

**EXPERIENCES AND NEEDS OF CAREGIVERS OF MENTALLY ILL  
PATIENTS ATTENDING AT THE DEPARTMENT OF PSYCHIATRY  
AND MENTAL HEALTH, MUHIMBILI NATIONAL HOSPITAL (MNH)  
IN DAR ES SALAAM, TANZANIA**

**By:**

**ATUTTA ROBERT**

**A dissertation Submitted in (Partial) Fulfillment of the Requirements for the Degree  
Of Masters of Public Health of  
Muhimbili University of Health and Allied Sciences**

**Muhimbili University of Health and Allied Sciences**

**September, 2013**

**CERTIFICATION**

The undersigned certify that they have read and hereby recommend for examination of the dissertation *experiences and needs of caregivers of mentally ill patients at the department of Psychiatry and Mental health, Muhimbili National Hospital* in fulfillment of the requirement for the degree of masters of Public Health of Muhimbili University of Health and Allied Sciences.

.....

**Lusajo Kajula**

**(Supervisor)**

**Date:.....**

**DECLARATION**

I **Robert Atutta**, 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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## **ACKNOWLEDGEMENT**

This dissertation represents a combined effort of a large number of individuals and it's my pleasure to acknowledge the concerned.

I wish to extend my thanks to Medical staff at the Department of Mental Health and Psychiatry, Muhimbili National Hospital for their support and facilitating me during the time of field data collection.

I would wish to also thank my supervisor, Lusajo Kajula for her advice, guidance, support, patience and encouragement through this whole time to produce this report. Thank you; this report would not have been accomplished without you.

I am very grateful to my fellow colleagues, Ruth Nabwire, Robert Majwala, Maria Polepole and Valeria Ndomba. Ruth, thank you for your advice in making this report a success.

I would like to thank my Aunt Dr. Maryrose Mutonyi for all her support to enable me to realize my dreams, thank you. I would also like to extend my gratitude to my sisters Asinasi Ajiambo, Shamim Kagoya, Judith, Grace and Sekela Mwasumbi and my brother Frank Onyango for their inspiration.

This work could not have been a success without the full support of my beloved wife Dr. Ikupa Mwasumbi and my beautiful lovely daughter Abigail who tolerated my absence when I was busy with the dissertation. Thank you so very much.

## **DEDICATION**

I dedicate this dissertation to you my Wife, Dr. Ikupa Mwasumbi since you were supportive through all the stages to its completion.

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### **List of Abbreviations**

- CMD- Chronic mental diseases
- ECI- Experience of care giving Inventory.
- FGD- Focus group discussions
- GNP- Gross net profit
- IDI- In depth Interviews
- MNH- Muhimbili National Hospital
- OPD- Out patient department

YLD- years of life disability

WMH- World mental health

## Abstract

**Title:** Experiences and needs of caregivers of mentally ill patients attending at the department of Psychiatry and mental health, Muhimbili national hospital (MNH) in Dar es salaam, Tanzania.

**Background:** Today, globally about 450 million people suffer mental or behavioural disorders. In Tanzania the estimated annual incidence of mental disorders is 22%. Family caregivers play a pivotal role in the treatment and care of their mentally ill relatives. Unless the important roles of family caregivers are supported in the future, this valuable resource may not be sustained. In Tanzania, little is documented about the caregivers' experiences and needs in caring for mentally ill patients.

**Methods:** A cross-sectional descriptive study using both qualitative and quantitative methods. Convenient non probability sampling was used to identify the caregivers that fit the criteria. Statistical analysis was done using SPSS software package for Windows, version 20. The audio taped interviews and discussions were transcribed verbatim for analysis using content analysis and a constant reiterative comparative method.

**Results:** In the quantitative study, 380 caregivers were interviewed, majority (49.5%) of them were parents; a total of 39.5% had cared for the patient for 2-5 years while 39.7% spending more than 32 hours a week in caring for their patients. 87.4% of the participants had no past experience of care of a mentally ill patient. The caregivers that have never taken care of a mentally ill patient had 45.9% higher odd than the ones that have ever cared in experiencing negative symptoms (OD=0.459, C.I= 0.237-0.889). Caregivers that cared for the patient for 2-5 years had higher odds (OD= 2.584; C.I. =1.279-5.220) than those who cared for less than 2 years in reporting that the patients were dependent on them. In qualitative study the following themes were found, Participants' experiences during care of the mentally ill patient, common concerns around acute phases of mental illness, impact of caregiving on family relations, impact of caregiving on financial status, performance of hospital structure and rehabilitation services.

**Conclusion and Recommendations:** Caregivers experience psychological distress and suffer physical, social and financial strains due to the roles they play while caring for their mentally ill patients. Caregiver needs should be addressed.



### **Operational definitions of terms**

**CAREGIVER:** someone who provides unpaid care in their own home or in the recipient's home to a family member, friend, or neighbour who has been diagnosed with a mental illness.

**RELATIVES:** a person connected by blood or marriage Includes cousins, nephews, nieces, uncles, grandchildren, grandmother, in-laws among others.

## **Chapter One: Introduction**

### **1.1 Background of the study**

Today, globally about 450 million people suffer from a mental disorder. According to WHO's Global Burden of Disease 2001, 33% of the years lived with disability (YLD) are due to neuropsychiatric disorders, a further 2.1% to intentional injuries. Unipolar depressive disorders alone lead to 12.15% of years lived with disability, and rank as the third leading contributor to the global burden of diseases. Four of the six leading causes of years lived with disability are due to neuropsychiatric disorders (depression, alcohol-use disorders, schizophrenia and bipolar disorder)<sup>1</sup> The estimated lifetime prevalence of having one or more of the disorders considered here varies widely across the WMH surveys, from 47.4% in the United States to 12.0% in Nigeria.<sup>2</sup>

Worldwide in the field of mental health care, there is a shift towards encouraging community care of psychiatric patients.<sup>3</sup> Caregivers - like family members or other relatives - are central to this practice most especially in Africa where the extended family system provides most of the social and economic support needed for ill patients<sup>4</sup>. Symptoms of the illness make life difficult for all around the psychotic person: delusions are unreasonable ideas, hallucinations intrude on behaviour, and thoughts may be disorganized. There may be threats or acts of violence. This continues and even when the person is quite stable there are tasks to be carried out; for example, seeing that the person takes medication as prescribed or applying for state disability payments. In addition, families do not understand mental illness and often cannot make sense of the behaviours of the ill person. Expenditures of time and money deplete family resources. Families may also be subject to abuse or violence by ill relatives<sup>5</sup>. Relatives report that family finances suffer the greatest impact due to the patients' mental illness. There is dependence of the patients on their relatives in an environment where there's no welfare support system perceived economic.<sup>6</sup>



In Tanzania the estimated annual incidence of mental disorders is 22%<sup>7</sup>. In a study done in urban Tanzania, the prevalence of past-year psychotic symptoms (endorsing at least one PSQ item) in two areas of urban Dar es Salaam, Tanzania, was 3.9%. The rate was significantly higher in the poorer area of Saba Saba (6.0%) compared to the relatively middle-income area of Ilala (2.1%) although this difference was no longer significant after adjustment for other factors. Factors independently associated with psychotic symptoms were two or more recent life events, presence of CMD and past-year cannabis use.<sup>8</sup>

However, concept of burden has been criticized because it attributes all negative consequences in the caregiver's life to the patient's illness without taking into consideration factors like normal life changes, personality of the caregiver and his/her busy social life. Moreover, caring for the mentally ill can be a source of positive transformation in a person's life and can provide caregivers with a sense of inner strength and satisfaction. This aspect has been ignored in previous studies on the concept of burden. To overcome the above limitations, the concept of 'care giving experience' has emerged.<sup>24</sup> Mental health professionals have to respond to the needs dictated by the local environment and are required to take into account existing attitudes towards mentally ill people.<sup>25</sup>

## **1.2 Problem Statement**

Mental disorders comprise five of the top ten leading causes of disease burden, around the world. The portion of the global burden of disease attributable to mental disorders is expected to rise from 12% in 1999 to 15% by the year 2020. The rise will be particularly sharp in developing countries due to factors such as the ageing of the population and rapid urbanization.<sup>1</sup>

Caregivers, such as family members or other relatives are central to this practice most especially in Africa where the extended family system provides most of the social and economic support needed for ill patients<sup>5</sup>. Family carers play a pivotal role in the treatment and care of their mentally ill relatives. Unless the important roles of family carers are

supported in the future, this valuable resource may not be sustained, to the detriment of those who suffer mental illness.

