The contents of the consent form were also verbally restated. The seven case vignettes were then presented to the respondent, and the first question on the interview guide "which of these conditions is familiar?" was used to initiate the discussion. When the respondent indicated that they had no more new information to offer on the current case vignette, they were asked whether any other condition on the list of case vignettes was familiar.

After the first five interviews had been conducted the pool of case vignettes was reduced to four. This was because some of the vignettes were consistently not selected for discussion by any of the participants, even when they were invited to do so. The case vignette on anxiety was selected by the first respondent, but during the course of the interview the respondent chose instead to focus on depression. Specifically, case vignettes on Anxiety, dementia, PTSD were eliminated, leaving depression, alcohol abuse, mania, and psychosis.

Although an interview guide was used, flexibility was allowed to follow up important leads as they arose during the interview. Individual interviews were conducted until no new information was obtained. An initial analysis was completed after every three interviews in order to obtain an understanding of the emerging issues. This information was used to determine necessary changes in subsequent interviews, in order to follow up on emerging mental health issues.

Three focus group discussions of 5-9 participants each were also carried out. The focus group discussions did not include respondents from the individual interviews. Two case vignettes were presented to each group and an interview guide was used to facilitate the discussions. The group was under no obligation to discuss both the case vignettes, and only one focus group elicited discussion of more than one case vignette. This is further clarified in Table 1, under the results section. All interviews were audio-recorded, with the informed consent of the participants and written notes were also made to ensure quality of the transcription.

Data management and analysis

Audio-recorded interviews were transcribed by two undergraduate psychology students. The analysis was performed electronically (using Atlas Ti version 5.0) and manually. The distinction between electronic and manual analysis for my data is further explained in the section on "searching for themes" below. Thematic analysis was used to analyze the data. Thematic analysis is "a method for identifying, analyzing and reporting patterns (themes) within the data" (Braun & Clarke, 2006, p.6). Thematic analysis allows for thick description of data (Braun & Clarke, 2006) and was deemed suitable for this study because the aim was to identify HIV counselors' perceptions concerning mental illness. Overall, the steps in analysis followed the process described by Braun and Clarke (2006).

1. **Familiarizing myself with the data**: The analysis began with repeatedly reading the transcribed interviews to become more familiar with the data. This was important as I did not transcribe the interviews myself. During this process I also translated some words and sentences that had been spoken in Luganda, although the interviews were conducted in English. The transcribed interviews were also checked against the original audio interviews to ensure accuracy.

2. **Generating initial codes**: After an in-depth understanding of the content was gained, initial codes were applied to relevant segments of the data. This was done using Atlas Ti software Version 5.0. Originally, a code list had been developed based on the theory of explanatory models of illness to provide an initial framework for coding. During the coding process, however, new codes had to be developed to cater for data that did not fit the initially developed code list, but were relevant for the analysis.

3. **Searching for themes:** Sets of codes referred to as 'Code families' (Muhr & Friese, 2004, p. 202) were automatically generated in Atlas Ti version 5.0. These code families were printed out and from this point, the analysis continued manually. The decision to revert to manually analyzing the data was for practical reasons; chief amongst them was to limit the expense of

enlisting the support of a senior researcher who had supervised the electronic analysis process to this point. The codes were therefore manually organized into broad themes.

4. **Reviewing themes:** A thematic mind map was created after each broad theme was thoroughly examined in comparison to the original data set.

5. **Naming and defining themes:** The broad themes were refined and further broken down into sub themes. The resulting themes and subthemes were reviewed to ensure that they captured the essence of the original data. Finally, each theme was clearly named and defined.

6. **Reporting:** extracts that clearly display the themes within the data were selected for incorporation into the analysis report.

Ethical issues

Ethical clearance for this study was obtained from Stellenbosch University Health Research Ethics Committee and from the Uganda National Council for Science and technology. Permission to conduct the research was also obtained from the centres where the study was carried out. Informed consent was obtained from all study participants. Consent forms were presented to all participants before the individual interviews and focus group discussions (see participant information leaflet and consent form for Individual interviews Appendix 3, and participant information leaflet and consent form for focus group discussion, Appendix 4).

Voluntary participation. Counselors working at the various study sites were invited to take part in the study. The voluntary nature of the study was clearly explained. Counselors were informed that they did not have to take part in the study if they did not want to and that they could withdraw and stop the interview at any time without any adverse effect. However, all counselors informed about the study gave their consent and participated.

Confidentiality. Counselors were assured that any information that may identify them or that may be linked to them would be kept strictly confidential.

Procedures to safeguard confidentiality. The following steps were taken to ensure confidentiality for each participant. Names of respondents were omitted from all study data and replaced with a number. All recordings were stored in a locked cabinet at a secure location. All soft copies of data were password protected. Information that could potentially identify a respondent was omitted from study notes and transcribed data. These documents were only accessible to my supervisor and myself. After data had been analyzed and the results reported, all data would be archived for two years after which it will be destroyed.

Participant incentives. Participants were given 10.000 Uganda Shillings (4 USD) for lunch and refreshments.

Anticipated risks. There were no physical risks associated with participation in this study. Possible risks were that individuals could experience pressure to enroll in the study from their supervisors. The interview format contained the risk of potential loss of confidentiality, interview fatigue and some counselors could face discomfort over having to acknowledge lack of knowledge about mental health issues. Study procedures were designed to reduce these risks.

Minimizing risk. The voluntary nature of the study was clearly explained during the informed consent process and participants were reminded regularly that they could withdraw from the study at any time without adverse consequences. Each participant's right to confidentiality was protected and the steps that would be taken to maintain confidentiality were outlined. Participants were offered a break during the interview if they displayed signs of fatigue and reminded that they could stop at any time. In addition, participants were reminded that their responses would not influence their job evaluation in any way.

Anticipated benefits. There were no direct benefits for participants. The potential benefit to the field of mental health and HIV/AIDS care and support was to gain a better understanding of the issues that HIV counselors face when supporting clients that may have mental illness. This understanding would enable policy makers and counselor trainers to design interventions that promote proper management of mental health issues in HIV counseling.

Reporting of Results

The research results were presented at the World Psychiatry Association regional meeting in Kampala Uganda (6th -8th Feb 2014). Copies of the research results, including recommendations, will be provided to all the centers where this research was conducted. An academic paper will be prepared for publication in a peer reviewed journal.

Chapter 4 Results

Introduction:

The results are presented in four parts. First, is a description study participants; second, is a description of the data analysis process by which the themes and sub themes were developed. The third part focuses on the themes and sub themes themselves which emerged from the research; and finally, the fourth part is a summary of the results.

Description of study participants

A total of 31 HIV counselors participated in the study. They were drawn from five HIV treatment centers within the district of Kampala. Of these 9 were male and 22 were female (see Table 1). Participants ranged from 30 to 48 years of age with a mean age of 36 years. The majority of participants (25 of 31, 60%) came from the Baganda tribe. All interviews were conducted in English. All respondents had at least two years working experience as HIV counselors. A total of ten individual interviews and three focus group discussions were conducted over a two month period. Each focus group consisted of 5-9 participants. A total of 21 counselors participated in the focus group discussions (see Table 1).

Defining themes and sub themes:

It is noteworthy that the themes and sub themes explained here focus on substance abuse, depression and suicidal ideations, psychosis and mania in no particular order. These are the case vignettes/disorders that respondents said represented a familiar condition.

