CHRONIC SORROW: LIVED EXPERIENCES OF CAREGIVERS OF SCHIZOPHRENIC PATIENTS IN BUTABIKA MENTAL HOSPITAL, KAMPALA, UGANDA

By

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ABSTRACT

Background.

Grief is a central experience by people diagnosed with mental illness, families, and friends. Chronic sorrow is defined as pervasive sadness and/or other emotional reactions commonly associated with grief that is permanent, periodic and potentially progressive in nature. It is viewed as a normal reaction to loss that may be to a single event or ongoing. During the experience of chronic sorrow, people feel emotional commotion, discomfort, & hopelessness. It may progress to pathological grief or depression. It may also trigger some of the psychiatric disorders in individuals who are vulnerable. No documented study in Uganda has addressed the problem of chronic sorrow among caregivers of patients with mental illness.

Objective

The theory of chronic sorrow was used to guide this study. The aim of the study was to explore the experience of chronic sorrow among caregivers of patients with schizophrenia in Uganda.

Methodology

This study employed a descriptive qualitative design using Focus Groups and In-depth interviews. The research was carried out at Butabika National Mental Hospital in Kampala. The study was conducted in Luganda. There were 10 in-depth interviews and 2 focused group discussions. The sample size was based on the principle of data saturation and purposive sampling technique was used. The caregivers who met the inclusion criteria, consented and were interviewed using the chronic sorrow questionnaire guide (caregiver version). The interviews were recorded, transcribed, translated to English and analyzed through content analysis of a framework by Graneheim & Lundman (2004**).**

Results

9 out of 10 caregivers experienced Chronic Sorrow. The triggers identified were, unending care giving, change in behavior (refusal to take drugs, refusal to go to hospital), management of crises (during relapse and side sides of drugs), society reaction to mental illness (abandoning and mistreating patients, discrimination) and missed companionship. Unhelpful factors were poor communication by health workers, stigma from community, Uncooperative

police. The coping strategies used were, interpersonal strategies, action oriented activities (keeping busy), positive thinking, avoidance, emotional (crying). Caregivers indicated that health workers should show understanding, communicate properly, and provide information, facts about mental illness to them and community. Taking mental health services nearer to the people throughout the country and follow up visits were also suggested.

Conclusions.

Caregivers of patients with schizophrenia are most likely to have chronic sorrow, the sadness and the grief related feelings are triggered by different factors which can be internal or external. Effective coping strategies are needed to be used by the caregivers in order to help them keep up with the task of caregiving and health workers have a great role to play.

Recommendations.

Refresher trainings in customer care and public relations should be carried out on a regular basis to remind health workers of their mandates and obligations. Communication and counseling skills should also be enhanced in teaching Institutions. Nurses should be prepared to assist caregivers and family members at any point of meeting within the health facility. Policy makers should increase the number of health workers in order to reduce on the work load and burnouts. Different stakeholders (Community, Police, Political leaders, Development partners) should be enlightened on their roles pertaining mental health in the country

CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled Chronic Sorrow: Lived experiences of caregivers of schizophrenic patients in Butabika Mental hospital Kampala, Uganda, in (partial) fulfillment of the requirements for the degree of Master of Nursing (Mental Health) of Muhimbili University of Health and Allied sciences.

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DECLARATION
AND
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I, **Connie Olwit,** declare that this dissertation is my own original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

Signature………………………………. Date……………

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LIST OF ACRONYMS

FGD: Focused group discussion

IRB: Institutional Review Board.

MUHAS: Muhimbili University of Health and Allied Sciences.

MUK, CHS: Makerere University, College of Health Sciences.

UCST: Uganda Council Of Science and Technology

WHO: World Health Organisation

OPERATIONAL DEFINITIONS

Chronic Sorrow. Periodic recurrence of permanent, pervasive sadness or other grief-related phenomena with ongoing disparity resulting from a loss experience.

Caregiver. A person caring, and living with a schizophrenic patient.

Coping. Dealing with and attempting to overcome difficulties.

External management methods. Interventions provided by health professionals or support provided by friends and family to assist individuals to cope with chronic sorrow.

Internal management methods. Positive personal coping strategies used to cope with the periodic episodes of chronic sorrow.

Loss experience. Losing a relative to schizophrenia, chronic mental illness.

Disparity A gap between the current reality and the desired reality as a result of having a schizophrenic patient.

Trigger event. A situation, circumstance, or condition that brings the negative disparity resulting from the loss into focus, or exacerbates the disparity.

Table of Contents

LIST OF TABLES

CHAPTER I
INTROUDUCTION

Background

Chronic sorrow is defined as pervasive sadness and/or other emotional reactions commonly associated with grief that is permanent, periodic and potentially progressive in nature (Eakes et al., 1998). It is at times referred to as chronic grief (Hummel & Eastman, 1991; Teel, 1991). Sorrow is defined as a pervasive sadness that follows a loss and it is widely acknowledged as an important component of grief. It is viewed as a normal reaction to loss that may be to a single event or ongoing. During the experience of chronic sorrow, people feel emotional commotion, discomfort and hopelessness. It may progress to pathological grief or depression. It may also trigger some of the psychiatric disorders in individuals who are vulnerable. The theory of chronic sorrow which is guiding this study was developed to provide a framework for understanding and working with people following a single or ongoing loss like the caregivers of schizophrenic patients.

A variety of factors such as change in policies, civil wars, beliefs leading to underutilization of resources, poverty, insufficient and inequitably distributed resources, globalization etc - have led to increased numbers of mentally ill individuals in the community (WHO, 2011; Ayo, 2011; WHO, 2001; Sanyu, 2007). As a result, family members are challenged to assume responsibilities of taking care of individuals diagnosed with chronic psychiatric conditions such as schizophrenia. The burden of family of such caregivers of schizophrenic patients is divided into subjective and objective (Idstad, Ask & Tambs, 2010; Talwar & Matheithau, 2010; Zahid & Ohaeri, 2010; Nasr & Kausar, 2009; Caqueo-Urizar, Gutierrez-Maldonado, & Miranda-Castillo, 2009; Yusuf & Nuhu, 2009; Roick, Heider, Angermeyer, Azorin, Brugha, Kilian et al., 2007; Roick, Heider, Toumi, & Angermeyer, 2006). Subjective burden includes perceived psychological distress such as feelings of loss, embarrassment in social situations, and depression, whereas objective includes the practical and concrete problems such as reduced social and family activities and financial difficulties (Idstad et al., 2010; Caqueo-Urizar et al., 2009).

Though grief is described as a central experience by people diagnosed with mental illness, families and friends, there is limited information on the experience of grief related feelings by caregivers of the schizophrenic patients, especially in developing countries (Young, Bailey, & Rycroft, 2004; Miller, 1996; Eakes, 1995; Atkinson, 1994). Anxiety and depression are the commonly documented psychological distress that the caregivers of the mentally ill experience (Idstad et al., 2010). Grief is often unspoken and experienced privately, possibly as self-blame, personal inadequacy or powerlessness (Young et al., 2004). The schizophrenic patients confront a lot of losses such as loss of independence, decreased functioning, social isolation, stigma, communication and all these multiple losses do not only affect them but also the caregivers (Talwar & matheithua, 2010; Eakes, 1995). According to the theory of chronic sorrow, the losses experienced cause disparity when people think about reality and the desired, leading to chronic sorrow (Teel, 1991; Eakes, Burke, & Hainsworth, 1998).

Widely accepted grief theories (Bowlby, 1980, Kuber-Ross, 1969), suggest that sorrow can be resolved through well established processes. The multiple losses that are experienced by caregivers for example, schizophrenic patients are described in the theory of chronic sorrow as the first antecedent of chronic sorrow (Eakes et al., 1998). Chronic sorrow was first described by Olshansky (1962) as a profound sadness that occurred periodically but persisted. This definition evolved from 4 studies that were carried out in 1980s on parents who have children with chronic conditions and disabilities (Eakes, 1995). These studies further expanded the list of common emotions experienced by parents to not only sadness or sorrow but also anger, fear, frustration, helplessness and other emotional characteristic of grief reaction (Eakes, 1995). Since then, a series of studies have been done on individuals with chronic illness, their caregivers, and individuals who had experienced the death of a family member (Eakes, 1995). Almost all the studies that have been documented were carried out in Europe, America, England context, and there is barely any information in Africa about Chronic sorrow. This study is designed to explore chronic sorrow in a different context, which is an African setting.

Chronic sorrow is considered a normal response to the ongoing negative disparity and usually the people who experience chronic sorrow use internal and external coping strategies throughout the experience (Eakes et al., 1998). However, if management strategies are ineffective, the disparity created by the loss will continue to intensify and may progress to a pathological grief state, such as depression or complicated grief (Eakes et al., 1998; Gordon, 2009). It is also possible that the chronic sorrow may trigger the onset of schizophrenia or any psychiatric disorder in the caregiver when there is genetic vulnerability from the family traits. Stress and emotional reactions may trigger emergencies episodes in the patient with schizophrenia hence requiring more hospitalization. All these will happen due to lack of balance between stresses and mental state (Salvatore et al., 2011; Butzlaff & Hooley, 1998).

It is of great importance for psychiatric nurses and other health workers to understand this phenomenon of chronic sorrow so as to identify the caregivers with it and offer helpful interventions to them. Nurses usually have primary contacts with caregiver, therefore it is important for them to understand the caregivers' experience of chronic sorrow. Preoccupation with categorizing and diagnosing mental illness has led to an emphasis on the tangible and objective, and a corresponding de-emphasis of the subjective, emotional, spiritual and symbolic components of health (Young et al., 2004). This study is designed to broaden the health workers understanding of the experience of chronic sorrow among caregivers of schizophrenic patients.

Problem Statement.

Globally, mental illness accounted for 12% of disease burden in 2000 and it was estimated that more than 25% of individuals develop one or more of the mental disorders during their lifetime (WHO, 2001). Mental disorders are known to represent four of the 10 leading causes of disability worldwide and schizophrenia is reported to be among the leading cause of severe disability which affects approximately 24 million people worldwide (WHO, 2001). In Uganda, it is estimated that 35% of the population that is approximately 9,574,915 people suffer from some form of mental illness with at least 15% requiring treatment and the burden of schizophrenia is 1% of the population (Sanyu, 2007).

In an African perspective, most schizophrenic patients are cared for in the community by their relatives and medical care is normally sought in case of crisis and when other alternatives fail like traditional medicine (Seloilwe, 2006; Ayo, 2010). Therefore, most of the time these caregivers bear the burden of care and it's long term subjective effect has not been widely explored. Chronic sorrow may be one of the subjective burdens that caregivers of schizophrenic patients bear since they have ongoing loss. Chronic sorrow is viewed as a normal emotional and understandable response to multiple losses, and literature clearly delineated it from pathological grief or depression (Burke et al., 1992; Hayes, 2001; Hobdell, 2004). The individuals who experience it can cope with it and carry on with daily activities. However according to the theory of chronic sorrow and other documented research, if there is ineffective management of chronic sorrow, it leads to increased discomfort and eventually may progress to pathological grief or depression (Eakes et al., 1998; Hobdell, 2004; Gordon, 2009). It exacerbates the trauma of having chronic illness hence increasing vulnerability to physical and mental dysfunction (Hayes, 2001, Eakes et al., 1998, Teel, 1991).