The World Health Organization (WHO) has for long proposed the development of community-based mental health services worldwide. Community based initiatives in the management of mental disorders however well intentioned, will not be sustainable unless the family and the community are involved in the intervention program with support being provided regularly by mental health professionals.<sup>11</sup>

Mental health problems have clear economic and social costs. Sufferers and their families or caregivers often experience reduced productivity at home and in the workplace. Lost wages, combined with the possibility of catastrophic health care costs can seriously affect patients and their families' financial situation, creating or worsening poverty. For both patients and families, the social consequences of mental disorders can include unemployment, disrupted social networks, stigma and discrimination, and diminished quality of life.<sup>13</sup> Little is known about caregivers' experiences in caring for mentally ill patients.

### **1.3 Rationale of the study**

Caring for a person who has a serious mental illness is challenging. This can be extraordinarily difficult and stressful for the carer. Caring for patients in the homes in Tanzania is traditional; hence caregivers are an irreplaceable resource for the mental health services system and the pillars on which the system currently rests.<sup>34</sup> Addressing the needs of these caregivers is therefore crucial for the survival of the system. In Tanzania little was documented about the experiences and needs of the caregivers towards the care of mentally ill patients hence the reason we carried out the study

#### **1.4 Research Questions**

1. What are the challenges faced by the caregivers while caring for mentally ill patients?
2. How do socio- demographic characteristics of the caregivers influence their care for mentally ill patients?
3. What are the needs of caregivers in caring for mentally ill patients?

#### **1.5 Objectives of the study**

##### **1.5.1 Main Objective**

To explore the experiences and needs of caregivers in caring for mentally ill patients attending the Muhimbili National Hospital, Department of Psychiatry and Mental Health.

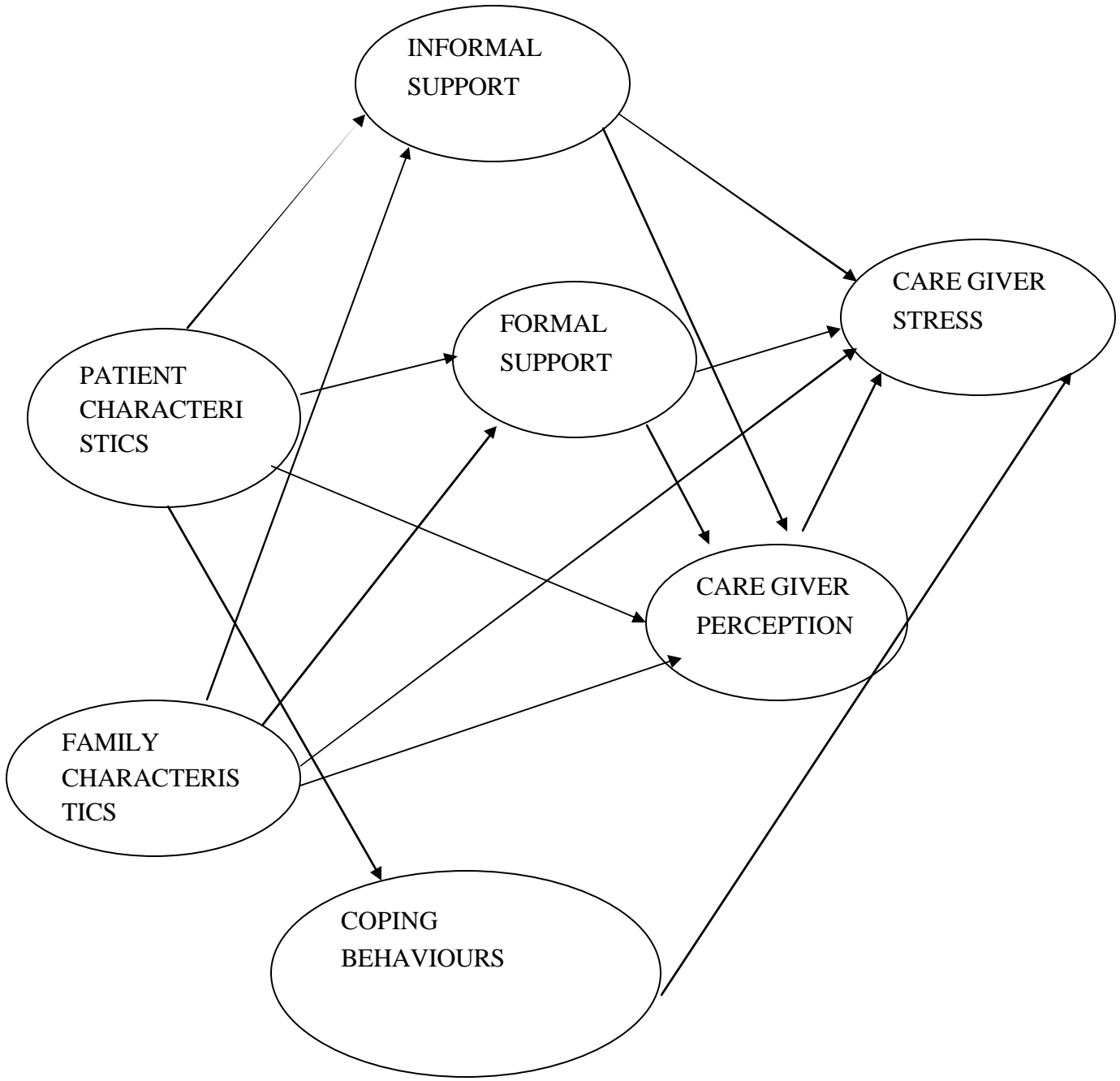
##### **1.5.2 Specific Objectives**

1. To determine the experiences of the caregivers in caring for mentally ill patients.
2. To determine the relationship between caregivers' socio-demographic characteristics and their care for mentally ill patients.
3. To describe the needs of the informal caregivers in caring for mentally ill patients.

## **1.6 Conceptual Framework**

A mentally ill patient when stable may perform his or her activities normally as any other person that is not mentally ill. The pathology of the illness shows up as hallucinations, delusions, withdrawal among other psychotic symptoms. These may render the patient either to harm himself or people around him. He may be lonely and refuse to associate with others as before the illness. These plus other manifestations of the illness make the care for such a patient difficult since even the caregiver may be a victim of the endangerment. The characteristics of family that the patient comes from play a bigger role as to improve or worsen the patient's illness. His behaviour may be controlled by restraining him by the neighbours, relatives or even policemen that's the informal support. The other aspect of the informal support is that got from the traditional healers that play a big role in the care of mentally ill patients since many people associate mental illness with witchcraft. A caregiver is at the centre of every aspect of the patient. His or her care to the patient is determined by the functioning of the hospitals and the informal support. If he is not satisfied by either of them will affect on how he/she cares for the patient. This coupled with the patient's symptoms and behaviour given the family characteristics that the patient comes from will affect the caregivers perception and hence the stress that is experienced in taking care of a mentally ill patient.