Table 1

Number of Participants per Interview Type

Study Site	Interview Type	Participant		Case Vignette(s) discussed	Total Number of participants
		Male	**Female**		
TASO Mulago	*II	1		Anxiety, depression	
	II	1		Psychosis	
	II	1		Depression	
	II		1	Mania, psychosis	4
MILD MAY Center	*FGD	3	6	Psychosis, Mania	9
	II	1		Depression	
Mengo Hospital	II		1	Substance abuse, Depression	
	II		1	Depression	3
Kawempe Kampala City Council Clinic	FGD		7	Substance Abuse, Psychosis	7
	II	1		Depression, Psychosis	
Nsambya Hospital	II	1		Psychosis	
	II		1	Substance Abuse, Depression	3

*II-Individual Interview FGD- Focus Group Discussion

The discussion about anxiety did not yield any substantial information and vignettes on dementia and PTSD were not selected for discussion by any of the respondents. These three disorders were not included in the analysis. The implications of this are further detailed in the discussion section. Another point to note is that the terms "mania" and "psychosis" were not used by any of the counselors to describe any set of symptoms as depicted by the corresponding case vignettes. The implications of this are also further discussed later. However, they were able to express their opinions concerning the case vignettes representative of these mental illnesses and this forms a considerable part of the results as shown in this section. The broad themes and the accompanying sub themes are described below:

1. **Clients' psychosocial reality**: Sub-themes within this were stress and psychological pain, poverty, social support, stigma, denial and disclosure.

2. **Counselors' medical and biological explanations**: This theme had two sub themes: HIV drugs and their influence on mental health and how disease progression was related to the client's mental health.

3. **Clients' supernatural belief systems**: The beliefs discussed by counselors mainly fell into two categories or sub themes, namely beliefs in African Traditional healing, witchcraft, ancestral spirits, as well as religions including Christianity and Islam.

4. **Counselors' perceptions of clients' physical and emotional problems:** Two sub themes emerged from this theme. These were: clients with strange behavior and emotional problems with physical manifestations.

5. **The counselor's daily reality:** This included three sub themes namely: counselors' self efficacy; no expertise, no time, and finally, dealing with the difficult client. This last sub theme contained three parts: confronting/threatening, ignoring the problem or the client, and lastly referral.

The names of the counselors and the HIV treatment centers have been replaced with codes to maintain confidentiality.

Theme 1: The client's psychosocial reality

This first theme was the description of the psychosocial issues that impacted an HIV positive person. The sub themes that emerged were: clients' stress and psychological pain, poverty, social support, HIV stigma, disclosure of one's HIV status and denial of HIV status.

1.1: Client's stress and psychological pain

According to the counselors, clients experienced stress and psychological anguish because they were living with HIV. This psychological pain could result from the client's negative thoughts, and their perception that life was hopeless, or useless since they were HIV positive.

...this is a young girl, she thinks that being positive is the end of life. That is the stress, that's when she doesn't sleep; she doesn't have any hope. This is the patient I had. First, she doesn't have a child. Then she said 'I am still young (and) I am HIV positive, really why am I on this earth? (R7II)

The counselors said that their clients often experienced multiple stressors; a situation which they described as being compounded by the fact that they were HIV positive.

I had this case for example ...he was HIV positive, his wife died via boda (public motorcycle) accident. So he was left with three children, the eldest child was three years. Now in this case he is a single father, has an issue of children which causes stress. He even wanted to commit suicide because of everything he was going through… .... The youngest child was tested and the results were positive so I also had to talk about the child. He is having HIV, he is stressed because of the partner's death, and then there comes the situation of the baby also being positive (R9II).

Participants explained that as a result of the constant stresses and psychological pain, clients often became depressed. This was sometimes followed by alcohol abuse in an effort to alleviate the psychological pain which they felt.

....there is that level of hopelessness. I don't know which word would describe that kind of situation, but I look at that as somebody who is bordering on depression (R2II).

....this client was complaining… 'They are saying I should stop alcohol but how do I deal with the pain you know I have….....At least when I take alcohol I feel good...…most will tell you 'when I take (alcohol) I will feel better (R8II).

1.2: Poverty

Poverty was described as playing a critical role in the life of an HIV positive person. For many clients, poverty was a source of stress that led to symptoms of mental illness. Counselors gave examples of clients whose problems were rooted in poverty and described their 'strange behaviour'. Such clients reported frustration because they were unable to provide for their families and saw no way out of their predicaments.

…A client says…. 'I have a wife at home, she is not working, I have no money and my children are supposed to go to school; who is going to pay school fees for them….' So slowly but surely the next step you see this person is running mad (R2II).

I can't tell but I think it was psychological torture…because she lost a husband when she was pregnant. She had five kids, three of whom were going to school; she wasn't working, they were staying in a slum, and the landlord chased them out of the house...she had no parents …she had nowhere to go (R4II).

When you try to dig deep, ahh you get somebody who is frustrated, because of abc….because their children are not going to school anymore, or the husband is not providing for them anymore…you get someone totally getting hopeless and they don't even have any kind of plans for themselves (or) for their families (R2II).

It was also suggested that alleviating poverty would help to alleviate the symptoms of mental illness:

You work on how to help this person…so that they can get some form of income generating activity…that way the person can get a way to pay their rent and take their children to

school…most of the time it is because they are stuck and have no way to go on, no capital. So

you help them to think about how to go about that and they will be better, when she starts

working then the sadness she came with starts to disappear, the appetite comes back (P3FGD3).

1.3: Social support

Counselors described the client's social support system as playing a key role in the client's life. Sometimes this support system broke down. According to the counselors, this would severely affect the HIV positive person leading to emotional and behavioral problems:

…When they come they have problems like you have heard, for example she may be in a

discordant relationship, the spouse is accusing her of being unfaithful….they feel guilty for

bringing HIV to the family and the person that would have supported them is instead accusing

them, so she no longer has any social support, she wants to kill herself, she is in a depression (P5

FGD3).

….others were being neglected by the family members .....so they decided to go and take alcohol,

come home late, sleep and wake up early in the morning and rush to go back to work to avoid the

onlookers (R7II).

Social support also played a pivotal role in the treatment process. Family members acted as treatment supporters that monitored the client's drug adherence. Counselors would work with family members to support clients with mental health problems. Several references were made to the 'caretakers at home', 'the treatment supporter' and 'the family support system':

…then we call the treatment supporter…we normally ask before we start someone on ARV's to

bring a treatment supporter to support this patient on ARV's (R7II).

....we used the caretakers at home, because she was staying (nearby) here at Kyengera (nearby village). So we used the caretakers at home together with the members here to support that girl (R9II).

1.4: HIV Stigma

HIV-related stigma was said to lead to many emotional and behavioral problems among HIV positive people. Clients were seen as being in a constant state of apprehension about the community's perception of them, because HIV infection was often associated with promiscuity. This state of apprehension was believed to lead to some of the mental health problems that HIV positive people may have had as reported by these counselors:

You see not all of them are really infected through sex though the big percentage is through sex…so that's what the world thinks about the HIV positive person. They actually think everyone has had it through promiscuous sex, so that perception also affects them (P5FGD2).

…you know all those problems…how am I going to tell people that I am HIV positive? So at the end of the day this person starts going, going and going slowly but surely… the next step you see this person is running mad (R4II).

Stigma was also said to result from the fact that the HIV positive persons may lose the means to support themselves economically, due to ill health. As a result the individuals would become dependent on other people. This inability to support oneself and one's children was presented by the counselor as a source of stigma:

....the stigma that is surrounding this guy…. so and so is saying this guy is a failure, the soldier is a failure, you know… and probably the comments you get from the family…you can't fend (for yourself) or for your own; you have to depend on someone else (R2II).