From the psychiatry point of view, ineffective management of chronic sorrow may have more consequences to caregivers of schizophrenic patients and the patients themselves. It may trigger the onset of other psychiatric disorders such as, major depression, anxiety, bipolar affective disorder or schizophrenia in persons who have the genetic vulnerability due to emotional turbulence (Gordon, 2009; Salvatore et al., 2011). Chronic sorrow lies in life events that involve expressed emotions which is a psychosocial predictor of relapse in schizophrenia (Lim, Chang, & Keefe, 2009; Butzlaff & Hooley, 1998). Due to the expressed emotions in chronic sorrow that are beyond specified threshold, it is possible that a relapse may be triggered among schizophrenic patients (Butzlaff & Hooley, 1998). Therefore, psychiatric nurses and health workers cannot afford to ignore this phenomenon.

This study is designed to broaden psychiatric health workers' understanding of the caregivers' feelings while taking care of schizophrenic patients. The information that will be obtained may help health workers improve care through changing practice.

Rationale of the study

The concept of chronic sorrow is still evolving and the management is not yet standardized, however several studies have suggested different ways of helping people with chronic sorrow. From an evidenced based practice report and other studies, it is important to recognize chronic sorrow as a normal response to loss. When chronic sorrow is triggered, health workers should provide support by fostering positive coping strategies and assuming roles that increase comfort (Gordon, 2009; Eakes et al., 1998). External management methods such as professional counseling, pastoral care or spiritual support to assist with grieving, use of therapeutic communication which providing an environment in which caregivers feel comfortable discussing their emotions. Reinforcing the internal coping strategies such as providing information about the illness, support groups, engaging in stress relieving practices, reading literature about schizophrenia, self awareness, and acceptance of the process of grieving a living loss (Atkinson, 1991; Eakes et al., 1998; Miller, 1996; Eakes, 1995; Young et al., 2004 Gordon, 2009).

However, there is evidence that health workers are unhelpful when caregivers are struggling with grief related feelings. They have bad attitudes, lack communication; lack of caregivers' involvement during treatment and very little information is given about the patient's illness (Atkinson, 1991; Eakes, 1995; Gerd, 2005). This could be due to lack of understanding of the caregivers' feelings. The findings of this study may broaden health workers' understanding of the experience of caregivers of schizophrenic patients and this may help improve care through changing practice. It may also help policy makers make some policies that promote family therapy practice among caregivers of schizophrenia.

Broad Objective.

To explore the experiences of chronic sorrow among caregivers of patients with schizophrenia in Uganda, in order to improve practice.

Specific Objectives

1. To describe the feelings, emotions and distresses translating as chronic sorrow among the caregivers of schizophrenic patients at Butabika Mental Hospital, Uganda

2. To identify the triggers of sorrow among the caregivers of schizophrenic patients Butabika Mental Hospital, Uganda.
3. To discover coping strategies used by the caregivers of schizophrenic patients Butabika Mental Hospital, Uganda.
4. To identify strategies that health workers can use to help caregivers of schizophrenic patients cope with chronic sorrow Butabika Mental Hospital, Uganda.

Conceptual framework

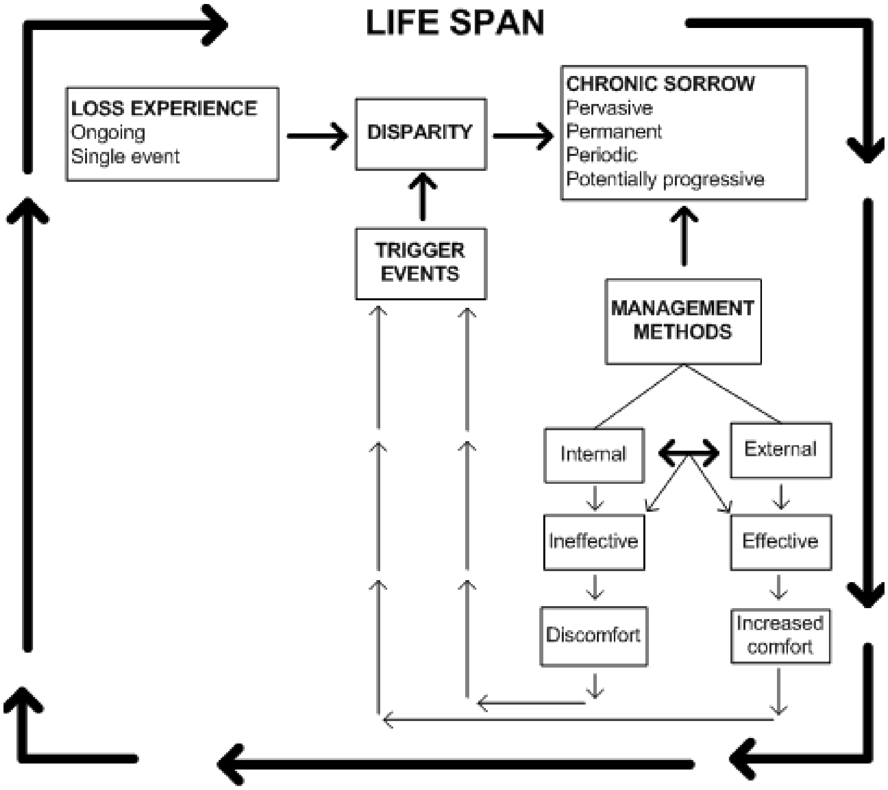
This study is utilizing the framework of Eakes et al. (1998) middle range theory of chronic sorrow which provides a framework for understanding and working with people following a single or ongoing loss. For example caregivers of schizophrenic patients have ongoing loss of losing an individual to a chronic illness that causes disability (Eakes, 1995; Atkinson, 1994). This framework illustrates two antecedents to chronic sorrow. The first antecedent is initiated when a single event of a living loss is experienced (for example, onset or time of diagnosis of chronic illness like schizophrenia). When family members find out that one of them is diagnosed with a chronic illness, such as schizophrenia they are likely to experience a pervasive sadness associated with the loss of functioning of the individual (Talwar & matheithau, 2010). This event may prompt a sense of loss and sadness related to caregiver recognizing an uncertain future for the individual in terms of quality of life, health and wellness.

The second antecedent to chronic sorrow is an unresolved disparity resulting from the loss. In the example pertaining to a schizophrenic individual, the family members' perception of the normal person does not coincide with the reality of having a schizophrenic individual who loses some of the functioning. Therefore, a gap between reality and fantasy occurs, creating unresolved conflictual disparity (Eakes et al., 1998). After the disparity has occurred, chronic sorrow typically manifests as a pervasive sadness that is usually described as permanent, periodic, and potentially progressive in nature.

Another element of chronic sorrow is the trigger events. They are also referred to as milestones, and these are those situations or circumstances that bring the disparity created by the loss into focus, thereby triggering grief related feelings associated with chronic sorrow.

Triggers of chronic sorrow vary depending on the nature of the loss experience (Burkes et al., 1999). Another key element of the theoretical model of Chronic Sorrow is management methods. The term is used to refer to both personal coping strategies used by individuals during the chronic sorrow experience (internal) as well as supportive interventions provided by helping professionals (external). As depicted in the theoretical model, effective internal and external management methods lead to increased comfort and may increase the time between episodes of chronic sorrow.

Below is the theoretical diagrammatic representation of the theory of Chronic Sorrow model.



Source: Eakes et al., 1998

This framework is used as a guide in this study. The study questions were derived from it, questions about chronic sorrow experience, trigger factors, and management strategies. This frame work will be used to analyze the information obtained from the caregivers of schizophrenic patients. It will also be used during implementation of research findings to broaden health workers understanding of what the care givers of schizophrenic patients and this will eventually drive them to help the caregivers accordingly hence improving practice.

CHAPTER II
LITERATURE REVIEW

Chronic sorrow was first described among parents who had children with mental retardation by Olshansky (1962) who observed grieved parents and noticed that they struggled to cope with the loss of a ‘perfect child’. Olshansky (1962) described chronic sorrow as profound sadness that occurred periodically and persisted in these parents throughout their life. Since then, chronic sorrow has been researched among individuals with chronic illness and their caregivers and people who have lost their beloved ones (Burke et al., 1999; Eakes et al., 1998). This study will mainly focus on the experience of chronic sorrow among caregivers of patients with schizophrenia, a chronic psychotic disabling mental illness.

With the different studies that have been carried out, the definition of chronic sorrow has been modified, building on Olshansky’s definition (Olshansky, 1962). Teel (1991), after conducting a concept analysis of chronic sorrow, described it as a recurring sadness, interwoven with periods of neutrality, satisfaction and happiness. Eakes et al (1998) defined chronic sorrow to be the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with ongoing disparity resulting from a loss experience. In 2002, Roos defined chronic sorrow in her book as “continuing, and recurring grief responses resulting from a significant sorrow or absence of crucial aspects of oneself (self loss) or another living person (other- loss) to whom there is a deep attachment. In 2004, Young et al described chronic sorrow as the mild form of grief. This contrasts with the other definitions by other researchers because Young et al (2004) based their definition on the intensity nature of the phenomenon. And yet researchers have documented that the intensity of sorrow among caregivers varies with time (Burke et al., 1999; Eakes, 1995). Some individuals experience less intensity and others more, while others experience the same level of intensity of sorrow and grief related feelings with time. The similarity in all the definition is that the chronic sorrow results from disparity that is created from the losses that the individuals experience, which are either single episodes or ongoing.

Chronic Sorrow and Caregivers

Atkinson (1994) researched on parents (n=25) who had an adult child with schizophrenia and parents (n=25) who had ‘lost’ an adult child through death or head injury that resulted in an organic personality disorder. In his findings, there were significant differences with regard to grieving reactions and substance abuse. Parents of children who had head injuries were abusing substances more than those who had schizophrenic adult children. This depicted ineffective coping mechanisms that were more practiced among these parents. Parents who had a schizophrenic adult child experienced ongoing grieving than the other parents, and he concluded that loss of a child through schizophrenia leads to a pattern of chronic grief. Similarly, Eakes (1995) found that 8 out of 10 parents with seriously mentally ill adult children experienced chronic sorrow. The grief-related feelings were most often triggered by the unending care giving responsibilities of the parents. Other triggers were management of crises, recognition of disparity between their situations and social norms, and confrontation with their child’s failure to achieve developmental norms. The parents employed mainly cognitive coping strategies which involved positive thinking, action oriented (keeping busy) and interpersonal techniques including- talking to each other. She also noted that those who experienced chronic sorrow indicated that health care professionals could assist through involving them in the treatment process and providing information about their child’s illness.

Northington (2000) researched on parents of school age children with sickle cell disease. In her findings, chronic sorrow was experienced by these parents and the milestones included both internal and external events. The parents reported that chronic sorrow was initially triggered by the child’s diagnosis followed by subsequent triggers over the course of child’s illness. Internal triggers were found to relate to future-oriented thoughts, such as thoughts of the child’s death. External factors triggering episodes of chronic sorrow were associated with the consequences of the illness itself, as well as concerns about costs of health care and education. The researcher concluded that caregivers of children with sickle cell engaged in a process of readjusting and redefining reality, hence, the cyclic nature of chronic sorrow. These findings were similar with those by Griffin and Kearney’s (2001) research on parents of children with disabilities. These parents often felt the pain and sorrow which were integral to the experience of being a parent of a child with a significant permanent disability. All these findings depict what is stated in the middle range theory of chronic sorrow that chronic sorrow is a normal response to loss. For these parents, chronic sorrow was the more common experience in comparison to time-bound grief and mourning. These parents were better able to relate to the concept of “chronic” and “periodic” sorrow as part of their everyday life in relation to their current situations and their children’s future.