**Figure 1:** Schematic Diagram Showing Conceptual Framework of Caregiving In Mental Health<sup>32</sup>



## **Chapter Two: Literature Review**

Compared to the western world, African society is much more tightly knit, with both stronger family coercion and greater social support. There is almost always an extended family to rely upon, and even severely ill persons are usually living with their family, although a minority of mentally ill persons may choose to move away from their families, often ending up as vagrants. Only in more extreme cases of violence or extremely deviant behaviour, or when the family's resources are stretched to breaking point, will mentally ill persons be excluded from their families, although they may be chained up or neglected. Overall, however, it is families, and to a lesser extent communities, who form the basis for mental health care in traditional societies.<sup>9</sup>

In a study done in India, family caregivers played a major role in providing care giving assistance to ill persons and their families. The shift towards community care for patients with mental disease resulted in transferring responsibility for day-to-day care of patients to their family members, which led to profound psychosocial, physical and financial burdens on patients' families. It was also discovered that even though many families were finding it extremely difficult and stressful to look after the patient, most refused to consider the idea of a separation, involving sending the ill member to an institution or a home.<sup>10</sup>

Most families of those with mental disorders are affected by the condition of their near ones. Families not only provide practical help and personal care but also give emotional support to their relative with a mental disorder. Therefore the affected person is dependent on the carer, and their well-being is directly related to the nature and quality of the care provided by the carer. These demands can bring significant levels of stress for the carer and can affect their overall quality of life including work, socializing and relationships. Research into the impact

of care-giving shows that one-third to one-half of carers suffer significant psychological distress and experience higher rates of mental ill health than the general population. Being a carer can raise difficult personal issues about duty, responsibility, adequacy and guilt.<sup>11</sup>

Given the prevalence of mental health and substance-dependence problems in adults and children, it is not surprising that there is an enormous emotional as well as financial burden on individuals, their families and society as a whole. The economic impacts of mental illness affect personal income, the ability of ill persons – and often their caregivers – to work, productivity in the workplace and contributions to the national economy, as well as the utilization of treatment and support services. The cost of mental health illnesses in developed countries is estimated to be between 3% and 4% of GNP. However, mental disorders cost national economies several billion dollars, both in terms of expenditures incurred and loss of productivity. The average annual costs, including medical, pharmaceutical and disability costs, for employees with depression may be 4.2 times higher than those incurred by a typical beneficiary. However, the cost of treatment is often completely offset by a reduction in the number of days of absenteeism and productivity lost while at work.<sup>12</sup>

Studies show that caring process can be very taxing and exhausting, especially if the care recipient had a severe mental disorder. The behavioural problems associated with mental disorders further increase the stress levels of the carer and therefore impact significantly on their mental health<sup>13</sup>. Another study conducted in a rural setting found out that physical and emotional abuse was imposed onto the parents or their children or both by the mentally ill patient.<sup>14</sup>

In a study done in Nigeria, almost half of the relatives had some degree of psychological distress i.e. 43.8% and 63.6% had more than average experience of burden. Relatives in this study spent on average 9 hours per day with the patient and 39 hours per week.<sup>15</sup>

In a study done to assess the experience of care giving at first episode of a Mental illness, it was found out that twelve per cent of caregivers exhibited psychiatric morbidity. This was

comparable to the percentage in the general population.<sup>16</sup> Family caregivers experience varying levels of powerlessness and invalidation in their interactions with mental health professionals. They report that often mental health professionals do not listen to what they say, rarely ask for their opinions, or take an ‘expert’ stand and do not involve them in decisions about the on-going treatment and care of their relative.<sup>17</sup>

In a qualitative study done in Ireland, most of the caregivers of mentally ill patients experienced separations or loss of contact with other family members. One of the perceived reasons for family isolation or disintegration was the stigma associated with mental illness, especially schizophrenia. Knowledge about the illness and treatment helped to reduce the feelings of anxiety of family members, and allowed them to better fulfill their caring role.<sup>18</sup>

A study done in Chile showed that mothers were the caregivers with the most negative attitude towards schizophrenia. This is probably because a large percentage of them are primary caregivers, taking responsibility for all the care of their schizophrenic child.<sup>19</sup> This is related to the greater involvement of mothers, both psychologically and in practice (in their role)<sup>20</sup>

A study showed that parents of adults with serious mental illness are at an increased risk for poorer health and mental health and marital disruption. It also suggests that parenting an adult child with bipolar disorder is associated with lower levels of work satisfaction among older age parents in the labour force.<sup>21</sup> Care giving often results in chronic stress, which comprises caregiver’s physical psychological health. Depression is one of the common negative effects of care giving. Care giving can also be beneficial, enabling caregivers to feel good about themselves, learn new skills, and strengthen family relationships.<sup>22</sup> Caregivers who bring their children to psychiatric treatment manifest substantially higher levels of mental health difficulties than adults in the general population. Indeed, over half (56.6%) of all caregivers manifested clinically significant levels of depressive symptoms.<sup>23</sup>



## **Chapter Three: Methodology**

### **3.1 Study Design:**

A cross-sectional descriptive study using both qualitative and quantitative methods was done. Method triangulation was used to improve the validity of the study, deepen and widen one's understanding about the problem.

### **3.2 Study Area**

The study was conducted at the Department of Psychiatry and Mental Health, Muhimbili National Hospital which is located at Kalenga Street in Upanga West, Dar es Salaam City, Tanzania,

### **3.3 Study population:**

The study population was caregivers who were identified as those who lived with the mentally ill patient, provided on going social support in the care of the patient or maintain regular contact of at least once a fortnight. They included either family caregivers or informal care givers. The patient must have been mentally ill for at least 1 year.

Inclusion criteria for caregivers were:

- above 18 years
- Continuous care giving of mentally ill patient for at least a year.

### **3.4 Quantitative study**

This was aimed at quantifying the caregivers' experiences that were measured using the ECI questionnaire, such that at the end of the study, we find out how the socio-demographic characteristics associate with the ECI score.

### **3.4.1. Sampling techniques**

Convenient non probability sampling procedure was used. The available caregivers that suited the criteria were selected from those that had accompanied the patients to the OPD clinic or those that visited the patients in the ward.

### **3.5 Qualitative study**

The purpose of the focus group discussions was to elicit the participants' spontaneous accounts of their experiences and needs in caring for mentally ill patients. This was aimed at acquiring a more detailed description of caregivers' experiences.

In-depth interviews were conducted. Six in-depth interviews (IDIs) and four focus group discussions (FGDs) were conducted. The focus group discussions consisted of 6-7 participants divided in male-female groups. A combination of IDIs and FGDs added to the strength of the study as some sensitive information were only discussed in individual interviews and not in a group. The focus groups discussions consisting of same sex participants facilitated expression since there was no shyness or gender discrimination of any kind.

### **3.6 Data collection procedures**

In the quantitative study, a number of 380 caregivers were invited to complete an Experience of Caring questionnaire, which requested for details on their socio-demographic characteristics, social networks, health, and ways of coping in caring for a mentally ill patient.

In the qualitative study, data was collected through four focus group discussions each comprising 6-7 participants of the same sex. The participants that suited the inclusion criteria were identified with the help of patient files and the central diary from the records department. Participants were then called for appointments and a similar procedure was followed to identify the six participants that participated in in-depth interviews.

Informed consent was obtained from each participant before completing the questionnaire, audio-taping the interviews and participating in focus group discussions.