1.5: Denial of HIV status

It also emerged that denial was common among HIV positive people, and that denial was as a result of HIV related stigma. Denial was said to be especially common after the individual had just found out that they were HIV positive. As this participant explains, living in denial predisposed one to mental health problems:

> *…Those ones are very many; they are in denial. People are always in denial and they think of so many things…you find someone with such effects but it is a result of one living in denial for so long, because of stigma, then you are so ripe for a breakdown, the stigma has already worked you* (P2FGD2).

1.6: Disclosure of one's HIV status

Counselors emphasized that it was important for an HIV positive person to disclose their status to at least one significant other. They said that following disclosure, the client would then have additional support besides their interactions with the counselor. This was said to increase the chances that the client would be able to cope:

> *We normally emphasize to disclose, you know after disclosing their status everything will be easier for us to work on them* (R7II).

> *….because this person is not sleeping, we encourage them to disclose to the person they love because if you go and disclose your status to someone, you feel better. As a counselor I can fail, I can talk to you but you fail to cope up with the situation, but you can tell a friend and she gives you (more) support than me. After knowing your status…disclosure is really important in HIV* (R10II).

Theme 2: Counselors' biological and medical explanations of mental illness

This theme includes counselors' discourse pertaining to their perceptions of the biological and medical aspects of HIV infection. It has two sub themes namely HIV drugs and disease progression.

2.1: HIV medication

Symptoms of mental illness were said to be common among patients who were taking certain HIV medication. The counselors said that these symptoms usually lasted for two weeks after initiation on particular ARV regimens. Efavirenz and zidovudine were the most commonly reported medications to cause such symptoms' among the clients.

> *For children, they might be given medicine like zidovudine sometimes and the child gets some issues concerning their brain* (R4II).

> *I know the brain disturbances happen many times, especially when you are initiating clients on a particular antiretroviral drug e.g. if you are giving Efavirenz* (R2II).

Some counselors stated that clients sometimes reported experiencing nightmares and hallucinations when they took their ARV's. Other clients reported a sense of depersonalization, and delusions that their bodies did not belong to them, which was a source of significant distress for them and their caretakers. However, according to the counselors, the clients did not understand that their problems (delusions and hallucinations) were being caused by the medication that they had started taking.

> *…on Tuesday I also got an experience, one called me around 11:00pm and she told me 'am only seeing big snakes in the room, they are going to eat me up'. I told her she was just imagining these things and I advised her to take some pill and sleep. Then she said 'but I have taken some pill but I keep seeing these snakes; they are going to eat me up'. But the ARV was a very good drug and its side effects are so minimal, except that torture within the two weeks of its initiation is when it will affect them* (P3FGD2).

….then someone called me last night and said, 'I feel like this body is not mine, as if I don't own my body, what can I do, can I take some water?'That was about one a.m. last night and they were taking the drugs… They went on….. 'am I allowed to take some water, actually I feel like a container, I do not feel my body, what should I do?' (P1FGD2).

2.2: Disease progression

Counselors explained that as the viral load increased and the client's immunity weakened, all body systems including the brain were affected. Mental health problems were also said to be more common among those clients who delayed seeking treatment for their HIV.

…HIV affects all systems, I have seen people with skin rash, I have seen people with say diarrhea, you get somebody with these frequent fevers, and you get someone with herpes zoster… You know, I have a feeling if the virus attacked those faculties that are supposed to control one's mental abilities they can easily disorganize one's head (R2II).

…Well it could also be that one has a lot of HIV, what we call high viral load that has eaten up the CD4 cells. Whenever someone has a very low CD4 count…the HIV will affect their heads (P1FGD2).

Theme 3: Clients' belief systems

Counselors' described the relationship between mental illness and the beliefs that the clients held. This made up the third major theme. Under this theme were two sub themes: traditional healing, witchcraft and ancestral spirits. This sub theme revolved around beliefs in African traditional healing as a way to treat illnesses sent by ancestral spirits, or caused by witchcraft. The second sub theme had to do with clients' religious beliefs; mainly Christianity and Islam with their beliefs in God or Allah.

3.1: Traditional healing, witchcraft and ancestral spirits

Counselors said that many clients believed in African ancestral spirits and witchcraft as possible causes of their symptoms. Some counselors stated that they also held similar beliefs. Although the counselors explained that their training did not extend to supernatural beliefs, they said that they could not ignore the effect of beliefs in witchcraft and/or ancestral spirits on their clients' mental wellbeing. According to the counselors, clients often gave plausible explanations about the efficacy of traditional rituals through which spirits that had been affecting them negatively were exorcised.

> *...Because we have different backgrounds, our interventions have a limit beyond which we can't go but am very sure that some of those things are real. That's what I can say, they are real and they happen* (P3FGD2).

> *...sometimes you can ask an individual and they say, even at home sometimes when this happens to me, we have to go back to the village and perform some traditional rituals…. In that case it is important to talk to the relatives whether there is a need for them to carry out some traditional healing…and the person comes back when they are fine…so sometimes it's true that it may be a traditional cause for the mental problem* (P2FGD3).

Other counselors argued that although they did not believe in witchcraft and ancestral spirits, they respected their clients' beliefs, as well as their clients' decision to seek help from traditional healers:

> *...sometimes if the relatives believe that the way to help the person is by performing certain rituals then I tell them to go ahead. On Tuesday I had a client who told me she had been having a severe headache and she feared she was going to die, so she went back to her ancestral home and cleared some grass around their family burial ground and she felt better* (P4FGD3).

This counselor went on to explain that clients have firm beliefs in the efficacy of these rituals, which the counselor needed to respect:

....I also tried to inquire how they knew that the ritual has worked or not and they sometimes go ahead to explain that on several occasions they have had such a problem, like when they were going to do exams and the problem came up, some rituals were performed and they got better… I asked…. 'so how do you know it has worked' and she answered, '....well, because the problem never came back!'. If a patient tells me that… then it is their right, their belief (P4FGD3).

The decision to allow the client to explore the option of traditional healing was premised on the expectation that the client may find relief because they believed the traditional healer could help them. As such, respect for the client's belief system was paramount and traditional practices were tolerated as long as they directly or indirectly resulted in relief of the client's symptoms and did not interfere with the treatments of the counselor.

As a counselor I can't refer someone to a traditional healer; obviously I would refer to a better person in my line of work ...but we also have to respect the client and their families...we as counselors give all the options and we discuss their implications; it is their decision where they decide to go. In fact some of them get better after they went because it is all about counseling, even those people (traditional healers) counsel (P2FGD1).

3.2: Religious beliefs

A distinction was made between African traditional belief systems and religious beliefs, the latter being mainly Christian or Islamic belief systems. Counselors stated that some of the strange behaviors that their clients displayed were rooted in these religious beliefs. This was described as being the case when clients gave away all their property, or gave up their money and property to the church or to their pastors. Clients often believed in a supernatural God who communicated with the praying supplicant and gave him/her commands which, when followed, would lead to healing from HIV.

She decided to give out her property believing that in giving out her property, she would get cured because God said you have to give (R10II).

They talk about (the holy) spirit; it may not be evil…but spirit…; they say, 'when I was praying I got this communication and I felt I was cured from HIV' (R8II).