Sex difference and Chronic Sorrow.

Hobdell (2004) and Damrosch and Perry (1989) documented difference in the experience of chronic sorrow among mothers and fathers. The frequency of chronic sorrow in mothers is reported more common compared to fathers. Damrosch and Perry (1989) conducted a small study comparing mothers and fathers in families having a child with Down’s syndrome on patterns of adjustment, chronic sorrow, and coping to enable professionals to gain a better understanding of how parents deal with the birth and rearing of handicapped children. Most fathers in this study depicted their adjustment as steady and gradual, while a majority of the mothers depicted their adjustment as having peaks and valleys. Parents preferred professional approaches that involved encouraging/allowing expressions of sadness, and appreciated positive feedback on how they could handle certain situation. After two decades, Hobdell (2004) researched on parents of children with neural tube defects. She used a big sample size of 132 parents and the parents were paired male and female. The results of this study revealed the parents as reporting a high intensity of acute grief and sadness with 86% of the participants experiencing chronic sorrow. The researchers found that there was a relationship between chronic sorrow and depression.

Similarly, Bowes et al. (2008) explored grief reactions and adjustment on 17 parents whose children had been diagnosed with diabetes 1. They found that parents experienced a resurgence of grief at critical times during their child’s development and mothers elaborated more on their emotions than fathers. But continuous feelings associated with grief, such as anger and guilt, were expressed by both fathers and mothers. The triggering events identified were hospitalization, illness relapses, administering insulin injections and transitioning from pediatric to adult diabetes services.

Grief feelings and mental health.

In 2004, Young et al's systemic, contextual and compassionate analysis on family grief and mental health showed that family members are likely to express grief in different ways and rates because of the emotional and practical dilemmas they experience. For example when a family member has an episodic condition, the family has to have the flexibility to find ways of maintaining the incapacitated family member's role so that their place in the family is not lost, and yet find temporary ways of fulfilling that role when illness makes this necessary. Being 'too' flexible and accepting may mean that the person experiencing the illness may feel excluded, and deprived of a contributing role in the family, and being loyal to the person experiencing the illness, and to their 'wellness', may leave families struggling to know how to survive as a family during acute crises. Because there is no medication for grief, a medically dominated system may not actively look for grief, nor recognize it in its more subtle or disguised forms. However, not addressing grief may entrench hopelessness, as family members continue to make unfavorable comparisons between the present and an idealized past. According to the theory of chronic sorrow, this creates disparity hence grief-related feeling or sorrow (Eakes et al., 1998). The anger, frustration, expressions may lead to further tension and conflict. Health workers are in an excellent position to inquire respectfully about the component parts of grief (e.g. anger, confusion), gently name the grief then act accordingly. Young et al (2004) recommended that simply recognizing and naming losses can be a great relief to them and their families given the unpredictable and chaotic nature of mental health crises and the busy, instrumental culture of many mental health services.

Gordon, (2009) documented an evidence based practice approaches of helping people with chronic sorrow. In his research, he recommended that nurses can better assist parents to deal with chronic sorrow by offering internal and external management methods of coping as illustrated in the mid-range theory of chronic sorrow (Eakes et al., 1998). Successful application of individualized management methods is achieved when a parent is able to balance the emotional and mental stress associated with the day-to-day demands. Internal coping strategies included, reading literature about the illness, engaging in stress relieving practices, seeking out social interaction with others who share similar feelings. External coping strategies include professional counseling, pharmaceutical interventions for symptoms like insomnia, pastoral care for spiritual support, therapeutic communication and making referrals services that can assist financial stressors.

Chronic Sorrow and Depression

Because of prolonged grief process like in chronic sorrow, there has been confusion between depression and chronic sorrow, and several researchers have tried to distinguish the two. The most recent documentation was by Hobdell, (2004) whose research was on parental chronic sorrow and depression following the birth of a child with a neural tube defect. She suggested that depression could be a dimension of chronic sorrow, rather than a separate construct. In 2002, Roos made reference to the relationship between depression and chronic sorrow in her book, “Chronic Sorrow, A Living Loss”. Roos believed that depression is a complication related to stressors that influence people who experience chronic sorrow. However, the two authors contrast greatly in their views. Other researchers distinguish chronic sorrow from depression through the DSM-IV-TR criteria (American Psychiatric Association, 2000) which is a widely used diagnostic manual (Hayes, 2001; Hobdell, 2007). In depression, the individual experiences self emptiness and reduced self regard however such feelings are not part of chronic sorrow. It is also possible to have both disorders co-existing in the same person (Lindgren et al., 1992). From the mental health point of view, chronic sorrow may trigger the onset depression or any major psychiatric disorder in a person who has high genetic risk/vulnerability, for example family history. When a person has genetic component of mental illness, some of the factors that trigger the onset of mental illness is psychosocial distress. Chronic sorrow is a life event which is among the latter factors which trigger mental illness (Salvatore et al., 2011; Lim, Chong & Keefe 2009).

Chronic sorrow and depression should be clearly distinguished because they require different approaches of therapy or may require combined approaches if they do co exist. Gordon (2009) insisted that labeling parents who experience chronic sorrow as depressed can lead to misdiagnosis and poor management of chronic sorrow, and can ultimately result in ineffective coping. To evade outcomes of misdiagnosis, an appropriate assessment of chronic sorrow should be done by a health care professional who regularly works with parents of children with disabilities or chronic illness. However, all the studies reviewed as well as those carried out in the past decades support the evidence of chronic sorrow in parents of children with various identified mental and physical disabilities or of premature infants with a potential for some degree of disability (Eakes, 1995; Burke et al 1999; Griffin & Kearney, 2001; Hobdell, 2004; Hobdell et al., 2007; Bowes et al., 2008). On the other hand, documented studies about chronic sorrow have been carried out in America, England and Europe, this study is designed to explore if the individuals in an African settings experience chronic sorrow. This will broaden the knowledge of experiencing chronic sorrow.

CHAPTER: III
METHODOLOGY

Study design

This study employed a descriptive qualitative study design using Focus Group Discussions, and In-depth Interviews. The aim of the study was to explore the experience of chronic sorrow among caregivers of schizophrenic individuals. The methods were triangulated in order to obtain as detailed information about the experience of chronic sorrow as possible. Triangulation is a very useful means of capturing more detail which this research was aiming at and it helps minimize the effect of bias and ensuring a balanced research study hence increasing the credibility of the study findings (Polit & Beck, 2008). During triangulation, there is overlapping of methods or techniques and somewhat complimenting each other hence balancing and giving a richer and a truer account (Polit & Beck, 2008).

Study site and setting

This study was conducted at Butabika National Referral and Teaching Mental Hospital in Kampala, Uganda at the outpatient department and female and male wards where relatives of patients came to visit the patients. It is the only psychiatric referral hospital in a country of about 32 million people. It has a bed capacity of 900 as per February 2010 and admits more than 6000 mental health patients annually (Wikipedia, 2010). Butabika hospital has an established staff of 426 which include psychiatrists, psychologists, psychiatric clinical officers, psychiatric nurses, social workers and other cadres of health care workers, as well as administration, finance and other support service staff (Butabika Hospital, 2008). Butabika lies in the south-eastern part of the city, in Nakawa division of Kampala city, Uganda’s capital city and adjacent to the shores of Lake Victoria. This location is approximately 12 Kilometers by road, east of Kampala’s central business district (Butabika Hospital, 2008).

Sample size

The sample size was based on the principle of data saturation. Data saturation occurs when the information being shared with the researcher becomes repetitive therefore inclusion of new participants does not result into new idea (Wood & Haber, 1994). There were 10 in-depth interviews and two focused group discussions. The groups were divided by sex. The group of female caregivers consisted of 7 members and male group consisted of 5 members. There were 2 withdrawals from the male focused group discussion because of the deterioration of the patient and one withdrawal from the in-depth interview because of an emergency call received. The caregivers who participated in the in-depth interviews were different from those who participated in the Focused groups.

Sampling procedure.

Sampling refers to the process of selecting a portion of the population to represent the entire population (Polit & Hungler, 1997). This study employed purposeful sampling where participants selected were most beneficial to the study. The purposive sampling technique was used in this study because the researcher aimed at getting people who are knowledgeable, articulate and willing to talk at in length so that details of the experience of chronic sorrow among caregivers is obtained. However, purposive sampling is a non probability sampling method thus giving less chance of obtaining representative sample but it is accepted in qualitative research because the aim of the studies that employ this design is to obtain as much individualized detailed information as possible (Polit & Beck, 2006). Sampling was done on the caregivers caring for the schizophrenic clients at clinic and those who had patients in the wards at the time of study were invited. The first 10 participants who consented to participant in the study were interviewed and the next participants were scheduled for the focused group discussion.

Inclusion criteria

The informants were selected according to the following criteria

1. Caregiver living with patient-relative who had been diagnosed with schizophrenia for more than 1 year (this is because for chronic sorrow to be experienced, a time lag should be given in order to distinguish it from sorrow or grief that resolves).
2. The caregiver should be 18 years and above
3. The caregiver should be living and taking care of the patient
4. The caregiver should be able to speak Luganda this is because it is the most spoken language in the central part of Uganda and the Research Assistants language.

Exclusion criteria

1. The caregiver who had just escorted the patient and not living with him/her.
2. Caregiver who was below 18 years.
3. Caregiver who didn't have enough time for the interview.
4. Caregiver of patient who had been diagnosed less than 12 months.

Study Population

A population is a well defined set that has certain specified properties (Wood & Haber, 1994). In this study;

Target population*:* This is the entire population in which the researcher is interested (Polit & Hungler, 1997). In this study the researcher is interested in all caregivers of Schizophrenic patients in Uganda.

Accessible population**:** This refers to those cases that conform to the eligibility criteria and that are accessible to the researcher as a pool of subjects for the study (Polit & Hungler, 1997). In this study, all caregivers of Schizophrenic patients in Butabika hospital were accessible.

Sample population**:** Caregivers of Schizophrenic patients in Butabika hospital who met the inclusion criteria and consented to participate in the study.

Study unit**:** A caregiver of Schizophrenic patient in Butabika hospital who has been recruited for the study.

Ethical Considerations

Ethical clearance was sought and obtained from the Muhimbili University of Health and Allied Sciences (MUHAS) Ethical and Publications Committee. Approval was obtained from Uganda Council of Science and Technology (UCST) for the research to be carried out in the country. Permission was then obtained from Butabika Mental Hospital research committee before any data collection.

Before the interviews and the focused group discussions, the study participants were fully informed about the purpose of the study and the procedure of data collection. Confidentiality was maintained throughout the research process. The researcher kept all research data locked in a box and the keys were kept only by the researcher. The participants were informed that there were no negative consequences if they refused to participate or withdrew from study. Their participation was voluntary and they were free to withdraw their participation at any time without prejudice or withdrawal of care services.

There was no need to seek consent of the patients as the focus of the study was the caregivers and their feelings of chronic sorrow. The study unit was the caregiver. After the study was explained to them, the caregivers consented to participate in the study and for their interview to be tape-recorded. The participants who evidenced chronic sorrow and had lost hope were referred to the counselor and those who needed information concerning the illness of the patient were given the information.

Data Collection and Procedure.