### **3.7 Instruments:**

#### **3.7.1 Instruments for quantitative study:**

1. Demographic data Questionnaire was constructed to collect the data regarding age, sex, educational status, previous experience of caring psychiatric clients, income of family members, and duration of caregiving to the patient, among others.
2. Experience of Caregiving Inventory (ECI) questionnaire: Used to assess the caregiving experience as perceived by the caregivers. It is a 66-item self-report measure of the experience of caring for a relative with serious mental illness<sup>28</sup>. It was developed specifically for use with relatives of patients with mental illness. Relatives rate the frequency with which they have thought about each item on a five-point Likert scale anchored at never and '(nearly) always'. The ECI is divided into 52 items measuring negative appraisal and 14 measuring positive appraisal. The internal consistency and construct validity of the ECI are good. It identifies 10 independent dimensions in relatives' appraisal of caregiving: eight negative and two positive. The negative subscales include: difficult behaviours (patient being moody, unpredictable); negative symptoms (being withdrawn, uncommunicative); stigma (feeling the stigma of having a mentally ill relative; how to explain patient's illness to others); problems with services (how health professionals do not take you seriously; finding out how hospitals and mental health services work); effects on the family (how the patient gets on with other family members; how family members do not understand the illness); loss (what sort of life the patient might have had; whether the patient will ever get well); dependency (being able to do the things you want to do; patient's dependence on you); need for back-up (difficulty looking after money; setting patient up in

accommodation). The two positive subscales include positive personal outcomes (I have learnt more about myself; I have contributed to others' understanding of the illness) and good aspects of the relationship with the patient (grown in strengths in coping with the illness; makes a valuable contribution in the household). The items are rated on a Likert scale (0 = never; 1 = rarely; 2 = sometimes; 3 = often; 4 = nearly always). The negative and positive measures can be summed to give two measures: total negative score (ECI-negative) and total positive score (ECI-positive). For this study, this inventory will be translated into Kiswahili (Tanzania's national language) using the methodology given by World Health Organization.<sup>25</sup>

### **3.7.2 Instruments for Qualitative study:**

The semi-structured in depth interview guide that was used for the interviews and focus group discussions included:

- What are some of your experiences as a caregiver?
- Please share with me some of your needs as a caregiver
- From your experience, what challenges does a caregiver of mentally ill patient face?

Each of these primary questions was followed by probing questions designed to elicit more complete descriptions from the caregivers.

### **3.8 Data processing and analysis:**

#### **3.8.1 Quantitative Study:**

The statistical analysis was done using the IBM SPSS statisticals software package for Windows, version 20. Descriptive analysis was computed using frequency with percentage for categorical variables. Chi square test was used to assess the association of experience of care giving and categorical variables. A multivariate analysis was done using logistic regression. The level of statistical significance was set at 0.05.

### **3.8.1 Qualitative study:**

The audio taped interviews and discussions were transcribed verbatim for analysis. The transcribed data was analysed using content analysis<sup>29</sup>. A four-step method was used to analyze the data:

1. Each interview was broken down into individual meaning units.
2. Similar individual meaning units were regrouped under a unifying theme.
3. Underlying characteristics were identified for each theme.
4. A summary table was built to compare themes and their related characteristics within and across participants in the study.

### **3.9 Ethical considerations:**

Approval for the study was obtained from MUHAS Research and Ethics Committee. Permission to conduct the study was obtained from the Clinical Services Director at Muhimbili National Hospital, Dar es Salaam, Tanzania.

Each selected study participant was informed about the purpose of the study, they were made to understand that participation in the study was totally on a voluntary basis and a participant was free to withdraw at any time during the study. They were also told that they were free to refuse answering any of the questions without any consequences. A written informed consent was obtained from all participants; the Muhimbili University of Health and Allied Sciences' Research and Ethics committee's informed consent form was adapted and modified for this study (Annex 1)

Confidentiality was assured all the time. All information obtained was taken confidentially; in order to maintain anonymity, no names or any participant identifying information appeared anywhere on the questionnaire.

### **3.10 Dissemination of results**

Study findings will be disseminated to the School of Public Health and Social Sciences' community – MUHAS and the department of mental health and psychiatry Muhimbili National Hospital.

### **3.11 Pre-testing of the tools:**

A pilot study was conducted on 10 randomly selected caregivers from the Mwananyamala Hospital that is a district referral hospital prior to test the questionnaire and interview guides after which some adjustments were made for example incorporation of patient's age and sex into socio-demographic variables. .

## **Chapter Four: Results**

### **4.1 Quantitative findings**

#### **Caregivers' socio-demographic characteristics**

Of the 380 caregivers interviewed 63.4% were female; majority (45%) of them aged 31-49 years; 54.2% were married 23.9% single while 6.1% were divorced. Majority (59.2%) of them were muslims while just more than half (51.3%) of the participants attended primary school with the minority (9.5%) attending college or university. Nearly half (43.9%) of the participants were businessmen/ women. Majority (49.5%) of them was parents; 22.9% were relatives. Majority (33.9%) of them earned approximately TShs. 200,000- 299,000 per month. For the majority (87.4%) of the participants, there was no past experience of care of a mentally ill patient. A total of 39.5% of caregivers had cared for the patient for 2-5 years. And a total of 39.7% of the participants spent more than 32 hours a week in caring for their patients.

**Table 1:** Frequency distribution of caregivers by selected socio-demographic characteristics

Variables	No. (n=380)	Percentage (%)
<b>Age:</b>		
30 or younger	76	20.0
31-49	172	45.3
50-64	111	29.2
65 or older	21	5.5
<b>Sex:</b>		
Male	139	36.6
Female	241	63.4
<b>Marital Status:</b>		
Single	91	23.9
Married	206	54.2
Divorced	23	6.1
Widowed	38	10.0
Cohabiting	22	5.8
<b>Religion:</b>		
Christian	150	39.5
Muslim	225	59.2
Pagan	5	1.3
<b>Education</b>		
Never went to school	17	4.5
Primary	195	51.3
Secondary	132	34.7
College/university	36	9.5



**Table 3:** Frequency distribution of caregivers by selected socio-demographic characteristics, continued:

<b>Occupation:</b>		
Student	20	5.3
Peasant	32	8.4
Formal employment	79	20.8
Informal employment	44	11.6
Businessman/woman	167	43.9
Others	39	10
<b>Relationship with the patient:</b>		
Spouse	18	4.7
Parent	188	49.5
Sibling	72	18.9
Relative	87	22.9
Neighbour	7	1.8
Others	8	2.1
<b>Income per month in TShs:</b>		
Less than 60000	79	20.8
60000-99000	46	12.1
100000-199000	52	13.7
200000-299000	129	33.9
≥300000	74	19.5
<b>Ever taken care of another mental patient:</b>		
Yes	48	12.6
No	332	87.4

**Table 4:** Frequency distribution of caregivers by selected socio-demographic characteristics, continued:

<b>Duration of care in years:</b>		
Less than 2	60	15.8
2-5	150	39.5
6-10	72	18.9
Above 10	98	25.8
<b>No. of hours spent with patient in a week:</b>		
Less than 1	6	1.6
1-4	22	5.8
5-8	63	16.6
9-16	74	19.5
17-32	64	16.8
Above 32	151	39.7

### **Caregivers' experiences of caring for mentally ill patients.**

A relatively large proportion of the caregivers (40.8%) mentioned that their patients were rarely moody. A total of 43.2% of the caregivers mentioned that their patients were never unpredictable. Nearly two thirds of the caregivers (60.3%) mentioned that their patients were never withdrawn. Slightly more than half (53.9%) of the caregivers mentioned that their patients were never uncommunicative. Majority of the caregivers (68.9%) never had any feeling of stigma of having mentally ill relative. Majority of the caregivers (72.1%) never had any difficulty in explaining patient's illness to others. Majority of caregivers (78.7%) mentioned that health professionals never took them unserious. Majority of the caregivers (68.7%) never got problems with how the hospital and mental services work. Just more than half of the caregivers (50.5 %) mentioned that patients often had misunderstandings with the family members. Majority (67.6%) of the caregivers mentioned that the family members understood the patients' illness. Most caregivers (57.9 %) often believed that their patients' sort of life might have better than it was if they did not have the illness. A higher percentage (44.5 %) of caregivers was sometimes or rarely unable to do the things they wanted to due to their patients' illness. However, nearly a similar percentage (44.2 %) was often unable to do the things they wanted to. Majority of the caregivers (63.2%) mentioned that their patients were often and almost always dependent on them. A larger percentage of caregivers (35%) often had difficulty looking for money to look after the relative while 35.0% never had difficulty looking for money. Majority of the caregivers (39.5%) never had problems setting up accommodation for the patient. Majority (80.8%) of the caregivers mentioned that care giving often made them learn more about themselves. Nearly half of the caregivers (48.4%) mentioned that care giving often contributed to others' understanding of the illness. Majority (81.3%) of the caregivers mentioned that they often grew in strengths in coping with the illness. More than half (67.1%) of the caregivers mentioned that care giving often made a valuable contribution in the household.