Some counselors expressed the view that the religious beliefs of a client could be beneficial during the course of therapy and as such, these beliefs were encouraged, as was the case with belief in traditional spirits. At some treatment centers, a cleric was an integral member of the care and support team, along with the doctors and counselors. Clients were often referred to these clerics depending on their clients' religious beliefs:

When counseling it is important to ask the person what they believe in…asking them what they think can help them…a Born Again can tell you they believe their pastors can give them a solution, so it is the client to give you a way forward, not for you to tell them what to do (P3FGD3).

We want to ask what religious affiliation she belongs to. Is she a Muslim, then we have an imam around; is she a Catholic, then we need to do a priest's intervention, is she Born Again, and we have a pastor around (P6FGD2).

Counselors also stated that they promoted the use of medication based on the client's religious beliefs:

….by assuring them that HIV per now has not got cured; the treatment (is necessary), and sometimes we even go into the Bible telling them that God helps those who help themselves, or is the one who gives wisdom to the doctors (R1II).

…we tell them, 'Jesus does not want us to die…I mean if he created these people to make these drugs so you can take your drugs while as well you are praying to get better (R4II).

Theme 4: Counselors' perceptions of their clients' physical and emotional problems

Counselors' perception of their clients' physical and emotional problems was the fourth theme to emerge. Two sub themes emerged; first was the counselors' observations about the behavior of clients

that had mental illness (clients with "strange behavior"). The second sub theme under this category was the counselors' conclusion that some of their clients had 'emotional problems with physical manifestations'.

4.1 Clients with "strange behavior"

Counseling sessions provided counselors with an opportunity to observe their clients. Often counselors observed behavior which they considered strange; which led them to believe that those clients may have a mental health problem:

…you look at the non verbal communication and body language and you realize that maybe there is something that is not really normal in your client….like always looking sideways or checking everywhere, looking at this and that and he is not really concentrated at all. And sometimes there is this funny shaking of different parts of the body. You get someone with their mouth moving up and down…somebody is blinking all the time…something that is out of the ordinary. Sometimes they talk to themselves or cry or laugh out of the blue (R2II).

…. Beatrice, one of the counselors working here, told us that at one time she had a client who could tell her that somebody is telling her to undress and she slowly takes off this, and takes off that…. but she doesn't realize that she is naked…. She is seeing and hearing someone saying 'Take it off! Take it all off!' …..and she removes all her clothes (P1FGD1).

4.2: Emotional problems with physical manifestations

Counselors were also of the view that some of the physical complaints and behavioral problems that their clients exhibited were rooted in emotional issues. Problems like loss of interest in sex, loss of appetite, general body weakness and illnesses like diarrhea. Some of these were seen as physical expressions of what the client was feeling emotionally.

….After the death of his partner he lost appetite and he developed diarrhea. He had general weakness… but everything came as a result of the wife's death (R6II).

Aahh… like this interesting one. People lost interest in having sex and aah they feel unworthy; they have no reason to live and when maybe a husband or wife is approaching them for… for sexual intercourse they feel like….maybe they are not up to the task because they feel hopeless (R2II).

Another counselor said that the individual's thoughts could evolve into physical or other actual manifestations like voices speaking to the individual. As such, what the client reports as spirits talking to them are actually manifestations of their subconscious thought processes.

…. I think that problem comes in when… you know there are some things that are kept to themselves or in the unconscious, these are things you think about….and after some time they come out and you start to really insist that the spirits are talking to you. They might not be real but… but sometimes when you might over think about some things, because you have so many problems…when you sit down those things come back and you start imagining some things that are not real; so you talk to yourself (P2FGD2).

Theme 5: The HIV counselor's roles, challenges and training needs

The focus of this theme was the counselors' description of their day to day experiences when dealing with clients who had mental health problems. This theme has three sub themes. The first subtheme was what counselors said they were able to do, to help their clients with mental illness. This sub theme was named 'counselors' self efficacy'. The second sub theme focuses on the constraints that the HIV counselors said they experience as they deal with clients who have mental health problems. Counselors often spoke about lack of expertise in dealing with mental health problems, and having insufficient time to explore clients' mental health issues. This sub theme was named 'no expertise, no time'. The third sub theme concerned what the counselors said happens when a client is 'difficult'. Here they would often provoke or threaten the difficult client, ignore the problem or the client or refer them elsewhere.

5.1: Counselors' self efficacy

Counselors described themselves as being able to manage mental health problems in their clients where other professionals failed. For example, counselors reported that they were often called upon when clients refused to talk to the nurses and doctors, or refused to take treatment.

> *...Sometimes we are called to the wards that these people are not taking treatment, they are not talking or are refusing to eat, and even then doctors may not know what to do and the nurses don't know what to do. So they call us…'can you talk to this person?' Then the person talks to you….and you deal with the problem* (R10II).

They also believed that their training enabled them to elicit clients' trust and that this is important when working with a client to effect behavior change.

> *...these clients as I told you… the people around him may not understand him. As a trained counselor, when you understand them and once they trust you, you can be able to talk to the client and they do change; they may begin to talk or eat* (P2FGD1).

Counselors explained that they had more contact time with the client at each clinic visit than the doctors or nurses. This provided them an opportunity to address the clients' problems as they arose. In cases where problems were not dealt with at that time or became more complex, the client often developed mental health problems. As such, counselors believed that their daily interaction with clients was a means of preventing mental health problems:

> *...When they come here and don't address issues, I believe later when the issues become complicated, it results into mental breakdown. So with our ongoing support to clients, we can prevent these mental illnesses from starting* (R8II).

5.2: No expertise, no time

Counselors faced two major challenges that interfered with their ability to intervene or help clients with mental health problems. First, they said that they lacked the expertise to handle some mental illness cases, or to identify symptoms of mental illness early. They also described facing overwhelming numbers of clients, which meant that each client received limited time. This often perpetuated the problem.

> *Lack of adequate training is one of the limitations because we don't have that training… here we cannot easily identify that this person has a mental problem or just a social issue (R5II).*

> *Counseling in the HIV setting is not the counseling that is supposed to be done professionally. Within an HIV setting, people just talk about HIV and that's all. They don't go deep to dig out the other information ….for example if the client is supposed to adhere to taking drugs and they don't…there may be reasons as to why. Maybe someone doesn't have food, maybe someone is mentally irritated. We do not totally bring out this. So that's why ours is 'do you take drugs? Are you fine?* (R9II).

Counselors therefore recommended that they be trained to manage mental health problems. They said that staff at HIV treatment centers often receives in-service training for example on new ARV treatment approaches and other factors affecting people living with HIV. However, they reported that this has not been the case when it came to HIV and mental health.

> *We need some training…because this is something we've not been doing consistently.   Like other trainings, you always need to be updated on different issues. But for these mental health issues, we have not really had trainings. Maybe the clinicians have; but not us* (R7II).

They believed that training on mental health issues would need to focus on routine screening for mental health problems among clients and assessment of problem chronicity. Counselors believed they

could be trained to manage some of the mild forms of mental illness. They also felt that it was important for them to know when they needed to refer the client for more specialized psychiatric treatment.

> *....Basically it is important to get training on assessment and how to realize that this case is psychiatric and not just social .... We also need help in how to manage some of the mild mental illnesses…and when they are advanced you can refer…and how to assess that this is beyond our level, when we can't handle and need someone else to help out…… because there are some cases that need medical interventions…then later on maybe we go into the one on one sessions* (R8II).

5.3: Dealing with the difficult client

The idea that some clients were 'difficult' also emerged from the interviews. Two methods were mentioned as the means to deal with such clients. One, the counselor could 'confront, provoke or even threaten' them; or they may choose to 'ignore the problem, ignore the client', or refer.