After the ethical clearance and permissions were granted (see appendix IV), the data collection process commenced. One of the nurses in the outpatient department was requested to be a Research Assistant (RA) and upon accepting, she was trained on the ethically acceptable recruitment process of the study. The purpose of the study, ethical considerations, the inclusion, and exclusion criteria were explained to the Research Assistant. The research assistant only helped in identifying potential participants because the clinic was very busy with few staff at that time. During the clinic days when the research assistant collected files, she would sort the files and identify the potential participants who were referred to the researcher. The researcher then explained the purpose of the study and how they would benefit from the study. The interviewer then sought and obtained a written informed consent from the caregivers who were willing to participate. The study participants were informed about the approximated time for the interview which was 20-30 minutes. Permission for the interview to be audio taped was sought and obtained verbally from the study participants. The face to face in-depth interviews and the FGDs were conducted in a room ensuring privacy of the study participants. The face to face in-depth interviews were guided by a modified version of Burke/Eakes Chronic Sorrow questionnaire which was piloted and modified accordingly before data was collected. The Burke/NCRCS Chronic Sorrow questionnaire (Caregiver Version) consists of 16 open-ended questions for caregivers and was translated to Luganda which is the most spoken language in the central part of Uganda. The Burke/NCRCS Chronic

Sorrow questionnaire (Caregiver Version) is designed to evaluate (1) occurrence of chronic sorrow, (2) intensity of the sorrow, (3) milestones at which chronic sorrow occurs, (4) individualized coping factors, (5) advice for others suggested by caregivers, and (6) professional. During the interviews, the non-verbal communications of study participants were noted in the note book. The study participants were thanked for participating in the study. The contacts of the study participants were got and it was clearly explained to them that they may be contacted in future in case some clarification was needed about the information given. They were assured that all the information and the contacts were confidential. The memory card and note books were then locked in the box up to when they were transcribed and translated from Luganda to English. The focused group discussions were also taped, transcribed and then translated from Luganda to English. There were four questions that were discussed and these involved describing feelings, emotions and distresses that caregivers experienced, coping strategies used and finally advice for health workers. These were part of the Eakes/Burkes questionnaire however some questions concerning the details of their feelings were left out because they are difficult to discuss express them in a group.

Trustworthiness

To increase the credibility of the study, the researcher included two different methods of data collection where participants with various perspectives for example various genders were involved. This contributed a richer variation of the phenomenon. The time that was taken to build rapport and trust with informants was sufficient. This helped the participants to feel at ease and shared their experiences freely and in depth. There was also persistent observation during the interviews to cross check whether the body expressions were persistent with information that was being shared. Data source triangulation was also used in the study in order to improve credibility. Member checks were also done after the data was collected and analyzed. Some of the study participants were called back, the findings were shared with them and they reacted to them. Some of the member checks were done at the end of the interviews by summarizing the information shared the participant.

To facilitate transferability, a clear and distinct description of characteristics of study participants, data collection and process of analysis was done. In the report, a rich and vigorous presentation of the findings with appropriate quotations was done.

Quality Control.

In order to ensure quality control, the research assistant was trained before getting involved in the study. The focused groups had the same questions to discus. The interview guide was piloted before it was used and adjustments were made accordingly.

Data analysis

Data was analyzed using the content analysis technique described by the Graneheim & Lundman, (2004) frame work. Audio taped in-depth interviews were transcribed verbatim and translated to English. These were then typed directly to the computer in Microsoft word program. The informants' words were captured word to word and were checked against the recorded interviews to ensure no information was missed. The interview transcripts were printed out to ease analysis. The interviews were read several times to obtain sense out of the whole scripts and the text about caregivers' experiences of chronic sorrow were brought into one text, which constituted the unit of analysis. The texts were divided into condensed meaning units, abstracted and labeled with codes. The codes were compared based on similarities and differences and sorted into categories and sub categories. Finally, the underlying meaning that was, the latent content of the categories was formulated into themes which were documented.

Dissemination

A copy of the report will be given to the Research & Ethics Committee of Butabika Mental Hospital and discussed with some of the study participants. The researcher will disseminate the research findings through national and international scientific conferences, and publish in a Nursing journal.

A report in the form of a dissertation was prepared for purposes of the award of the degree of Master Of Nursing Of MUHAS. Copies of this report will be given to MUHAS library, the School Of Nursing, and the Department of Psychiatry. A copy will also be given to the UCST and Butabika Hospital as well as the Department Of Psychiatry Of Makerere University and Uganda’s Ministry Of Health.

CHAPTER IV
PRESENTATION OF RESULTS

Social demographic characteristics.

There were three males and seven female who participated in the in-depth interviews and five males and seven females in Focused Group Discussions. Over all there were 8 males and 14 females who participated in the study. Among the participants 5 were spouses, 9 siblings, 6 parents (Mums only) and 2 children. The mean age was 38years and ranged from 21-68 years. For the in-depth interviews 7 of the participants had income generating activities while 3 didn't have.

Table 1: Summary of findings.

Themes	Categories	Codes
Chronic sorrow	Feelings/ emotions	Sadness, anger, fear, frustration, confusion devastation, pain, shock, worry
Triggers	Unending caregiving	Hospitalization, symptoms, excessive use of energy/time, financial constraints, overwhelming responsibility, losing independence, fear of unknown safety, and thinking of the future
	Change in behavior	Refusal to go hospital, take medication, and resentment.
	Managing of crises	Relapse management, side effects of medications' management.
	Societal reaction	Beating/mistreating the mentally ill, abandoning the mentally ill, mentally ill loitering on the streets, wrong perceptions,

		stigma
	Missed companionship	Missing the role of the person, Not trusting the person's reasoning
	Health worker related	Poor communication, inflexibility, poor Customer care, Not showing understanding.
Coping mechanisms	Interpersonal	Talking to other people, sharing with a friend in the same situation, listening to encouraging programmes on radio, television (TV), reading encouraging words, going to church and praying to God.
	Action oriented activities,	Watching movies, TV, listening to radio, jobs, and sports.
	Cognitive strategies	Positive thinking, acceptance
	Emotional strategies.	Crying, avoidance and keeping feelings to self

The experience of chronic sorrow.

The presence or absence of chronic sorrow was determined by comparing participants' responses to the operational definition. Nine of participants who were interviewed evidenced chronic sorrow. They described arrange of grief related feelings associated with initial knowledge of a person having schizophrenia and recounted numerous situations and circumstances over time where these feelings were re-experienced. Caregivers who evidenced chronic sorrow reported the feelings and other grief related feelings to be periodic (on and off) over a prolonged period of time. Among the participants who evidenced chronic sorrow, five cried during the in-depth interview which was an expression of overwhelming emotions that they had. A vivid picture of permanent, periodic, pervasive nature of the chronic sorrow experience among caregivers was clearly evidenced in this 26 year old lady with a mother who was diagnosed with schizophrenia 18 years ago. She said:

"I feel very sad, I feel pain, and I feel like crying (cries). This sadness comes and goes, but it can never go away unless when God decides and I know that she is gone she is gone. If it's not that, I will always feel sad."

Another example was expressed by a single mother who had a mentally ill son, she said:

"At times I would cry to God wondering how long these problems were going to last. I would think it was better to die and leave this world than watch my child in that state."

The one participant who did not exhibit the characteristics of chronic sorrow as per the operational definition had good coping strategies which were revealed during the interview. There was a lot of support from family members and they have a lot of health education from the health worker who saw them and whatever situation that came up they would inquire from the health worker. The patient has never relapsed since he was diagnosed, probably because of the family support and the controlled side effects of the medication. The patient was actually able to go back to school after a period of time and continued with his education.

When the participants were asked to recall the feelings they experienced when they first released that their relative was mentally ill, they described a variety of feelings including sadness, shock, confusion, despair, fear, devastation, pain, anger. An example of these feelings was expressed by a 42 year old single mother who had a son who was diagnosed with schizophrenia 2 years ago. She said:

"I felt so bad, so sad. Am a single mother and this child has been helping me. I was so devastated. People said he was bewitched and others said probably it was because of cannabis, I was in a state of confusion,"

The most prevalent feelings expressed by caregivers in describing both initial reactions to the relative's mental illness and feelings experienced periodically over the course of their relative's illness were those of sadness/bad, devastation and frustration. An example is by a 29 year old lady whose elder sister was diagnosed with schizophrenia since 2005. She said:

"I felt really bad because it was something that had never been in our family and we were wondering where it was coming from. I felt so devastated (cries)." "What increases my sadness is her lack of acceptance. I want to help her, be there for her but probably because am younger she doesn't want help from me yet I know she needs help. That saddens me."

Another caregiver whose husband was diagnosed with schizophrenia expressed her feelings of first experience this way.

"At the beginning I had a lot of fear. I took a week without eating or sleeping. I really felt so bad, I thought I was going to die, and at some point I felt I was becoming mentally ill. Now days I have lots of worries, my children have to go to school. At times my heart beats to the extent that somebody next to me can hear (cries). "

The feelings and emotions expressed in the focused group discussions (FGDs) were not any different from those expressed in the in-depth interviews. Among the 12 caregivers who participated in the FGDs, feelings of sadness were cited most frequent, followed by disturbance/stress, anger, pain. Other grief related feelings that were reported were devastation, fear, worry, frustration, confusion and shock.

The intensity of the grief related feelings were reported to be more intense at the beginning than later for the majority of the participants. Eight out of the nine who evidenced chronic sorrow experienced more intense grief related feelings at the beginning than later however one participant who experienced the opposite. Some of the caregivers compared their feelings to the feelings somebody would have if they lost a beloved one. But after taking their relative to hospital and knowing that the symptoms can be controlled with medication they get hope with time that the patient will be fine hence less intensity of feelings even when they are triggered.

Trigger factors.

Caregivers reported reoccurrence of grief related feelings characteristic of chronic sorrow to be triggered by many factors. These were categorized into, unending caregiving, change in behavior, management of crises, society reaction to mental illness, and missed companionship. Unending caregiving refers to events that evoke the realization of the continuous, unrelieved responsibilities associated with caring for a family member with a chronic condition. This included hospitalization, symptoms, excessive use of energy/time, financial constraints, overwhelming responsibility, and losing independence. An example was given by a 28years old lady who had a brother with schizophrenia.

"It is painful to leave him in the hospital. In fact I used to work but I had to stop, and at times when I move a bit I find him on the road looking for me. He is like a baby."

The second category was 'change in behavior' which included refusal to hospital, refusal to take medication, and resentment. These were illustrated by one of the caregivers who evidenced chronic sorrow.

"His refusing to take medicine would make me feel worse. Even refusing to come to the hospital because with little money I had we would have used public means to come to the hospital. I felt a lot of pain in my heart and I even asked God why he didn't die during his childhood because he used to be so sickly."

The third category was 'society reaction to mental illness' which involved beating or mistreating the mentally ill, abandoning the mentally ill hence loitering on the streets, and the wrong perceptions about mental illness hence stigma.

"I got scared, couldn't eat or sleep yet I was tired. I kept thinking about his safety, where to begin from because in the past he has been assaulted. I had a lot of sadness in my heart."

Management of crises was reported by many of the caregivers who reported that it was saddening to see their relatives relapse and also react to medication and they were looking forward to the time they would get better. An example of missed companionship patient was demonstrated by a 26 year old lady, married with a child whose mother is mentally ill.

"…there are times when I look at my child and keep saying eeh my daughter if only your grandmother was fine, I would have taken you there and you stay with her during holidays like others do. I feel that thing; it really pains me (cries). Sometimes I want to share with her my personal issues in marriage but I can't."