**Table 2: Frequency distribution of caregivers' responses according to the experience of caregiving inventory (ECI)**

<b>Variables</b>	<b>Never</b>	<b>Rarely</b>	<b>Often</b>
Patient being moody	146(38.4)	155(40.8)	79(20.8)
Unpredictable	164(43.2)	159(41.8)	57(15.0)
Being withdrawn	229(60.3)	97(25.5)	54(14.2)
Uncommunicative	205(53.9)	113(29.7)	62(16.3)
Any feeling of the stigma of having mentally ill relative	262(68.9)	62(16.3)	56(14.7)
Any difficulty in explaining patients illness to others	274(72.1)	81(21.3)	25(6.6)
How health professionals do not take you seriously	299(78.7)	49(12.9)	32(8.4)
How hospital and mental health services work	261(68.7)	82(21.6)	37(9.7)
How patient gets on with family members	77(20.3)	111(29.2)	192(50.5)
How members do not understand the illness	257(67.6)	66(17.4)	57(15.0)
What sort of life the patient might have had	44(11.6)	116(30.5)	220(57.9)
Whether the patient will ever get well	57(15.0)	95(25.0)	228(60.0)
Being able to do things you want to do	43(11.3)	169(44.5)	168(44.2)
Patient's dependency on you	26(6.8)	114(30.0)	240(63.2)

**Table 3: Frequency distribution of caregivers' responses according to the experience of caregiving inventory (ECI), continued:**

Difficulty looking after money	133(35.0)	112(29.5)	135(35.5)
Setting patient up in accommodation	150(39.5)	128(33.7)	102(26.8)
I have learnt more about myself	13(3.4)	60(15.8)	307(80.8)
I have contributed to others' understanding of the illness	62(16.3)	134(35.3)	184(48.4)
Grown in strengths in coping with the illness	3(0.8)	68(17.9)	309(81.3)
Makes a valuable contribution in the household	23(6.1)	102(26.8)	255(67.1)

Sometimes and rarely were collapsed together as *rarely*, while often and almost always were also collapsed together as *often*.

### **Relationship between socio-demographic characteristics and experience of caregiving of mentally ill patients**

At univariate analysis, caregivers who had ever cared for a mentally ill patient experienced difficult behaviours more than the ones who had never (p value=0.006). Housewives that constituted the majority of the others group experienced difficult behaviours most followed by peasants. (P value=0.025). Neighbours experienced difficult behaviours more than the rest.(P value 0.018). Caregivers that have ever cared for a mentally ill patient experienced negative symptoms more often compared to those who had never cared for the mentally ill patient before.( P value= 0.023). Pagans reported experiencing stigma more than the other denominations. (P value=0.001). Caregivers that cared for their patients for less than two years often mentioned that there were problems with the services (P value=0.012). Those that spent 1-4 hours in a week caring for the patient mentioned that there were effects on the family (P value =0.006). Caregivers aged 65 and above (P value=0.002), that are married (P value =0.000), earning Tshs 300000 and above, and those spending 9-16 hrs a week in caregiving are the ones that most mentioned that patients illness is a loss. Caregivers that attended primary education (P value 0.021), had care for the patient for 2-5 years (P value= 0.028) and those that spent more than 32 hours a week (P value =0.001) reported that the patients were dependent on them. The caregivers that were divorced (P value= 0.000), those that earned less than 60000 per month (P value=0.000), those that have ever cared for a mentally ill patient before (0.008) and those that had cared for the patients for less than 2 years (P value=0.032) reported that they often needed back up while caring for their patients. Males (P value= 0.039), those aged 50-64 years (P value = 0.001), those earning 200000-299000 (P value= 0.023), those that have cared for a patient for 5-10 years (P value= 0.027), and those spending 1-4 hours a week in caregiving (P value=0.000) reported that they had positive personal outcomes due to caregiving roles. Caregivers aged 30 and below (P value=0.007), those earning below 60000 a month (P value 0.000), those that have never cared for a mentally ill patients before (P value = 0.025), those that have cared for less than 2

years and those that spent 1-4 hours a week in caregiving (P value= 0.015) reported that they have not had good aspects of relationship with the patient.

**Table 4a:** Relationship between difficult behaviours and experience of caregiving

Variables	Total n=380	High score (percentage)	Chi square(df)	P- value
<b>Difficult Behaviours</b>				
<b>Ever taken care of mentally ill patient?</b>			8.485(1)	0.006
Yes	48	22(45.8)		
No	332	85(25.6)		
<b>Occupation :</b>			12.747(5)	0.025
Student	20	4(20.0)		
Peasant	32	13(40.6)		
Formal employment	79	18(22.8)		
Informal employment	44	6(13.6)		
Businessman/woman	167	50(29.9)		
Others	38	16(42.1)		
<b>Relationship with patient</b>			13.514	0.018
Spouse	18	5(27.8)		
Parent	188	54(28.7)		
Sibling	72	25(34.7)		
Relative	87	15(17.2)		
Neighbour	7	5(71.4)		
Others	8	3(37.5)		

Table 4b: Relationship between Negative symptoms and experience of caregiving

	<b>Negative symptoms</b>			
<b>Ever taken care of mentally ill patient?</b>			5.524	0.023
Yes	48	16(33.3)		
No	332	62(18.7)		

4c. Relationship between difficult behaviours and experience of caregiving

	<b>Stigma</b>			
<b>Religion</b>			22.028(2)	0.001
Christian	150	13(8.7)		
Muslim	225	12(5.3)		
Pagan	5	3(60.0)		



4d. Relationship between problems with service and experience of caregiving

	<b>Problems with services</b>			
<b>Duration of care in years:</b>			10.897(3)	0.012
Less than 2	60	11(18.3)		
2-5	150	8(5.3)		
6-10	72	4(5.6)		
Above 10	98	12(12.2)		

4e. Relationship between effects on family and experience of caregiving

	<b>Effects on family</b>			
<b>Hours spent in caring in week</b>			16.248(5)	0.006
Less than 1	6	1(16.7)		
1-4	22	8(36.4)		
5-8	63	12(19.0)		
9-16	74	11(14.9)		
17-32	64	12(18.8)		

Above 32	151	53(35.1)		
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4f. Relationship between loss and experience of caregiving

	<b>Loss</b>			
<b>Age:</b>			14.561(3)	0.002
30 an below	76	44(57.9)		
31-49	172	133(77.3)		
50-64	111	85(76.6)		
65 and above	21	19(90.5)		
<b>Marital status :</b>			41.904(4)	0.000
Single	91	68(74.7)		
Married	206	167(81.1)		
Divorced	23	10(43.5)		
Widowed	38	30(78.9)		
Cohabiting	22	6(27.3)		
<b>Income:</b>			12.249(4)	0.015
Below 60000	79	61(77.2)		
60000-99000	46	27(58.7)		
100000-199000	52	33(63.5)		
200000-299000	129	99(76.7)		
300000 and Above	74	61(82.4)		
<b>Hours spent caring for</b>			19.298(5)	0.002

<b>patient in a week:</b>				
Less than 1	6	4(66.7)		
1-4	22	10(45.5)		
5-8	63	51(81.0)		
9-16	74	62(83.8)		
17-32	64	40(62.5)		
Above 32	151	114(75.5)		