5.3.1: Confront, provoke or threaten: Some counselors mentioned confrontation and threats as a method that could be used with clients who were presenting with behavioral difficulties. This was particularly the case when clients were abusing alcohol, despite several warnings about the effects of alcohol on the body of an HIV positive person. Such a client needed to be forced to make a choice between alcohol and ARV's. In essence, this threat would 'shock' the client into changing their behavior.

> *Sometimes we threaten them! …like I said when we study counseling there are things we are not supposed to do but it's not always applicable in life's reality..…. So you threaten, you say: '.....now we're going to take you off ARV's because your liver is overloaded….' This may wake up the client to stop the alcohol* (P4FGD3).

The same method was said to be useful when dealing with clients that tried to commit suicide.

> *…You get someone who wants to commit suicide. One, you won't just say…, 'please sorry, but help us and don't do it'. For that one you just provoke him/her. You say 'go ahead; you have even*

delayed, you are late. You want me to get you a rope?! I will give you one.' Yes! You begin with that. Next, you will find him/her sitting and listening to your advice… (R1II)

5.3.2: Ignore the problem; ignore the client: Counselors often spoke of their frustration in dealing with some clients, especially where they felt that the client insistently did not try to do their part to get better as in substance abuse clients. One counselor described a situation in which the counselor chose to ignore the client and their problem. This was common in cases where the client was abusing alcohol despite several warnings. Such a client was perceived to be wasting time that would be better spent helping other clients who felt motivated to get better.

> *I'm going to be very frank with you. It's not that we discriminate patients but, honestly, you can see such a person is wasting time. Everybody has talked about the alcohol problem with the same person… one client asked me, 'Do you know that I own a bar?' After that I simply wrapped up the session, gave her the medication and sent her on her way….I admit it was not the best way to deal with that client but… but honestly…she is going to waste your time and yet the numbers are overwhelming. Others are waiting in the line. (P2FGD3).*

5.3.3: Referral: Counselors spoke about referral of clients with mental illness. Referral was said to be the only way forward for cases where the counselors felt they could not do anything for the client.

> *Normally we collaborate with other organizations, after knowing she has this problem which we have failed to handle. If we can manage we continue slowly. She could not sleep all night. All she did was praying to the Lord, singing hymns and reading the bible. We had totally failed to reach her. So we give them the referral to Butabika (Mental) Hospital (R10II).*

In other cases, referral was said to be necessary for medical intervention, but the counselors would also continue with their psychological intervention.

> *What I know is counseling, which will be the first thing. After counseling the client, the doctor will identify some things that will need some tablets for her to rest at least to cool the temperature*

that she has been having. You never know even she has malaria; yeah so …of course they need

medication in one way or another (R4II).

Referral was also said to be necessary when the counselor had limited time.

There's work load here also. It's because such people need a lot of time and a lot of patience.

Then if you're seeing your tray is piling up and you're not making head way with this person, so

you may want to refer them immediately to someone you feel can help them (R5II).

Summary:

Counselors described HIV positive individuals having to deal with several psychosocial challenges that might result in the client developing mental health problems. These challenges included poverty, lack of social support and the client's failure to accept their HIV status. It was posited that alleviating these challenges, for example, family problems would help to alleviate some of these mental health issues. Early intervention was emphasized, which included encouraging the clients to disclose their HIV status to significant others in order to gunner social support.

The link between HIV drugs and disease progression to their clients' mental illnesses was also mentioned. These often required medical attention. The counselors pointed out that their clients' belief systems, whether it was belief in African traditional or other religions would affect the clients' perception of their mental health problems and hence their help seeking behaviors. The importance of respecting such clients' beliefs was emphasized, and that sometimes clients got relief from alternative modes of therapy, partly because they believed in the efficacy of those alternatives or they fitted their explanatory models. Some counselors also expressed their own beliefs in supernatural causes and healing of illness and this influenced their approaches to helping clients.

Counselors believed that they could manage some mental health problems. However, they also acknowledged that sometimes their interventions were limited due to lack of training in handling mental

illnesses and the overwhelming numbers of clients they had to deal with daily. When clients were difficult, they felt it was sometimes necessary to threaten or provoke them, especially in cases of alcohol abuse and suicide ideation. In other cases, the counselors could choose to ignore the problems or the clients, especially if it was perceived that the client was not doing their best or was not motivated enough to rid themselves of the problem. Again, this was common in alcohol use problems. Lastly, referral was said to be necessary if the counselors perceived that the client needed medical/psychiatric intervention for their mental problem or they felt inexpert in handling the problem.

Chapter 5

Discussion, Recommendations and Conclusion.

Introduction

This chapter discusses the main findings of the study in relation to reviewed literature. Recommendations for further research are also made. Implications for policy and practice are presented, followed by the conclusion.

Characteristics of Participants

The study participants were HIV counselors in Kampala district which is the hub of HIV service provision in Uganda. The majority of participants were Baganda, probably owing to the fact that Kampala district is located within the historical kingdom of Buganda. In addition, the average age of HIV counselors was 36 years, which is quite high but I did not find any evidence to suggest that these HIV counselors are generally older than counselors in other domains.

HIV counselors knowledge/awareness of mental health problems among people with HIV/AIDS

In this study, HIV counselors were given an opportunity to select case vignettes that they were willing to discuss. The counselors consistently selected vignettes depicting symptoms of depression and suicidal ideations, psychosis, mania and substance abuse. Case vignettes depicting symptoms of anxiety, PTSD and dementia were consistently not selected, and were eventually eliminated from the pool of case vignettes presented for discussion during individual interviews and focus group discussions. One plausible implication of this is that the counselors may have more knowledge about some mental

illnesses, and could recognize the symptoms thereof; which affected willingness to discuss case vignettes depicting such symptoms, rather than the ones the counselors had little or no knowledge about.

It is of note that no diagnostic labels were used by respondents in all the interviews. In most cases, the counselors suspected that the clients had a mental health problem, but were unable to name the problem. This can be attributed to the fact that HIV counselors' training (Uganda Ministry of Health, 2005) does not highlight mental health problems associated with HIV/AIDS. Other studies have also pointed out that lack of knowledge and skills to manage mental disorders is common among low level health service providers (Atkin et al., 2005; Hansen et al., 2001). These studies revealed that detection and referral of mental illness cases by nurses was low, although the nurses would suspect that the patient may have a mental illness (Atkin et al., 2001).

HIV counselors acknowledged the fact that people living with HIV/AIDS were susceptible to mental health problems such as depression which has been reported in the Ugandan literature (Akena & Musisi, 2010; Musisi et al., 2010; Musisi, Nakasujja & Zziwa, 2006; Nakasujja, Musisi & Ashaba, 2005). These studies have reported a higher prevalence of depression among HIV positive people than in the general population.

Although they could not necessarily attach a name to the set of symptoms that depicted depression or psychosis, the counselors in this study displayed a clear understanding that such client's physical symptoms could be explained by their emotional problems. For example that a client could fail to sleep or have reduced appetite because they are worried, or begin to hear voices that other people could not hear due of their obsessive thoughts. This shows that HIV counselors already have an appreciation of the mind and body interaction and this is an opportunity that can be utilized when training counselors to better detect mental health problems.