During the FGDs, when the members were asked about the distresses while taking care of the patients, there were several factors that were reported. The most frequent factors were in the category of unending caregiving and societal reaction to mental illness. Under 'unending caregiving,' relapse, symptoms, lack of resources and impact on family members (fear of unknown and safety, thinking of the future) were reported. Societal reaction to mental illness involved abandoning the mentally ill on streets, societal perceptions that pressurized the caregivers. This was clearly portrayed by the members in the female group who has a son with schizophrenia.

"Some people talk evil about me, some abuse once you refuse to go to witch doctor or traditional healers. One day, someone told me that we made medicine for wealth through the child. That is why he is mentally ill. I felt very bad and frustrated. There are so many things out there when you have a patient. We did not want to go to witchdoctors but that was what everyone was saying. "

Another scenario is from one of the male member of the FGD whose father was diagnosed with schizophrenia.

"*Rumor has it that the drugs of this place make someone not active, that the drugs can damage his brain."*

The seven caregivers pointed out health workers as the most stressing factor. This can be well captured from one of the member from the male FGD who stated that

"Health workers are the most painful thing for me. It's true we have patients who make us sad but health workers make us sadder."

Among the most distressing factors were communications oriented and showing understanding and flexibility. Poor communication involved long waiting hours when the caregivers come with the patients for review without communication, no timely communication incase of any problems, means of communication, miscommunication from students without supervision and poor customer care. There were 15 citations from seven members from FGDs and two in-depth interviews. An example is from one of the citations from the male FGD.

"…a nurse comes with files, speaks English then you request her to repeat in Luganda so that you understand well but you then see her in another mood, she becomes angry, quarrels. Then what happens because you didn't understand English, your patient's file comes and you don't get to know. They read your name and you do not hear, so other people come and leave you there…That thing makes me feel sad, angry, I feel very bad!"

Coping mechanisms

To identify coping mechanisms used by caregivers to deal with the recurring feelings associated with chronic sorrow, each individual was asked when they feel down about their situation, what do they do to feel better? And what they would tell other caregivers to do if they are in that situation. The FGDs were asked what they do to overcome stressors. The responses were categorized into Interpersonal, action oriented activities, cognitive and emotional strategies. These coping strategies can also be classified as external and internal coping strategies where the interpersonal strategies would fit in the external group and the internal coping would include action oriented activities, cognitive and emotional strategies. The category of interpersonal strategies which included talking to other people who shown understanding, looking for support from surrounding people, sharing with a friend in the same situation, listening to encouraging programmes on radio, television (TV), reading encouraging words like from a bible, going to church and praying to God (trusting and having faith in him). An example of encouraging programmes was cited by a 42 years old single mother with a son who is schizophrenic.

"I am a religious person, I have faith in God. While at home, I tune to Christian radio stations and listen. I get encouraged after listening to people's stories and I get to know that am not alone. There are people who are worse than me. I know God brings and takes. I realize that even with money people get problems and suffer even more than me.

Action oriented activities which were aimed at distracting the caregivers through being busy were also cited frequently. These included watching movies, TV, listening to radio, jobs, and sports. This was clearly demonstrated by 26 years old lady who is living with her brother was diagnosed with schizophrenia since 2004.

"Being busy is helpful. The candles I make and supply make me busy the whole day. You don't get time to think about it. It helps a lot because by the time you are going to bed you are too tired to think so you just sleep."

Almost all the caregivers identified God as the solution to their problems and worries. Many of them resorted to prayers, trusting God and having faith in him. These helped them to shift their focus to something else so that they don’t think about care giving and the problems surrounding it.

Emotional coping included crying, avoidance (getting short breaks like moving away from home), and keeping feelings to self. This was evidenced during the interviews when four of the nine caregivers who evidenced chronic sorrow cried during the interviews and one did during the female focused group discussion. Cognitive strategies included burden acceptance and positive thinking which were used by two caregivers who experienced chronic sorrow with 4 references.

Helpful/not helpful.

Information was also sought regarding factors the parents found helpful or not helpful as they tried to adjust to their relative’s diagnosis and cope with the chronic sorrow experience. Relatives and friends were reported to be helpful during these situations by most caregivers. The friends were ranging from neighbors, church members, fellow age mates, and area local leaders. The relatives ranged from husbands, brothers, sisters, parents, aunts and uncles. They were helpful in terms of offering sympathy, consoling & comforting, counseling, going company, advising, seeking alternative solutions like going for divine healing in church. A 52 years old mother reported how the church members were helpful.

“The church people, actually Y’s work is to be in church. He has friends there and they are helpful. Actually they are the ones who took him to mental hospital. I was not there.

Health workers were also reported to be helpful in terms of providing medication to reduce the symptoms on hospitalization with severe symptoms. The most references given by most of the caregivers were providing medication. There were 2 caregivers out of the nine who evidenced chronic sorrow who reported the health worker to be friendly and encouraging and 1 caregiver from female FGD who has 2 references where the health workers were very welcoming, and willing to help. However health workers have been viewed on a negative note by the majority of the caregivers as seen in theme of triggers.

Unhelpful factors were reported to be stigma, cracking jokes about the mental illness and laughing when the relative is sick. A clear example was reported by 21years old boy who had his sister who was schizophrenic for about 18years.

"The people around keep talking about my family that we are mentally ill, and as youth you can joke about certain things and then somebody say; do not bring on me insanity like that of your sister. It can be in a joking way but I feel bad. There are times when she is sick and they laugh!"

The police were also identified as being unhelpful when they were needed most especially when support was needed to bring the patients to hospital when they were potentially dangerous to the other people. Some of police officers were uncooperative and not willing to help. The health system was also frustrating for some of the caregivers. Some of the caregivers cited that health system was hectic and many times frustrating. Some of the forms get lost and many at times the order is not followed.

Recommendations from caregivers.

Caregivers were asked what the health workers can do in order to help them deal with the feelings, emotions and distresses they encounter. The following themes came up, showing understanding, health education of caregivers and community sensitization, communication, counseling, resources, accessible services and follow up visits. Showing understanding, counseling and health education were the most frequently cited recommendations. Under health education several topics were suggested and the most common were teaching about mental illness, handling patients so that they can be closer, what to do during emergency, expectations while caring for the patients. Community sensitization included educating the community about mental illness, their responsibilities, and changing their negative perception towards mental illness. Resources involved availability of drugs, facilitation of health workers, and involvement of the police. Lastly the theme of communication had a variety of concerns that needed improvement. These ranged from customers care, proper, timely communication.

CHAPTER V
DISCUSSION OF RESULTS:

Over all there were 8 males and 14 females who participated in the study. There were more females than males because the female took up the role of caregiving and the men were more of caretakers. The female are the ones who stay with the patients at home and also bring them to hospital while the most of the men go looking for money which they provide to facilitate the care giving.

Chronic sorrow.

Nine out of ten participants (90%) evidenced chronic sorrow. This experience of chronic sorrow is similar to other findings by other researchers on parents with different losses that are ongoing or single loss. For example among the studies that were carried out by NCRCS out of 98 persons, 87 (88%) evidenced chronic sorrow (Burke et al., 1999), Olwit & Jarlberg (2007) found similar findings (88%) among the people with facial disfigurement in Uganda. Burke et al. (1999) further explained that chronic sorrow could be the normal response of ordinary people to events that emphasize the disparity between their expectations and the reality. The high incidence of chronic sorrow that has been found and has been documented by other researchers indicate that most of the people who experience single or ongoing loss should be helped with positive coping strategies since the majority are most likely to have chronic sorrow.

The intense emotional experiences in this study are consistent with the findings in the western part of the world. Confusion, sadness, devastation, anger, fear and worry were also expressed by family members and caregivers in different studies (Eakes, 1995; Ozgul, 2004; Richardson et al., 2011). And re occurrence of these feelings was evoked by several factors that they face during the process which in this study are regarded as trigger factors. The intensity of the grief related feelings were reported to be more intense at the beginning than later for the majority of the participants. This finding is quite different from that of Eakes et al. (1998) who found that the intensity of the feelings varied from person to person. This could be because of the mixture of the grief related feeling at the beginning. They are usually in disbelief, shock, confusion, devastation not knowing what to do especially with the societal beliefs and not knowing what is going on. Therefore with this finding it could be very important for the health workers to offer some time to talk to the caregivers especially the first time they bring the patient to hospital in order to allow them to express their emotions/feelings and help clear out any misperceptions, health educate them about mental illness and positive coping strategies as suggested pervious by the caregivers during the interviews.

Triggers

The most predominate triggers were found to be in the themes of unending care giving, change in behavior, societal reaction to mental illness and management of crises. These findings are similar to the finding by Burke et al. (1999) who documented that family caregivers mainly reported their triggers of chronic sorrow to be management of crises, unending caregiving, comparison with norms (social, developmental, personal) and anniversaries. The anniversaries were not mentioned at all by any of the participants probably because of the African culture of not holding onto the calendar events like remembering the anniversaries and morning them or celebrating them. And with the mental illness, the relapses were very common triggers which keep beginning up new dates. Unending caregiving involved hospitalization, symptoms, excessive use of energy/time, financial constraints and impact on family members (overwhelming responsibility, losing independence) and it was the most frequently mentioned trigger among the caregivers. These findings are not surprising because of mental illness being a chronic condition, and ongoing loss. The patients may relapse hence portraying odd behavior which may result into a lot of suffering for the patient and the caregiver.

Hospitalization triggered their emotions and different explanations were given by caregivers. For example, the environment and surrounding situations that the patients have in hospital, patients being mixed with others of different conditions and severity, thinking of the responsibilities they have at hand and those left by the patient due to relapse and hospitalization. These affected them emotionally and triggered grief related feelings. This finding is similar with Roick et al. (2006) findings where caregivers of schizophrenic patients shown high levels of stress responses when their patients are hospitalized than at baseline when the patients were at home. However in this study, hospitalization was at the same time being viewed as helpful. Caregivers felt that once the patients were brought to the hospital, they received treatment and got better. Most caregivers also felt relief from the trouble that was being caused by the mentally ill patient.

Excessive use of energy/time and financial strain are the resources that are needed by the caregivers in order to take the patients to hospitals when they relapse, review and maintain the patients in a functional state. When the patients are in acute condition, they are dangerous to self and the surrounding people. Some can have excessive energy that they caregivers need a lot of manpower to get them to hospital. This is the time when the police was needed most because mere seeing the police the patients would have some fear but when they are contacted, the caregivers report that they are not willing to help. This necessitates hiring some strong men to help bring the patient to hospital. The financial strain may also be in form of buying drugs when they are not available in the hospital. The impact on family members includes excessive responsibilities, and losing independence. The caregivers cited several times that the patients are like babies and should be treated that way. They have to give up a lot to take care of the patient and some of them lack support from other relatives or family members and with time when the responsibility becomes overwhelming, it triggers sorrow in them. These findings were termed as objective burdens by other researchers (Idstad et al., 2010; Caqueo-Urizar et al., 2009).