4g. Relationship between dependency and experience of caregiving

	<b>Dependency</b>			
<b>Duration of care in years:</b>			9.042(3)	0.028
Less than 2	60	36(60.0)		
2-5	150	119(79.3)		
6-10	72	54(75.0)		
Above 10	98	76(77.6)		
<b>Education level:</b>			9.570(3)	0.021
Never went to school	17	12(70.6)		
Primary level	195	155(79.5)		
Secondary level	132	98(74.2)		
College /university	36	20(55.6)		
<b>Hours spent caring for patient in a week:</b>			20.561(5)	0.001
Less than 2	6	4(66.7)		
2-4	22	10(45.5)		

5-8	63	43(68.3)		
9-16	74	52(70.3)		
17-32	64	48(75.0)		
Above 32	151	128(84.8)		

4h. Relationship between difficult behaviours and experience of caregiving

	<b>Positive personal outcomes</b>			
<b>Age:</b>			15.632(3)	0.001
30 and below	76	44(57.9)		
31-49	172	59(34.3)		
50-64	111	36(32.4)		
65 and above	21	10(47.6)		
<b>Sex:</b>			4.297(1)	0.039
Male	139	45(32.4)		
Female	241	104(43.2)		
<b>Income:</b>			11.345(4)	0.023
Below 60000	79	40(50.6)		
60000-99000	46	22(47.8)		
100000-199000	52	22(42.3)		
200000-299000	129	38(29.5)		
300000 and above	74	27(36.5)		
<b>Duration of care in years:</b>			9.220(3)	0.027
Less than 2	60	32(53.3)		
2-5	150	51(34.0)		
6-10	72	23(31.9)		

Above 10	98	43(43.9)		
<b>Hours spent caring in a week:</b>			47.238(5)	0.000
Less than 1	6	2(33.3)		
1-4	22	15(68.2)		
5-8	63	13(20.6)		
9-16	74	11(14.9)		
17-32	64	29(45.3)		
Above 32	151	79(52.3)		

4i. Relationship between good aspects of the relationship with the patient and experience of caregiving

	<b>Good aspects of the relationship with the patient</b>			
<b>Age:</b>			12.069(3)	0.007
30 and below	76	33(43.4)		
31-49	172	46(26.7)		
50-64	111	26(23.4)		
65 and above	21	3(14.3)		
<b>Income:</b>			23.582(4)	0.000
Below 60000	79	37(46.8)		
60000-99000	46	17(37.0)		
100000-199000	52	13(25.0)		
200000-299000	129	22(17.1)		
300000 and above	74	19(25.7)		

<b>Ever taken care of mentally ill patient?</b>			5.171(1)	0.025
Yes	48	7(14.6)		
No	332	101(30.4)		
<b>Duration of care in years:</b>			20.053(3)	0.000
Less than 2	60	29(48.3)		
2-5	150	47(31.3)		
6-10	72	13(18.1)		
Above 10	98	19(19.4)		
<b>Hours spent caring in a week:</b>			13.967(5)	0.015
Less than 1	6	2(33.3)		
1-4	22	12(54.5)		
5-8	63	15(23.8)		
9-16	74	22(29.7)		
17-32	64	24(37.5)		
Above 32	151	108(8.4)		

## **Multivariate analysis of the association between socio-demographic variables and experience of caregiving**

In multivariate analysis, past experience of care of mentally ill patient was significantly associated with experience of difficult behaviours and negative symptoms. Caregivers that have never taken care of a mentally ill patient had 37.2 % higher odds than the ones that have ever cared in experiencing difficult behaviours (OD= 0.372, C.I. 0.192-0.719). The caregivers that have never taken care of a mentally ill patient had 45.9% higher odd than the ones that have ever cared in experiencing negative symptoms (OD=0.459, C.I.= 0.237-0.889). The caregivers that had cared for their patients for 6 to 10 years had 26.2% higher odds than the ones that spent less than 2 years (OD=0.262; C.I.= 0.079-0.872) while those that cared for 2 to 5 years had 25.1 % odds compared to those that spent less than 2 years in reporting problems with services. The caregivers' perception of loss after their patients were found to be mentally ill increased with their age. For example for 31-49 years (OD= 2.750; C.I.= 1.358-5.571), 65 above (OD= 7.036; C.I.= 1.358-36.470). Caregivers that were divorced (OD= 0.225; C.I. = 0.078-0.654) and those that were cohabiting (OD= 0.134; C.I. =0.041-0.444) had higher odds than the ones that were single in perception of loss because of the patient's illness. Caregivers that cared for the patient for 2-5 years had higher odds (OD= 2.584; C.I. =1.279-5.220) than those who cared for less than 2 years in reporting that the patients were dependent on them. Caregivers who were divorced (OD=3.687; C.I. =1.211-7.733) and widowed (OD= 3.060; C.I. =0.911-7.200) had higher odds than those that were single in reporting that they needed back up while caring or their patients. The caregivers with high income, those that have cared for longer duration and those that have never cared for a mentally ill patient other than the current one had higher odds in reporting that there were

good aspects in relationship with the patient through their caregiving role. For example; above 300000tshs (OD=0.376; C.I. =0.177-0.800) above 10years of caregiving (OD=0,300; C.I. =0.134-0.672) and those that never cared for mentally ill patient before (OD=3.528; C.I. = 1.412-8.812). Caregivers that were aged 31-49 years (OD=0.414; C.I.= 0.232-0.741) and those aged 50-64 years ( OD= 0.359; C.I.= 0.191-0.676)had higher odds compared to those aged 30 and below in having positive personal outcome through the caregiving role.

The caregivers with high income, those that have cared for longer duration and those that have never cared for a mentally ill patient other than the current one had higher odds in reporting that there were good aspects in relationship with the patient through their caregiving role. For example; above 300000tshs (OD=0.376; C.I. =0.177-0.800) above 10years of caregiving (OD=0,300; C.I. =0.134-0.672) and those that never cared for mentally ill patient before (OD=3.528; C.I. = 1.412-8.81)

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**Table 5:** Multivariate logistic regression of difficult behaviours according to caregivers' experiences of caregiving.

Variables	Odds ratio	95% C.I	p-value
<b>Difficult behaviours</b>			
<b>Occupation:</b>			
Student	1		
Peasant	2.179	0.571-8.322	0.255
Formal employment	0.909	0.256-3.222	0.882
Informal employment	0.504	0.119-2.132	0.352
Businessman/woman	1.359	0.417-4.434	0.611
Others	2.522	0.671-9.477	0.171
<b>Relationship with patient:</b>			
Spouse	1		
Parent	0.923	0.303-2.815	0.888
Sibling	1.311	0.405-4.247	0.652
Relative	0.511	0.153-1.711	0.276
Neighbour	6.149	0.823-45.913	0.077
Others	1.273	0.202-8.018	0.797
<b>Ever taken of mentally ill patient :</b>			
Yes	1		
No	0.372	0.192-0.719	0.003

**Table 6a:** Multivariate logistic regression of negative symptoms according to caregivers' experiences of caregiving.

	<b>Negative symptoms</b>		
<b>Ever taken care of mentally ill patient?</b>			
Yes	1		
No	0.459	0.237-0.889	0.021

**Table 7b:** Multivariate logistic regression of stigma according to caregivers' experiences of caregiving.

	<b>Stigma</b>		
<b>Religion:</b>			
Christian	1		
Muslim	0.922	0.554-1.534	0.754
Pagan	0.922	0.100-8.538	0.943

**Table 8c:** Multivariate logistic regression of Problems with services according to caregivers' experiences of caregiving.