Counselors' perceptions of mental illness

The counselors made various attributions about their clients' mental health problems; but in many cases, the client's symptoms were seen by counselors merely as an expression of the daily stress of living with HIV. For example, symptoms of depression such as loss of sleep and loss of appetite were attributed to poverty, which worsens the HIV positive person's general quality of life. Although it is true that these symptoms may exist in a person that is not depressed, it is also possible that the person in question may be clinically depressed since this is common in HIV infection, as explained earlier. On the other hand, poverty is highly correlated with depression in Sub Saharan Africa (Patel & Kleinman 2003); and people living with HIV are also commonly affected by poverty for a number of reasons. This state of affairs may be compounded by interrupted access to medical care, especially if the HIV positive person has to travel long distances to access the HIV treatment center (MOH, 2005). This may be felt even more keenly by the client that has a poor social support network, a client who will not receive any assistance getting to the medical center when they are too ill. This evidence emphasizes the need to investigate all symptoms of depression among HIV positive people to rule out clinical depression.

The idea that symptoms of mental illness are often perceived as normal has also been established by other authors. According to Patel (1995) the tendency to somatically label some symptoms is common in Sub Saharan Africa. In such cases the client's symptoms are not considered as mental illness and there is a strong probability that the HIV service provider may not offer the client any psychotherapy or refer them for further treatment for their symptoms. This is in line with research that shows that providers tend to ignore explanations that are not in line with their own explanatory models (Lynch & Medin, 2006), and that providers' explanatory models generally influence the kind of treatment options that are offered to the patient (Lobban et al., 2003).

Other perceptions of clients' symptoms included the biological/medical explanations, and cultural as well as religious attributions for mental illness causation. Biological and medical explanations among non medical professionals such as counselors have been reported. Schnittker et al. (2000) found that

mental illnesses are sometimes attributed to imbalances in the brain. Counselor's medical explanations of mental illness may also be influenced by their close interaction with medical professionals at the HIV clinics as proposed by Aidoo and Harpham (2001) or by the media (Schnittker et al., 2000).

The counselor's cultural explanations for mental illness are consistent with the view that mental illness is often culturally defined in Sub Saharan Africa (Fosu, 1981; Okello & Ekblad, 2006; Patel, 2005). Mental illness in Sub Saharan Africa is often attributed to the supernatural, and is believed to be caused by spirits (Patel, 2005). Religious explanations for mental illness have also been reported in the literature, for example, by Good (1987), and Aidoo and Harpham (2001), who propose that mental illness is sometimes seen as the will of God. This is another scenario where efficacious psychotherapy or drug related treatments may be ignored in favor of religious or cultural beliefs. The result is that the client's mental health problems may go undiagnosed, especially in cases where the counselor holds similar cultural and religious beliefs due to their own background. In some cases the counselors tolerated, rather than endorsed the cultural and religious explanations for clients' symptoms. This is similar to the view of Aidoo and Harpham (2001), that professionals tolerate cultural and religious views, simply because they appreciate the value that such beliefs held in their societies, but they do not spontaneously offer these views themselves.

Clients' symptoms as an expression of the stress of living with HIV

Counselors commonly attributed clients' depressive symptoms to the stress of living with HIV/AIDS. Poverty, stigma and lack of social support were said by counselors to be rife in the lives of HIV positive individuals. In the counselor's understanding, this is what predisposed HIV clients to having symptoms like lack of appetite, low mood and lack of sleep. This is a common finding, with symptoms of depression also being attributed to relational problems or the economic situation of the client (Aidoo & Harpham, 2001). It has also been reported that HIV patients' low mood is viewed as understandable or to be expected (in face of their life situation); that it does not represent any psychopathology and therefore

does not require treatment. The implication of normalizing symptoms in this manner is that clinically depressed patients may not be offered the (pharmacological and psychological) treatment that they need. Musisi and Akena (2009) point out that HIV positive individuals do not routinely suffer from depression and the recommendation that HIV patients who complain of any symptoms of depression should routinely be assessed for depression comes into play at this point (Musisi & Akena, 2009).

It is possible that some of the approaches HIV counselors may take to address mental health concerns may be unhelpful or even detrimental to the clients. For example the counselors encouraged disclosure of one's HIV status for those clients that were having mental health problems. Although disclosure may gunner social support for the client who is depressed, it may not be necessarily helpful for the client with mania or psychosis; and even raises an ethical concern as to whether the client with a mental illness is able to understand the reasons and the limits for this disclosure.

Cultural and religious explanations

HIV counselors held various cultural and religious explanations for their clients' mental health problems. This is similar to other professionals in African settings and lay people in general (Okello & Ekblad, 2006; Patel, 1995). The tendency to attribute psychotic symptoms to ancestral spirits or witchcraft is common in Africa (Patel, 2005) and sufferers are often expected to carry out a traditional ritual in order to appease the ancestral spirits. Traditional rituals were believed by counselors to be efficacious in relieving psychiatric symptoms, but this was not the case for neurotic symptoms. Patel (1995) and Elialilia and Musisi (2006) have made a similar argument, that neurotic symptoms are often not perceived to represent an illness. They are attributed to the sufferer's daily stressors, and are expected to resolve when the stressor is removed; therefore these symptoms do not require treatment.

Some counselors did not make such attributions, but showed an understanding of their clients who held such beliefs. These counselors appreciated the importance of their clients' perceptions of their mental illness and hence their health seeking in search of treatment of the manifest mental illness

(Kleinman, 1980). The clients' decision to opt for traditional healing or faith healing over Western medicine and treatment was therefore respected. These counselors, however, still encouraged their clients to take Western medicine in addition to these other alternative treatments. Elialilia and Musisi (2006) explained this as African duality; which refers to the tendency to believe that illnesses have a traditional cause (for example spirits) while at the same time accepting that Western medicines are efficacious in relieving the symptoms of these illness. In essence, the client may be encouraged by the counselor to accept some form of Western therapy, such as medication or psychotherapy for their symptoms; while at the same time consulting with a traditional healer about the root of the illness. The danger of this would be that if the traditional healer supposes that the illness has a purely traditional cause, the client may be discouraged from taking the necessary medication.

Medical and biological explanations

The counselors agreed that symptoms of mental illness could result from increased HIV viral load, disease progression or that they may appear as a side effect of medication. This is a common finding in studies on the link between HIV/AIDS and mental illness (Maling, 2009; Musisi & Kinyanda, 2009; Nakimuli-Mpungu et al., 2006). Schnittker et al. (2000) have also proposed that non-professionals may endorse a biological cause such as heredity or chemical imbalance in the brain as some of the natural causes for mental illness.

Counselors' stigmatizing perceptions

Patients with alcohol abuse problems in particular tended to be perceived by the counselors as simply 'refusing' to control their drinking problem. This often made the counselors less likely to act in therapeutically helpful ways to their clients. Similar observations have been reported by others, including Lobban et al. (2003) and Weiner (1988, 1990) who said that when service providers, for example, nurses thought that some patients were able to control their symptoms such as patients with depressive thoughts

and negative self perceptions it was common for such patients to be perceived as a nuisance and be given less attention and assistance. Clients with alcohol abuse problems may also not get sufficient attention, due to the counselor's belief that the client is able to control their drinking behavior. This occurred in face of overwhelmingly huge numbers of clients that HIV counselors had to contend with on a daily basis, and resulted in the client with a substance abuse problem being ignored. In addition, the counselors' stigmatizing views undermined the ethics of counseling and resulted for example in threatening the client with withdrawal of ARV treatment if they did not stop using alcohol. Threats such as this are likely to increase the chances that clients will hide their alcohol abuse, for fear of censure by the counselors, which would further reduce the client's adherence to ARV treatment. This also has implications for programs targeting alcohol abuse because self reports by clients would erroneously depict low levels of alcohol use. In cases where the individual is correctly assessed as having an alcohol abuse problem, then treatment may not be effective because the clients would report swift recovery, for fear of reprisal. The factors underlying alcohol abuse such as co morbid depression may also be left unattended to. If the service provider is not aware of the tendency for clients to under report on their problem, then treatment would ultimately have little or no effect.