Change of behavior was also frequently reported to be among the trigger of sorrow among the caregivers. This change in behavior would have a big impact on the patient and the caregiver. Most of the trigger factors are interrelated and they lead to the other. For example refusing to take medications which may be due to the side effects, or refusing to go hospital all lead to relapse hence patients manifesting symptoms of mental illness which necessitates hospitalization. Management of crises involves handling the relapsed patients who are very dangerous to self and the people surrounding them and the several side effects of the medication. This is very common because the drugs that are commonly used are the typical anti psychotics which have lots of side effects on the patients. Change in behavior and management of crises all point towards the positive symptoms in schizophrenia and these reported to cause a lot of stress to caregivers. Boye & Malt (2002) posited that relatives of acutely admitted psychotic patients revealed strong stress responses similar to those that persons reveal when exposed to a life threatening illness. Therefore the caregivers should be encouraged to utilize the services offered by the hospital during these moments because of the high levels of stress which trigger chronic sorrow.

The theme of societal reaction to mental illness was mainly cited in terms of negative perceptions and stigma. These resulted into mistreatment of patients in the societies and some abandoned by relatives and friends. The patients on the streets have been cited as a trigger of the caregivers' feelings. Some of the caregivers cited references of the abandoned patients on the streets killing other members of the society, raping, beating and so forth. When they see patients on the streets they keep wondering wonder even their relatives might turn out that way. Some of the community members impose their wrong and negative perceptions of mental illness on the caregivers which pressurizes them. Stigma, discrimination and wrong perceptions surrounding mental illness have been reported by several researchers (Young et al. 2004; Richardson et al. 2011; Buizza et al. 2007; Angermeyer & Matschinger 2003). It is therefore important for the mental health stakeholders and policy makers to move towards a direction of addressing this issue. Health educating the public would be very important and availing more resources to facilitate this intervention would be helpful.

Missed companionship was also cited among the trigger by 3 participants. The patients are missed in their various roles in the family. This creates disparity between their expectations and reality hence triggering the grief related feelings. For example as mothers they have special roles and no one can take that place. When there are situations and the caregivers want to confine in them as mothers at times they can't because they don't trust their reasoning abilities. This finding is consistent with the findings in other studies. It was common for the parents/ caregivers to have disparity and feel chronic sorrow because the expectations of each parent/ caregiver has for the child/relative were no longer being met and the hope of a normal child/ relative was a flight of the imagination (Burke et al., 1999; Griffin & Kearney, 2001; Richardson et al., 2011).

Coping mechanisms

The theoretical model of Chronic Sorrow shows that effective internal and external management methods lead to increased comfort and may serve to extend the time between episodes of chronic sorrow (Eakes, 2001). The coping strategies identified by the caregivers (interpersonal, action oriented, emotional and cognitive) were similar to those reported by Lindgren (1996), Hainsworth (1996) and Eakes (1995). However if the mechanisms are to be classified in terms of internal and external strategies as per the theory of Chronic Sorrow, the caregivers use more internal strategies than external. This finding contrast with the findings by Olwit & Jarlberg (2007) who found out that the facially disfigured people in Uganda use more of external coping strategies than internal. This could be because of the discrimination and stigma that surround mental illness in the communities due to wrong perceptions. On the same note, it is not surprising that although the majority of the caregivers used interpersonal strategies to cope, person to person talking was mainly among the family members or relatives. It is a precaution taken because of the society’s perceptions of mental illness and people’s different interests. This is further supported by the findings of Buizza et al (2007) were relatives and parents frequently reported negative attitudes and prejudices by the community to be one of the common stigma experienced. Caregivers task themselves to identify persons in the community who can be helpful. These findings imply that some effort is needed in order to streamline the wrong perceptions and misperceptions in the communities.

Some of these emotional strategies were mainly used when the situation was too much for the caregivers to handle. When some of them felt that their emotions were overwhelming, they would cry to release some of it and others would move away from home (avoidance) while other family members are taking over the caregiving. However the wishful thinking and the avoidance are more of negative coping which need to be dealt with by the health workers while interacting with the caregivers. They need to use more of positive coping strategies than the negative that ones. For example the cognitive strategies (burden acceptance & positive thinking) that were identified by some of the caregivers. These strategies help the caregivers to think forward while looking at the positive side of life and they get hope.

Helpful/not helpful.

Relatives and friends were reported to be helpful during the whole experience. They provide the moral support and show understanding. It was very important for the caregivers because at least it made them feel they were not alone in the hard situations. Health workers were also reported to be helpful in terms of providing medication to reduce the symptoms however they were also reported to be very unhelpful especially when it came to communication and the mental health system. To some of the caregivers, these were very frustrating and triggered anger in them. These findings are similarly reported by Eakes (1995) and Richardson et al. (2011). This could be due to the work load that the health workers have due to shortage of health workers in the country hence exhaustion. It could also be because the male are used to being the caretakers and are not used to the system of the hospital. Many of them had limited time and when they come to the hospital they want to leave as quickly as possible in order to catch up with other roles. Therefore any delay at the hospital would affect them. However, communication was cited as a big problem and this calls on the administrators to deal with the issues that may influence health workers behave that way, for example the workload.

The police were also identified as being unhelpful. Some of the police may not know their role in the mental health system that’s why they act uncooperative when approached by caregivers or they have different priorities. It is very important for the roles of different sectors in mental health to be clearly stipulated and for the people to know their contribution towards mental health in the country.

Conclusions.

Caregivers of patients diagnosed with schizophrenia experience Chronic Sorrow in Uganda. This is evidenced by the responses in the description of their feelings and grief related feelings from the time of diagnosis up to date. There were nine out of ten who experienced Chronic Sorrow and the common triggers were in the different themes of unending care giving, change in behavior, societal reaction to mental illness and management of crises. Health workers were reported to be unhelpful especially when it came to communication, the community which has wrong perceptions about mental health and stigma. Finally the police were also reported not be cooperative when approached and not willing to help.

Different coping strategies were employed by the caregivers and they were placed under different themes which included, interpersonal strategies, action oriented activities, emotional and cognitive strategies.

Implication for Nursing:

- Nurses must understand that chronic sorrow exists among caregivers of patients with schizophrenia. Support should be extended to these caregivers through physical, psychological, and spiritual care, since it is well known that health is a state of complete physical, mental, social and spiritual well being and not merely the absence of disease or infirmity.
- Nursing interventions should be directed not only to patients but also the caregivers and family members of the patients because it is evidenced that mental illness does affect the whole family of the patient and the community at large. Showing empathy and understanding are very important elements while interacting with caregivers or family members.
- Nurses should assess what coping mechanisms are being used by the caregivers, and re enforce positive strategies depending on the circumstances surrounding the caregivers. They should offer time to the family members of mentally ill patients to express their feelings and help them accordingly.
- Nurses should be health educate the public on mental health related issues in effort to reduce stigma or discrimination and creating awareness of their role in mental health.
- The nurses should initiate and encourage the caregivers to join support groups that are helpful in coping with the stresses involved in care giving.

Recommendations.

Practice

- Hospital administrators should organize refresher trainings in customer care and public relations should be carried out on a regular basis to remind health workers of their mandates and obligations.
- Health workers educators should ensure that communication and counseling skills is enhanced in teaching Institutions by the health workers educators.
- Nurses should be prepared to assist caregivers and family members at any point of meeting within the health facility. Offer adequate time for the caregivers to express themselves and air out their different concerns.

Policy measures

- Policy makers should increase the number of health workers in order to reduce on the work load and burnouts. This will result in effective service delivery to the patients and family members.
- Different stakeholders should ensure that some resources are channeled towards facilitating activities among the caregivers that will help improve that services offered by the mental institutions.
- Policy makers and hospital administrators should ensure that different stakeholders (Community, Police, Political leaders, Development partners) are enlightened on their roles pertaining mental health in the country.

Future Research

- Further studies should be carried out in developing countries regarding the experience of chronic sorrow in different situations of losses.

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APPENDIX 1: CONSENT FORMS.

LUGANDA VERSION.

EKIWANDIIKO EKY'OKUKKIRIZA OKWETABAMU:

YUNIVASITE YA MUHIMBILI EY'EBYOBULAMU WAMU NE EBY'ASAYANSI EKITONGOLE EKY'EBYOKUNONYEREZA N'OKUKUBA MUKYAPA EBITABO EBY'EBINONYEREZEDDWAKO.

Okukkiriza okwetaba mukunonyereza kumbeera ez'abalabilira abalwadde bakazoole zebayitamu mu Kampala.

Nkulamusiza! Amannya nze Connie Olwit, nze naansi akola kukunonyereza okugenderera okunonyereza okumanya ennaku abalabilira abantu abalina obulwadde obwakazoole mu Kampala, Uganda.

Ekigendererwa ky'okunonyereza:

Ekigendelerwa ky'okunonyereza kuno kw'ekumanya ennaku abalabilira abantu abalina obulwadde bwakazoole abajjanjabibwa muddwaliro lye Butabika. Kino kiyinza okuyamba ab'ebyobujjanjabi okutegeera okunyolwa kwebalimu n'okubayamba okubeera abegendereza enyo mungeri gy'ebakolagana n'ababalabilira, kyongere mumpuliziganya ennungi wakati w'abebyobulamu n'ababalabilira. Kino kijja kuyigiriza ab'ebyobulamu engeri y'okubayambamu okugeza okubabuddabudda.

Okwetabamu kulimu bino

Bwokkiriza okwetaba mukunonyereza kuno, ojja kubaako by'obuuzibwa era ebyo bijja kukwatibwa kulutambi lwamaloboozi.
Ebibuuzo ebinaabuuzibwa mujja kubaamu ebyo ebikukwatako gwe, kyolowooza n'ebwowulira okuva omuntu oyo gwolabilira bweyazuulibwa n'obulwadde obwo.
Kino kijja kutwala ng'eddakiika 20.

Okukuuma ebyama

Buli nsonga gyoyogera ejja kukwatibwa kulutambi lwamaloboozi era biteekebwe mukyuuma kikalimagezi nga biliko enamba yo yokka. Buli kijja okukufunibwako kijja kukuumibwa buttiribiri. Okunonyereza kuno tekujja kubaamu ebyo ebinakumanyisa butereevu nga amannya go.
Enamba ey'omuntu eyetabyemu yejja okukozesebwa mukunonyereza kuno. Batono nyo kubakola kukunonyereza kuno abajja okusobola okutuuka n'okulaba eby'okunonyereza kuno. Eby'okunonyereza kuno bwewinawandiikibwa oba okutegeezebwa abalala munkuŋŋana ez'ebyasayansi; amannya go n'ebikukwatako ebirala ebisobola okukumanyisa tebijja kubaamu.

Eby'obulabe

Tetusuubira kubaawo bulumi bwonna bukutuukako olw'okuba wetabye mukunonyereza kuno.

Eddembe ly'okuvaamu n'ebirala byolina okulondako

Okwetaba mukunonyereza kuno kwa kyeyegalire ddala. Oli waddembe obutaddamu kibuuzo ekyo kyowulira nti kikubuzaako emirembe okukiddamu. Bwosalawo obuteetabamu, oba bwosalawo okulekerawo okwetabamu, ow'oluganda lwo ajja kweyongera okukolebwako nga bwakolebwako bulijjo muddwaliro lino. Osobola okulekerawo okwetaba mukunonyereza kuno ekiseera kyonna, wadde nga wali wakkiriza dda. Bwotakkiriza kaakati naye nga wandyagadde okwetabamu oluvannyuma, tujja kubeera beetegefu okukuyingiza. Okugaana okwetabamu, oba okuva mukunonyereza tekijja kuvaamu kubonerezebwa oba kufiirwa kyonna kyobadde oganyurwa oba byolina okufuna.