	<b>Problems with services</b>		
<b>Duration of care in years</b>			
Less than 2	1		
2-5	0.251	0.095-0.660	0.005
6-10	0.262	0.079-0.872	0.029
Above 10	0.622	0.255-1.514	0.295

**Table 9d:** Multivariate logistic regression of Effects on family according to caregivers' experiences of caregiving.

	<b>Effects on family</b>		
<b>Hours spent caring in a week</b>			
Less than 1	1		
1-4	2.857	0.282-28.960	0.374
5-8	1.176	0.126-11.020	0.887
9-16	0.873	0.093-8.205	0.905
17-32	1.154	0.123-10.805	0.900
Above 32	2.704	0.08-23.752	0.370

**Table 10e:** Multivariate logistic regression of loss according to caregivers' experiences of caregiving.

	<b>Loss</b>		
<b>Age:</b>			
30 and below	1		
31-49	2.750	1.358-5.571	0.005
50-64	2.461	1.134-5.339	0.023
65 and above	7.036	1.358-36.470	0.020
<b>Marital status:</b>			
Single	1		
Married	1.148	0.568-2.321	0.701
Divorced	0.225	0.078-0.654	0.006
Widowed	0.981	0.330-2.916	0.973
Cohabiting	0.134	0.041-0.444	0.001
<b>Income:</b>			
Below 60000	1		
60000-99000	0.475	0.195-1.157	0.101
100000-199000	0.497	0.211-1.166	0.108
200000-299000	0.897	0.422-1.904	0.776
300000 and above	1.033	0.428-2.493	0.942
<b>Hours spent caring in a week</b>			
Less than 1	1		
1-4	0.104	0.010-1.025	0.052
5-8	0.516	0.057-4.673	0.556
9-16	0.752	0.085-6.630	0.797

17-32	0.264	0.031-2.239	0.222
Above 32	0.485	0.059-3.954	0.499

**Table 11f:** Multivariate logistic regression of Dependency according to caregivers' experiences of caregiving.

	<b>Dependency</b>		
<b>Education level:</b>			
Never went to school	1		
Primary level	1.859	0.573-6.030	0.302
Secondary level	1.532	0.466-5.037	0.482
College/ university	0.574	0.155-2.129	0.407
<b>Duration of care in years:</b>			
Less than 2	1		
2-5	2.584	1.279-5.220	0.008
6-10	1.394	0.627-3.103	0.415
Above 10	1.550	0.729-3.299	0.255
<b>Hours spent caring in a week:</b>			
Less than 1	1		
1-4	0.271	0.036-2.016	0.202
5-8	0.702	0.106-4.671	0.715
9-16	0.700	0.107-4.581	0.710
17-32	1.073	0.163-7.047	0.941
Above 32	2.173	0.342-13.798	0.411

**Table 12g:** Multivariate logistic regression of Need for back up according to caregivers' experiences of caregiving.

	<b>Need for back up</b>		
<b>Marital status:</b>			
Single	1	0.680-2.279	
Married	1.245	1.275-10.659	0.478
Divorced	3.687	1.211-7.733	0.016
Widowed	3.060	0.911-7.200	0.018
Cohabiting	2.561	0.911-7.200	0.075
<b>Relationship with patient:</b>			
Spouse	1		
Parent	1.316	0.408-4.241	0.646
Sibling	3.213	0.937-11.014	0.063
Relative	2.584	0.753-8.865	0.131
Neighbour	2.211	0.314-15.587	0.426
<b>Income per month (Tshs):</b>			
Below 60000	1		
60000-99000	0.803	0.361-1.1787	0.591
100000-199000	0.447	0.208-0.961	0.039
200000-299000	0.411	0.219-0.773	0.006
300000 and above	0.316	0.154-0.648	0.002
<b>Ever taken care of mentally ill patient?</b>			
Yes	1		

No	0.527	0.268-1.038	0.064
<b>Duration of care in years :</b>			
Less than 2	1		
2-4	0.515	0.263-1.011	0.054
5-10	0.874	0.409-1.867	0.727
Above 10	0.674	0.328-1.384	0.282

**Table 13h:** Multivariate logistic regression of good aspects of relationship with the patient according to caregivers' experiences of caregiving.

	<b>Good aspects of relationship with the patient</b>		
<b>Age:</b>			
30 and below	1		
31-49	0.528	0.277-1.006	0.052
50-64	0.498	0.243-1.021	0.057
65 and above	0.244	0.058-1.032	0.055
<b>Income per month in tshs:</b>			
Below 60000	1		
60000-99000	0.571	0.243-1.338	0.197
100000-199000	0.472	0.203-1.098	0.081
200000-299000	0.203	0.099-0.414	0.000
300000 and above	0.376	0.177-0.800	0.011
<b>Ever taken care of mentally ill patient?</b>			
Yes	1		

No	3.528	1.412-8.812	0.007
<b>Duration of care in years:</b>			
Less than 2	1		
2-5	0.567	0.286-1.126	0.105
6-10	0.237	0.100-0.563	0.001
Above 10	0.300	0.134-0.672	0.003
<b>Hours spent caring in a week:</b>			
Less than 1	1.680		
1-4	0.618	0.194-14.565	0.638
5-8	0.820	0.079-4.834	0.647
9-16	1.248	0.107-6.303	0.849
17-32	0.482	0.168-9.242	0.829
Above 32	1.482	0.067-3.471	0.469

**Table 14i:** Multivariate logistic regression of Positive personal outcomes according to caregivers' experiences of caregiving.

	<b>Positive personal outcomes</b>		
<b>Age:</b>			
30 and below	1		
31-49	0.414	0.232-0.741	0.003
50-64	0.359	0.191-0.676	0.001
65 and above	0.629	0.225-1.753	0.375
<b>Sex:</b>			
Male	1		



Female	1.576	0.991-2.508	0.055
<b>Income per month in tshs:</b>			
Below 60000	1		
60000-99000	1.100	0.513-2.362	0.806
100000-199000	0.766	0.369-1.513	0.474
200000-299000	0.478	0.260-0.878	0.017
300000 and above	0.716	0.364-1.411	0.335
<b>Duration of care in years</b>			
Below 2	1		
2-5	0.528	0.278-1.005	0.052
6-10	0.437	0.208-0.922	0.030
Above 10	0.777	0.392-1.541	0.470

## **4.2 Qualitative findings**

### **Caregiver socio-demographic characteristics**

A total of 30 caregivers were interviewed from 6 in- depth interviews and 4 focused group discussions. Three of the FGDs were for male participants while five IDIs were for female participants.

The mean age of the participants was 41 years with the youngest and oldest participants 23 and 69 years respectively. The mean duration of care for the mentally ill patients was 6 years with minimum and maximum duration being 2 and 15 years respectively.

Most of the participants were males, sibling and were living with the patient.

**Table 15:** Caregiver socio-demographic characteristics

Variables	No. (n=30)
<b>Age in years:</b>	
Mean (SD), Range	41(11.22), 23-69
<b>Sex:</b>	
Male	19
Female	11
<b>Relationship with patient</b>	
Spouse	3
Parent	7
Sibling	18
Relative	1
Neighbour	1
<b>Lives with patient</b>	
Yes	20
No	10
<b>Duration of care in years</b>	
Mean (SD ), Range	6.03 (3.45), 2-15

Seven themes were identified and discussed as below:

**1) Participants' experiences during care of the mentally ill patient**

There were a variety of feelings that manifested among participants while taking care of mentally ill patients ranging from happiness to sadness.

Majority of the participants had negative feelings about the patients' symptoms especially during the acute phases. These negative feelings included among others sense of fear, feeling

bitterness, stress, feeling sad, painful feelings, feel bad, sorrow, punishment, no happiness and disturbance. The following participants explain;

*“It’s a big punishment; the first thing, I have no help at home from my husband, the patient’s father died. I am the father and mother”.* (Parent 42years)

*“You find yourself staying with the patient with fear, at times when you are with him you are person of fear that any time he can do anything”.* (Sister 36years)

*“Really for me I feel so depressed....”* (Sister 23years)

The above parent’s view suggests that there was little if any help in caregiving roles towards the patient from the husband since he wasn’t the father.