The counselor's stigmatizing perceptions also came to the foreground when dealing with clients with suicidal ideations. These clients were also at risk because they were sometimes threatened and provoked by some counselors. This has serious ethical implications because it moves away from the therapists' ethical code of conduct and violates values such as unconditional positive regard and the responsibility to "do no harm" (APA, 2010). Such stigmatizing perceptions also reduce the chances that clients will report their suicidal ideations during counseling sessions, which may lead to increased cases of attempted and completed suicide.

HIV counselor's perception of their role in mental health service provision

HIV counselors described a sense of high self efficacy and confidence in their ability to manage some mental health problems among their HIV positive clients. According to Lobban and colleagues (2005), this increases the chances that they will endeavor to offer help to clients with mental health problems. At the same time however, some of the counselors' beliefs that a client's psychotic or other mental symptoms were caused by ancestral spirits or witchcraft, or that they could only be healed through prayer may reduce the chances that the client would be referred for specialized psychiatric treatment. Lobban, Barrowclough and Jones (2003) have also demonstrated the link between the service providers' perception of illness and the treatment options offered to the client. These authors additionally report that service providers will recommend treatment options that are in line with their explanatory model of the client's illness, which sometimes leads to poor management and treatment of mental illness cases.

Limitations of the study

One of the limitations of the current study is that only counselors in Kampala district were interviewed. This is an urban area, and some insights may have been left out from counselors working with HIV patients from rural areas. These results cannot, therefore, be generalized to all HIV counselors in Uganda. It is possible that HIV counselors in rural areas may express firmer beliefs in the supernatural as compared to their urban counterparts, as it is reflected in the study by Okello and Ekblad (2006) who depicted cultural explanatory models of mental illness as being widespread in rural Uganda. Other factors affect HIV positive people more in rural areas such as poverty and poor access to medical centers (MOH, 2005) and the effect of these factors on mental illness may not have been properly illustrated by this study which focused on a convenient sample of counselors in an urban setting. Therefore, it would be beneficial to carry out another study with a larger sample in more diverse areas of Uganda (including rural areas) to be more representative of the Ugandan population of HIV counselors. In addition, the use of vignettes to elicit participants' beliefs on mental illness resulted in their conclusions being limited to the responses

given to the cases they chose to discuss and cannot be assumed to be identical to the participants'

responses to real life situations.

Recommendations for policy and practice

Based on the results of this study, and on the counselors' own recommendations, policies and

interventions need to be put in place to help HIV counselors better manage mental health problems. The

first step in improving mental health service provision in HIV treatment centers would be a training needs

assessment for HIV counselors in particular. Earlier studies have established that Uganda's health system

in general is poorly equipped to support the provision of mental health services (Hanlon et al., 2014). One

of the barriers to provision of mental health services identified by the PRIME project in participating

countries is lack of awareness and stigmatizing views towards mental illness (Hanlon et al., 2014), and

this is clearly illustrated by this study.

The urgent need to enhance integration of mental health care in HIV service provision can be met

through various interventions, and some interventions can be employed to achieve this in the short term,

while others are long term.

Short term interventions

There is a need for dissemination of the results of the current and similar studies which should

serve to help HIV counselors reflect on their personal practices, especially regarding their own

perceptions of mental illness. HIV counselors need to understand how their perceptions of mental illness

directly affect their service provision e.g. whether or not to refer a client for specialized psychiatric

intervention. These results should therefore be disseminated to all HIV treatment centers in Uganda that

provide counseling services. This can be done at center level or during national HIV/AIDS conferences.

Furthermore, awareness needs to be built among HIV counselors about the mental health problems that

affect people living with HIV/AIDS, including the symptoms of these problems and the indications for

the wide variety of diversified treatments. This can be done alongside the dissemination of the results of the current study.

Long term interventions

HIV service provision policies need to be revised to emphasize mental health aspects. The training curriculum for HIV counselors needs to be reviewed to include mental health aspects of HIV/AIDS. These should include symptoms of mental health problems of HIV and treatment procedures, particularly highlighting the role of the HIV counselor in the treatment process. This calls for integration of mental health care in all HIV intervention services, including prevention services. HIV treatment centers need to streamline procedures for integrated management of mental health problems among their HIV positive clients. The bulk of mental health problems cannot be handled by the counselor alone, given the overwhelming numbers of clients and their mental health problems, some of which require specialized psychiatric attention. As such, HIV treatment centers need to consider employing mental health specialists such as psychiatrists and clinical psychologists at their centers, or at least identifying nearby established mental health units where clients can be referred to receive specialized mental health care as the need arises.

Conclusion

HIV counselors were found to have knowledge concerning some mental health problems affecting people living with HIV/AIDS, for example, depression and psychotic symptoms. However, they also held some explanations for the mental health problems displayed by HIV positive clients that could potentially interfere with their service provision. Although HIV counselors portrayed a sense self efficacy to manage mental health problems among their HIV positive clients, their interventions were limited by their lack of expertise to deal with specific mental health problems. This indicates a need for training and streamlining of HIV treatment and support to target mental health aspects of HIV infection in the care of HIV-positive clients. The HIV counselor is in a unique position to provide mental health services and

referral within the HIV clinic, and to their community in general. Ultimately, all this calls for a policy of

integration of mental health care in all HIV care interventions including prevention strategies.

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Appendices

Appendix 1: Case vignettes

Case 1:

Namatovu is a 38 year old woman. For the past four weeks she has been feeling unhappy and no longer enjoys her usual activities and pastimes. She says that her mind is closed and she describes herself as feeling "empty". Also she has difficulty sleeping and has not been eating well. She complains of low energy. She no longer enjoys sex. Her thoughts are always wondering and distant and feel that life is not worth living. She thinks about and wishes to die or even kill herself/himself.

Case 2:

Mukasa is a 27 year old man. For the past one week his mother has reported him as being very excited, he goes for long hours without sleep, during which time he is very talkative but keeps jumping from topic to topic. His appetite has increased greatly and he seems to have so much energy, more than usual. He sleeps for only two hours a night, he then starts doing housework at 4 a.m before everyone else wakes up but does not finish any task. Recently he gave away all his clothes and shoes and has been giving away money. He says He is important because God chose him to be an answer to the suffering in the world.

Case 3:

Nambi is a 22 year old woman. She recently tested HIV positive. She has been avoiding the HIV clinic because she fears being around other patients, she avoids talking about or listening to people talking about HIV. She complains that she is having nightmares in which she is being buried and cannot escape. She is also very concerned about her body, constantly checks her weight and gets very anxious when she notices any slight rash on her body. Nambi says she doesn't feel like a 'normal' person, she has lost interest in

things she used to enjoy. She also feels hopeless about the future and she keeps saying she regrets that she will never get married and will never have children.

Case 4:

Mbiire is a 42 year old man that just cannot stop worrying, although he does not explain clearly what he is worried about. He complains that he is always feeling 'on edge', he is always tired and has difficulty concentrating, and sometimes he feels like his mind is just blank. He is very irritable and easily gets annoyed, he has difficulty falling asleep, sleeps very few hours at night and wakes up feeling tired. His work is suffering because he cannot stop worrying.