Emigaso

Tewali kyojja kuganyurwa buterevu. Wabula bwokkiriza okwetabamu, okwetabamukwo kujja kuyamba okutegeera abantu nga gwe byemuyitamu n'engeri ab'ebyobulamu bwebayinza okubayambamu. N'okwogera kukyoyitamu kimanyiddwa okuba nti kikukakanya.

Bwoba olumiziddwa

Tetusuubira kubaawo kulumizibwa kwonna kukubaako olw'okwetaba mukunonyereza kuno. Singa wabaawo okulumizibwa kwonna kumubiri oba mubirowoozo olw'okwetaba mukunonyereza kuno, tujja kukujjanjaba n'okukubuddabudda nga tusinziira kunkola ey'obujjanjabi mu Uganda. Tewajja kubaawo kuliyilirwa kulala kwonna.

Ani ow'okutuukilira

Bwobeera n'ebibuuzo kukunonyereza kuno, olina okutuukilira Akulira Okunonyereza kuno Naansi Connie Olwit, essimu 0782744668 okuva mu Yunivasite Ya Muhimbili Ey'ebyobulamu wamu n'Ebyasayansi, akasanduke ka posta 65001, e Dar es Salaam. Bwobeera n'ebibuuzo ebikwata kuddembe lyo ng'eyetabyemu, oyinza okukubira Akulira eby'okunonyereza Prof. M. Aboud, Akulira Emirimu gy'Okunonyereza n'Okukuba Mukyapa Ebitabo eby'Ebinonyerezeddwako mu yunivasite eyo akasanduke ka posta 65001, e Dar es Salaam, essimu 2150302-6.

Omukono:

Okkiriza okwetabamu?

Eyetabyemu akkiriza ……………………… Eyetabyemu TAKKIRIZA ………………..

Nze, ____________________________________ nsomye ebiri mukiwandiiko kino.

Ebibuuzo byange biddidwamu. Nzikkiriza okwetaba mukunonyereza kuno.

Omukono ogw'omujjulizi abaddewo(omuntu/ amulabilira bwaba tasobola kussoma)

____

Omukono ogw'ayamba kubanonyereza________________________Enaku z'omwezi_________

ENGLISH VERSION

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

DIRECTORATE OF RESEARCH AND PUBLICATIONS, MUHAS

Consent to Participate in a project lived experiences among care givers of schizophrenics in Kampala.

Greetings! My name is Connie Olwit , I am a nurse working on a research project with the objective of exploring the experience of chronic sorrow among the caregivers of schizophrenics in Kampala, Uganda.

Purpose of the Study

The purpose of this study is to explore the lived experience of caregivers of schizophrenics attending Butabika hospital. This may improve the health workers" understanding of response to loss and help them be more sensitive when dealing with caregivers hence improving communication among health workers and caregivers. This could also enlighten health workers on how best they can help you for example through positive coping strategies.

What Participation Involves

If you agree to join the study, you will be interviewed and the interview will be recorded. The questions that will be in asked during the interview include those about demographics, thoughts and feelings since the person you are taking care of was diagnosed. It will take about 20 minutes to complete the interview.

Confidentiality

All information that will be recorded will be transcribed and entered into computers with only the study identification number. All information that will be got from you will be protected. The study will not include details that directly identify you, such as your name. Only a participant identification number will be used in the study. Only a small number of researchers will have direct access to the survey. If this study is published or presented at a scientific meeting, names and other information that might identify you will not be used.

Risks

We do not expect that any harm will happen to you because of joining this study.

Rights to Withdraw and Alternatives

Taking part in this study is completely your choice. You are free to skip any question if you feel uncomfortable to disclose information. If you choose not to participate in the study, or if you decide to stop participating in the study your relative will continue to receive all services that you would normally get from this hospital. You can stop participating in this study at any time, even if you have already given your consent. If you refuse now, but wish to enter the study later, we will be ready to accept you. Refusal to participate, or withdrawal from the study, will not involve penalty or loss of **any** benefits to which you are otherwise entitled.

Benefits

There are no direct benefits to you. However if you agree to participate in this study, your contribution will be useful in understanding what people like you go through and how best the health workers can help. Talking about experiences is also known to be therapeutical.

In Case of Injury

We do not anticipate that any harm will occur to you as a result of participation in this study. However, if any physical injury or psychological disturbance resulting from participation in this research should occur, we will provide you with medical treatment and psychological help like counseling according to the current standard of care in Uganda. There will be no additional compensations to you.

Who to Contact

If you ever have questions about this study, you should contact the Principal Investigator Connie Olwit, RN (0782744668) Muhimbili University of Health and Allied Sciences, P.O.Box 65001, Dar es Salaam). If you ever have questions about your rights as a participant, you may call the Principle Investigator or Prof. M. Aboud, Director of Research and Publications at MUHAS, P.O. Box 65001, Dar es Salaam. Tel: 2150302-6.

Signature:

Do you agree to participate?

Participant agrees ……………………… Participant does NOT agree ………………..

I, ___________________________________ have read the contents in this form.

My questions have been answered. I agree to participate in this study.

Signature of participant _______________________________________

Signature of witness (if person/caretaker cannot read) ________________________

Signature of research assistant _________________________________Date_________

APPENDIX 2: INTERVIEW GUIDE TOOLS:

LUGANDA VERSION.

ENDAGILIRO Y'EBIBUUZO EBY'OKUBUUZA MUKUNONYEREZA

Njagala okubaako ebibuuzo byenkubuuza kubwolowooza n'ebwowulira okuva ……………..……..(amannyage) bweyazuulibwa okuba n'obulwadde obwakazoole. Njagala okumanya endowoozayo, banaansi basobole okwegendereza n'okuyamba mungeri enungi enyo abantu ngagwe. Naye, ekisookera ddala njagala okutandika n'ebibuuzo ebyo ebikukwatako olwo tweyongereyo n'ebirala ebikwatagana n'ebwolowooza, byoyitamu n'ebwowulira.

Ebbanga ly'omaze ngobeera n'omulwadde

1. Wamanya otya nti ………………….(amannyage) alina obulwadde bw'akazoole?
2. Osobola okujjukira engeri gyewawulira kwolwo lwewasooka okukimanyaako? (Oyinza n'okwongerako kiki ekyaliwo mubwongo bwo)
3. Kiki ekyasingira ddala okukuyamba okukutebenkeeza bwewawulira amawulire ag'akwata kumbeera y'obulwadde bwa ………………………?
4. Waliwo ekintu kyonna ekyaliwo ekitakuyamba? (Oba yee, wa ekyokulabirako)
5. Jjukira emabegako kungeri gyewayisibwamu ng'otegedde embeera y'obulwadde bwa ……………………., waliwo ekiseera kyonna lwewabaawo ekintu n'oddamu okufuna ebirowoozo byebimu ………………………. (Kozesa ebigambo eyetabyemu byeyakozeseza okuddamu namba 2 waggulu) ng'ebyo ebyaliwo? (Oba YEE, buuza ebibuuzo okuva ku namba 7-16; bwekiba NEDDA , buuza ekibuuzo namba 6)
6. Owulira otya kaakati bwolowooza kumbeera y'obulwadde bwa ………………………?(Bwannyonyola n'ekiba nti alina buli kiseera ebirowoozo byokunakuwala, buuza ekibuuzo namba 7, bwekiba nedda buuza ekibuuzo namba 14)
7. Bambi mbulirako wakiri ekimu (Bwoba obuuza ekibuuzo namba 6, kozesa n'ekigambo 'nebirala' wano) ekiseera lwewawulira bwootyo? (Oyinza n'okwongerako nti: mbeera ki eyaliwo? Osobola okunnyonyola bwewawuliramu?)

8. Abamu kubalabilira bagamba nti ebintu ebimu ebibeerawo byebivaako okudda kwebirowooza bino. Waliwo wabaddewoko ekiseera ekirala lwewafuna ebirowooza ebyo? (Oba yee, osobola okumbulirako ebimu kubiseera ebyo?)
9. Oyinza kugerageranya otya embeera yakaakati n'ebirowoozo byewalina nga wakamannya embeera y'obulwadde bwa ………………………?
    a. Eneeralikiriza nyo okusinga luli
    b. Eneeralikiriza nyo ngaluli
    c. Teneeralikiriza nyo
10. Abantu abalala baakimanya nti wali mubirowoozo ebyo? (Oba yee, baamanya batya?)
11. Bwewali olaga ebirowoozo ebyo, waliwo omuntu yenna eyakuyamba enyo? (Oba yee, baali baani? Osobola okujjukira kyebakola ekyakuyamba enyo?
12. Bantu ki abatakuyamba yadde? Mungeri ki?
13. Bwowulira ng'abikusobedde olw'embeera y'obulwadde bwa ………………………, okola ki okuwulira obulungi ko?
14. Kansubire nti okunonyereza kwange kujja kutuyamba okuwa amagezi aganamaddala okusobola okuyamba abantu abalabilira abantu abalina obulwadde obwakazoole. Oyinza kubagamba ki kyebaba basuubira? Balina kwetaaga kumanya ki?
15. Olina kyoyagala okugamba banaansi oba ab'ebyobulamu kuby'okuyamba abantu nga gwe?

16. Nga tutuuka kunkomelero y'okukubaganya ebirowoozo. Njagala okubaako ekintu kimu kyenkwebuuzako. Abamu kubalabilira bagambye nti baanakuwala nyo-nyo bwebategeera embeera y'obulwadde bwa ………………………, era bwewabaawo ekintu, nate batera nyo okuddamu okunakuwala. Abalala abalabilira ssibwebawulira; kituufu gyoli?

ENGLISH VERSION

I would like to ask you some questions about some of thoughts and feelings you have experienced since………..(name) was diagnosed with schizophrenia. I am interested in learning your point of view so that nurses can become more sensitive and helpful to people like yourself But first, I would like to ask a few questions on demographic information then we shall explore your thoughts, experiences, and feelings.

Duration of which you have been Living with the patient

1. How did you first learn that…….(name) had schizophrenia?
2. Can you recall your feelings when you first learned about it? (May add what went through your mind)
3. What was most helpful to you in adjusting to the news about ……..'s condition?
4. Was there anything in particular that happened that was not helpful? (If yes, please give me an example)
5. Thinking back to how you reacted at first to the news of…….'s condition, has there been a time when something happened and you had those same feelings of..….. (Use individual's words in his/her response to #2) all over again? (If yes, ask questions 7-16, if no ask question 6)
6. What feelings do you have right now when you think about ……..'s condition?(If feelings consistent with chronic sorrow are described, ask question 7, if not ask question 14)
7. Please tell me about one (If using question 6, insert 'other' here) time when you felt this way? (May add: what were the circumstances? Can you describe your feelings?)
8. Some caregivers say that certain events tend to bring up these feelings again. Were there other times when you had these feelings? (If yes, can you tell me about some of these times?)
9. How would you compare these later experiences to your feelings when you first learned of ……..'s condition?
    d. Usually more intense

   e. Usually just as intense
   f. Usually less intense

10. Were other people aware that you were having these feelings? (If yes, how did they know?)
11. When you were experiencing those feelings were any people particularly helpful? (If yes , who were they? Can you recall what they did that helpful you?
12. What people were least helpful? In what way?
13. When you feel really down about his/her …..'s condition, what could you do to feel better?
14. I hope that my study will help us give really practical advice to people who are providing care for individuals with schizophrenia. What would you tell them they can expect? What will they need to know?
15. Is there anything that you would tell nurses or other professionals about helping people like yourself?

16. As we come to a conclusion of our discussion, let me just check some point with you. Some caregivers have said that they felt really sad when they learned about their ……………………’s condition and that every so often something happens and they feel the sadness all over again. Other caregivers haven’t felt that way, which is true for you?

APPENDIX 3: FGDs GUIDES:

LUGANDA VERSION

EBIBUUZO BY’OKUKUBAGANYA EBIROWOOZO MUKIBINJA.

1. Nnyinyonyola bwowulira n’embeera gyoyitamu ng’ojjanjaba omulwadde wo?

2. Biki ebikubonyabonya byoyitamu ebitera okuza ennaku n’okunakuwala ng’olabilira omulwaddewo?

3. Okola ki okuvvunuka ebikubonyabonya ebyo?

4. Ab’ebyobulamu basobola kukola ki okusobola okukuyamba okuyita mubwowulira, embeera n’ebikubonyabonya byosanga?

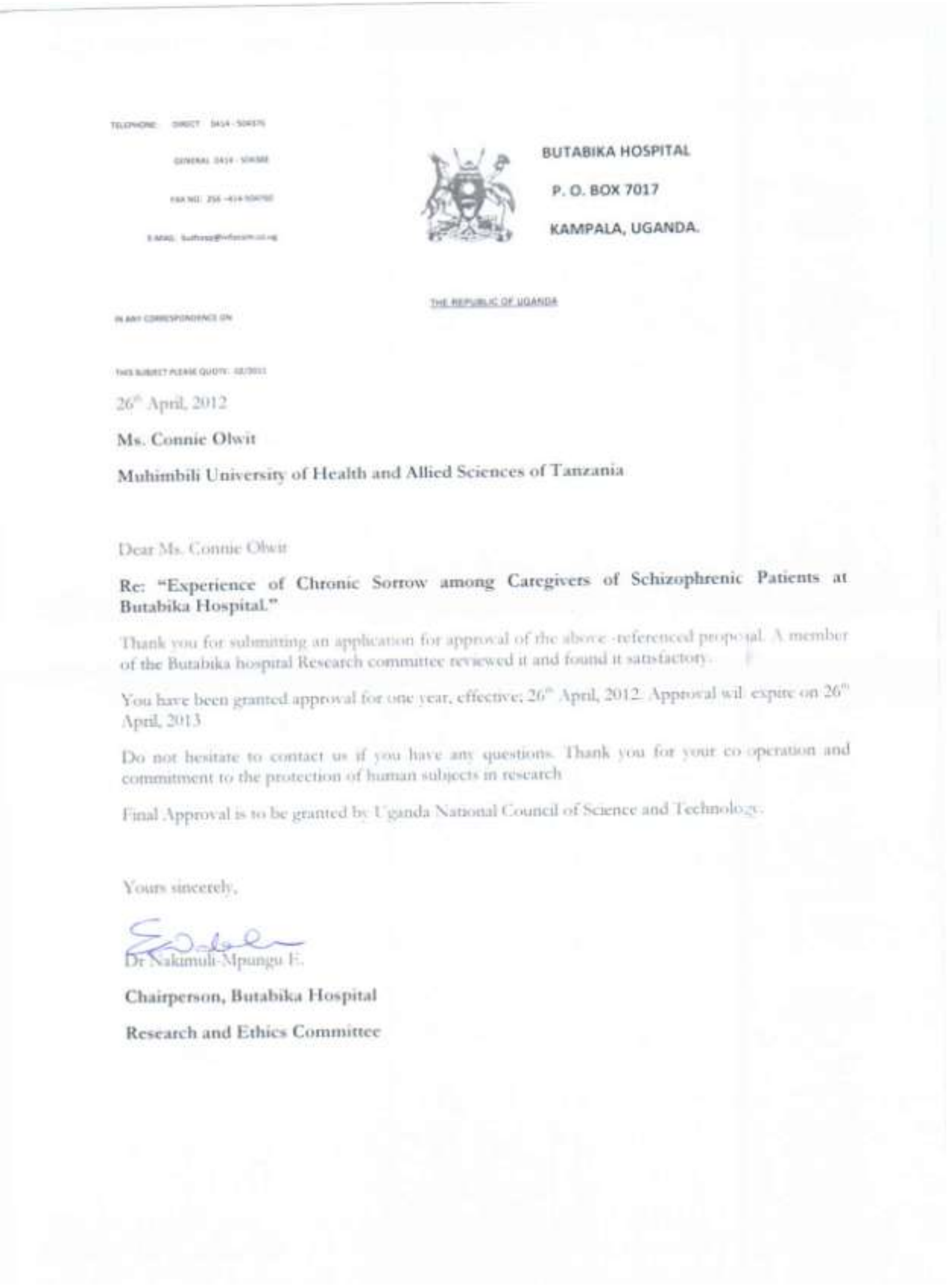
ENGLISH VERSION

1. Describe the feelings and emotions that you experience when caring for your patient?

2. What distresses do you encounter that bring back the sadness and grief related feelings when caring for the patient?

3. What do you do to overcome these distresses?

4. What can help workers do in order to help you deal with the feeling, emotions and the distresses you encounter?



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BUTABIKA HOSPITAL
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THE REPUBLIC OF UGANDA

IN ANY CORRESPONDENCE ON
THIS SUBJECT PLEASE QUOTE: [illegible]

26th April, 2012

Ms. Connie Olwit

Muhimbili University of Health and Allied Sciences of Tanzania

Dear Ms. Connie Olwit

Re: "Experience of Chronic Sorrow among Caregivers of Schizophrenic Patients at Butabika Hospital."

Thank you for submitting an application for approval of the above -referenced proposal. A member of the Butabika hospital Research committee reviewed it and found it satisfactory.

You have been granted approval for one year, effective; 26th April, 2012. Approval wil expire on 26th April, 2013.

Do not hesitate to contact us if you have any questions. Thank you for your co-operation and commitment to the protection of human subjects in research.

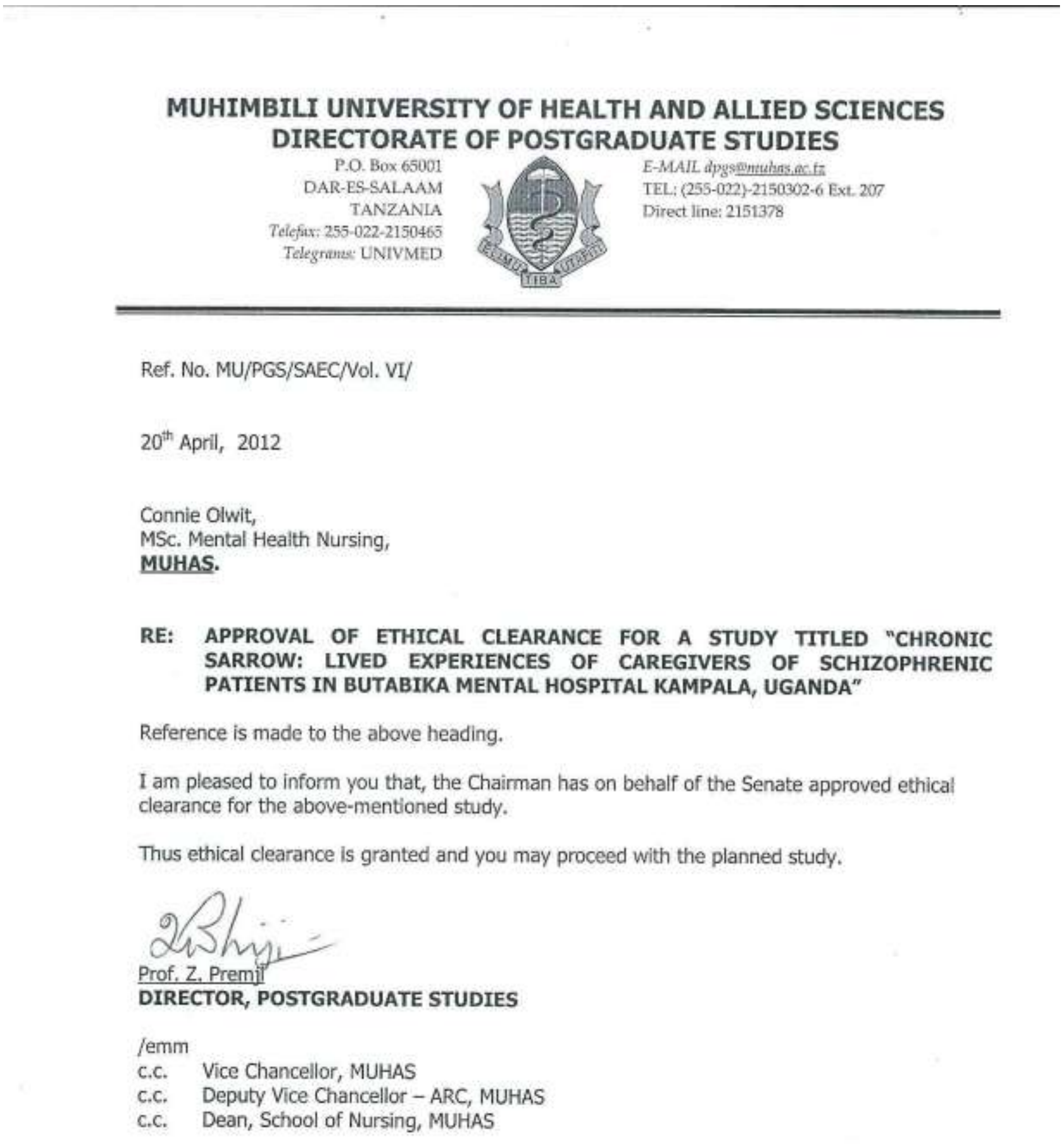
Final Approval is to be granted by Uganda National Council of Science and Technology.

Yours sincerely,

Dr Nakimuli-Mpungu E.

Chairperson, Butabika Hospital

Research and Ethics Committee



MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
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Ref. No. MU/PGS/SAEC/Vol. VI/

20th April, 2012

Connie Olwit,
MSc. Mental Health Nursing,
MUHAS.

RE: APPROVAL OF ETHICAL CLEARANCE FOR A STUDY TITLED "CHRONIC SARROW: LIVED EXPERIENCES OF CAREGIVERS OF SCHIZOPHRENIC PATIENTS IN BUTABIKA MENTAL HOSPITAL KAMPALA, UGANDA"

Reference is made to the above heading.

I am pleased to inform you that, the Chairman has on behalf of the Senate approved ethical clearance for the above-mentioned study.

Thus ethical clearance is granted and you may proceed with the planned study.

Prof. Z. Premji
DIRECTOR, POSTGRADUATE STUDIES

/emm
c.c. Vice Chancellor, MUHAS
c.c. Deputy Vice Chancellor – ARC, MUHAS
c.c. Dean, School of Nursing, MUHAS

Uganda National Council for Science and Technology
(Established by Act of Parliament of the Republic of Uganda)
UNCST

Our Ref: SS 2797

May 4th, 2012

Ms. Connie Olwit
Makerere University
College of Health Sciences
Department of Nursing
P. O. Box 7072
Kampala

Dear Ms. Olwit,

RE: RESEARCH PROJECT, "CHRONIC SORROW: LIVED EXPERIENCES OF CAREGIVERS OF SCHIZOPHRENIC PATIENTS IN BUTABIKA MENTAL HOSPITAL, KAMPALA, UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **April 27, 2012.** The approval will expire on **April 27, 2013.** If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,

Winfred Badanga
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION/CORRESPONDENCE

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