Case 5

Musa is a 45 year old man that has been fired from his job because he was always missing work or going to work while drunk. He has been arrested three times for driving while drunk. His wife left him because he used to home drunk and beat her and the children. He comes to the clinic smelling of alcohol but denies having taken any alcohol. He always tell lies about his drinking behavior, either saying he does not drink at all or drunk just one bottle. He refuses to stop, even when he is told that he cannot mix alcohol with his Ante Retroviral drugs

Case 6

Munene is a 50 year old man, his wife reports that he has become very forgetful; sometimes he does not remember his own children when they come to visit. It is sometimes difficult to understand him when he speaks; sometimes he speaks very slowly and takes very long to answer when asked a simple question. He moves very slowly and sometimes seems to forget simple tasks like how to dress or even feed himself.

Case 7:

Nakku is a 17 year old girl. For the past one week she has been insisting that some spirits come to visit her and that the spirits are messengers of her ancestors. She says that they speak to her and has told her to eat sand so that she will be cured of HIV. She keeps saying that the spirits are in form of people, watching her and they are standing nearby. However no one can see the people that she is talking about. Sometimes she falls to the ground and rolls about, then speaks in a strange language that no one can understand, it is thought that she is communicating with the spirits.

Appendix 2: Interview Guide

1. Are any of these conditions familiar?

2. Tell me about a case you came across during your work that was similar to any of the conditions described.

3. What name do you give that condition?

4. What do you think causes that condition?

5. How do you think that person can be helped?

6. How do you think you would handle that person if he/she came to you?

7. How do you think you can be helped in your work to handle that person better?

Appendix 3: Participant Information Leaflet and Consent Form for Individual Interview

Title of the research project:

Exploring knowledge and explanatory models of mental illness among HIV counselors in Uganda

Reference number:

Principal investigator: Ms. Lynda Nakalawa

Address:

Makerere University School of Psychology.

Department of Mental Health

P.O.BOX 7062

Kampala, Uganda

Contact number: +256 782 334450

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

Please note that the information that you share during this interview will not be used against you in anyway and will have no bearing on your job appraisal as a counselor

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This research study is being conducted among HIV/AIDS centers within Kampala, which provide both treatment and counseling. A total of 6 centers are taking part in the study.

HIV/AIDS is associated with a number of mental illnesses and we want to find out whether HIV counselors can be helped to identify and treat mental illness. We believe that you can help us by telling us what you know about mental illness and your experience with mental illness among your clients and how you feel you can be supported to better identify and treat it.

During the interview, I will sit down with you in a comfortable place at your centre. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except me, the transcriber and my supervisor will have access to the information documented during your interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape. The tape will be kept separate from the transcripts developed from it. The information recorded is confidential, and no one else except me, the transcriber and my supervisor will have access to the tapes. The tapes will be destroyed after 28 weeks.

Why have you been invited to participate?

You are invited to take part in this research because we feel that your experience as a counselor can contribute much to our knowledge of HIV counselors understanding of mental illness.

What will your responsibilities be?

This research will involve your participation in an individual interview that will take about one hour.

Will you benefit from taking part in this research?

There will be no direct benefit to you, but your participation is likely to help us find out more about how to help HIV counselors better understand and handle mental illness.

Are there in risks involved in your taking part in this research?

There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics. However, we do not wish for this to happen. You do not have to answer any question or take part in the interview if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

Who will have access to your personal information?

We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key. It will not be shared with or given to anyone except my research supervisor.

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you and your center before it is made widely available to the public.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. However, we will give you 10.000 UG.SHS for your lunch and refreshments. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

You can contact Prof. Mark Tomlinson on markt@sun.ac.za if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I ……………………………..…………. agree to take part in a research study entitled 'Exploring knowledge and explanatory models of mental illness among HIV counselors in Uganda'

I declare that:

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is voluntary and I have not been pressurised to take part.

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....…........……………. on (*date*) …………....……….. 2005.

Signature of participant   Signature of witness

Declaration by investigator

I *(name)* …………………………………………..……… declare that:

I explained the information in this document to …………………………………..

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

I did/did not use a interpreter.

Signed at (*place*) ....…........……………. on (*date*) …………....……….. 200

Signature of investigator   Signature of witness

Appendix 4: Participant Information Leaflet and Consent Form for Focus Group Discussion

Title of the research project:

Exploring knowledge and explanatory models of mental illness among HIV counsellors in Uganda

Reference number:

Principal investigator: Lynda Nakalawa

Address:

Makerere University School of Psychology.

Department of Mental Health

P.O.BOX 7062

Kampala, Uganda

Contact number: +256 782 33445

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

Please note that the information that you share during this interview will not be used against you in anyway and will have no bearing on your job appraisal as a counsellor

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This research study is being conducted among HIV/AIDS centers within Kampala, which provide both treatment and counseling. A total of 6 centers are taking part in the study.

HIV/AIDS is associated with a number of mental illnesses and we want to find out whether HIV counselors can be helped to identify and treat mental illness. We believe that you can help us by telling us what you know about mental illness and your experience with mental illness among your clients and how you feel you can be supported to better identify and treat it.

We are asking you to help us learn more about HIV counselor's explanations concerning mental illness. We are asking you to take part in this research project. If you accept, you will be asked to take part in a discussion with 4-5 other HIV counselors. This discussion will be guided by me. The group discussion will start by me making sure that you are comfortable. I will also answer any questions about the research that you may have. Then I will ask you questions about mental illness and give you time to share your knowledge. The questions will be about mental illness, what you know about it and how it affects people living with HIV/AIDS. You do not have to share any information that you are not comfortable sharing.

The discussion will take place at your centre and no one else but the people who take part in the discussion and me will be present during this discussion. The entire discussion will be tape and video-

recorded, but the tapes will be kept separate from the transcripts developed from them. The information recorded is confidential, and no one else except me, the transcriber and my supervisor will have access to the tapes. The tapes will be destroyed after 28 weeks.

Why have you been invited to participate?

You are invited to take part in this research because we feel that your experience as a counselor can contribute much to our knowledge of HIV counselors understanding of mental illness.

What will your responsibilities be?

This research will involve your participation in focus group discussion that will take about one hour and a half.

Will you benefit from taking part in this research?

There will be no direct benefit to you, but your participation is likely to help us find out more about how to help HIV counselors better understand and handle mental illness.

Are there in risks involved in your taking part in this research?

There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics. However, we do not wish for this to happen. You do not have to answer any question or take part in the interview if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

Who will have access to your personal information?

We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key. It will not be shared with or given to anyone except my research supervisor.

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you and your center before it is made widely available to the public. We will ask you and others in the group not to talk to people outside the group about what was said in the group. We will, in other words, ask each of you to keep what was said in the group confidential. You should know, however, that we cannot stop or prevent participants who were in the group from sharing things that should be confidential

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. However, we will give you 10.000 UG.SHS for your lunch and refreshments. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

You can contact Prof. Mark Tomlinson on markt@sun.ac.za if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I ……………………………..…………. agree to take part in a research study entitled 'Exploring knowledge and explanatory models of mental illness among HIV counselors in Uganda'

I declare that:

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is voluntary and I have not been pressurized to take part.

I may choose to leave the study at any time and will not be penalized or prejudiced in any way.

I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....…........…………….. on (*date*) …………....………. 2005.

....

Signature of participant   **Signature of witness**

Declaration by investigator

I *(name)* ………………………………………..……… declare that:

I explained the information in this document to ………………………………..

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

I did/did not use a interpreter.

Signed at (*place*) ....…........…………….. on (*date*) …………....……….. 2005.

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Signature of investigator   Signature of witness