A considerable number of participants that experienced negative feelings mentioned that it reaches a time when one gets “tired” or exhausted of taking care of mentally ill patient. The following participant explains:

*“The patient completely knows that ‘they do not want me do this, If I do it I will be this way’ but due to peer influence he does it. That is when one gets tired putting in mind that he or she sets time aside to take care of the patient but the latter doesn’t understand... there you give up due to his actions”*(Husband 44years)

The participant’s view above suggests that peer influences may worsen the patient’s behaviour and therefore possibly increasing the negative feelings of the caregivers.

It was suggested by a group of participants that it’s better off having a mentally ill patient since his/her childhood than the opposite.

*“There are two situations; if you have been taking care of a mentally ill patient since childhood, it’s not as worse when a person grew up well, studied, and later gets mentally unwell due to for example drug abuse- you feel so much hurt in the second case....”* (Brother 52years)

The participant's view above suggests that he is very much hurt when his relative gets mentally ill while an adult due to for example drug abuse.

However, few participants mentioned that they feel that taking care of a mentally ill patient is comforting and they do not see it as inconveniencing.

*"I personally feel very ok because I stay with the patient at home and I come for clinic at Muhimbili ..."* (Parent 58years)

A number of participants have reported encountering physical trauma directly from the patients;

*"That person is not alright; when he saw me he put his hand below the chair and brought out a machet (panga). I asked him, what is the panga was for, and what are you going to cut or chop with the panga this time of the day? I saw him stand up, he raised the panga and was about to chop me! I swayed and part of the panga hit me on my hand. I then realized that my child could kill me..."* (Parent, 53yrs)

*"We were fighting because at that time of illness she is so energetic, so when you fight with her it so happens that she hurts you physically..."* (Sister 23 years)

The participants' views above suggest that patients and caregivers end up in a fight.

## **2) Common concerns around acute phases of mental illness**

Majority of the participants admitted that the patients during the acute phase have a lot of energy and they wondered where it comes from. Consequently they beat up people, destroy property among others.

*"For me the problems I get from my child when he gets ill, he becomes violent because he is now changed...."* (Mother, 40 years)

*“When the illness erupts, you must really be preparedly tough, my son would normally feel sorry for me and give some money to hire a taxi to go to hospital, the patient becomes so strong that it would require about ten strong men to hold him.....I then beg him politely praying that he agrees and I take him by a taxi to hospital....” (Sister 48yrs who looked sad)*

*“So at that time I get problems because I have already paid transport fee up to the hospital and It happens that I return patient to Mwananyamala (a referral hospital)...”. (Parent 42years)*

Participants’ views above suggest that efforts are needed in taking patient to hospital when acutely ill and it involves spending money.

### **3) Impact of care giving on family relations**

Majority of the participants have blamed the other family members for not helping out in the care of the mentally ill patients. They believe that the caregiving role has been left to them alone despite the belief that all relatives are supposed to get involved in the caregiving roles.

*“What irritates me most is when you have relatives here in town but they do not care about the patient at all. Even if I abandoned the patient they would not mind or do anything. This attitude irritates me that I even went to the Social Welfare offices and complained. They just told me to go back and sort it out through family meetings.” (Brother, 34yrs)*

*“I have not known the reason yet as to why they do not cooperate, they complain that they have no capacity (money) I told others that the patient has been admitted at Amana (referral hospital) they did not show up, now admitted at this hospital for now 2 weeks they haven’t come yet, I do not understand which capacity they mean because even the transport fee!! Or they do not have understanding.... I fail to understand...” (Uncle 43years)*

*“Drug abuse has contributed., because other relatives just ask how the patient doing is? Recently he was admitted, now he is sick again! Today one asked how is the patient, I told*

*him he is hospital sick, he answered that one doesn't want to leave the habit of drug abuse.....so that is the reality". (Parent 69years)*

*"The one who responds easily when the patient is ill is the one that is left to take care for example I am told a patient has escaped from home, I begin looking for him. If you tell another family member that the patient is not seen he doesn't show interest...a female caregiver is left with the caregiving role more times than the male caregiver..."( Aunt 38years)*

The above participants' views suggest that they are left with the caregiving role.

Many participants suggested that the misunderstandings among relatives stem from the decision on where to take the patient when he/she is ill. The following participant explains:

*"Divisions in the families exist, why? They say the medications just calm the illness, they do not cure completely. If they say it heals, why don't patients heal instantly?, so it's a must for us to take him everywhere so that we save him and if there is I need to get saved, they say "pepo" spirit and tell him to stop using medications. But as we argue with them, that is how divisions arise, so there are some who may refuse to go there and take him hospital"*  
(Brother, 36years)

The above participant's view suggests that caregivers look for a total cure of mental illness hence the trial of options.

Majority of the participants reported that one that stays with the patient and offers substantial care to the patient is the one who takes a decision on where to treat the patient when ill. The following participants explain:

*"That is true, for instance, as for our patient, just like the rest have said; the person staying with the patient is the one giving a final decision. Other relatives can give suggestions on what should be done, since they are not directly responsible for the patient."* (Brother, 52years)

Within the family, there is no peace among the family members due to the behaviour of the patient. The following participants explain:

*“... I send him to Segerea (a prison in Dar es Salaam), so that we may have peace here, he can kill someone. (Brother 52years)”*

*“The changes are not good, because my husband’s relatives have been involved and they see me as if I mistreat him, so there has been a division between them, my husband and I.”*  
(Mother 42years)

*“Yes there is a very big difference because before patient’s illness my sister was my best close friend, after the illness I am the worst enemy even to the extent she does not want to see me”* (Aunt 52 years)

The above mother’s view suggest that divisions in families to the extreme, cause marriages to break up.

#### **4) Impact of caregiving on the caregivers’ financial status**

Majority of the participants said that the care they offer to their patients affects their progress economically.

*Economically, we are affected, because we don’t have enough of time to look for money. Most of our time is spent on caring for the patient; so that’s where we are affected most. (Brother 37years)*

They are forced at times to stay home with the patient or take him or her to the hospital during acute phases of the disease and routine outpatient clinics. The following participant explains:

*“We Africans it is until you move out that you will get money, without going to work you can’t have money. So you can’t go on staying home caring for a patient when there is no money yet the patient needs to eat... that way the economy is not good”. (Husband 44years)*



The participants attributed expenditure towards among others; paying for transport to hospital and to the escorts that's police or strong men around the domicile especially when acutely ill. The following participant explains:

*“And you can't take the police without talking to them well...you have to give them money ...and transport fare...” (Brother 52years)*

With the fear of having poor treatment and care of their patients at the public hospital, some participants opt for private services either at the hospital or away from the hospital. The following participant explains:

*“There is a private practitioner ....whenever we take a patient it is a must that at least 300000 is paid... we attended there while contributing among relatives but we ended up quarrelling among ourselves...., we feared to bring him here due to poor care we thought he would be beaten by other patients...” (Brother 39years)*

However some of the participants said that they were not affected financially through the care of their mentally ill patients. The following participant notes:

*“Aaah I financially have not been affected...” (Father 58years)*

Majority of the participants were happy and praised the government for the free service that they receive in treating mentally ill patients. The participants explain as below:

*“Thanks to the government, because if we were paying for drugs, the problem would have been much bigger” (Brother, 34yrs)*

*“I would like to thank you for the services here because we have not gotten any serious financial problems; we only face small expenses for transporting the patient, giving to the police, hiring a taxi... But we don't have any expenses for treatment”. (Brother 52yrs)*

## 5) Perceptions of the caregivers towards the service providers at the hospital

Majority of the participants praised the doctors' service that they attend to the patients politely with passion and happiness and they have gotten improvement from the mental illness.

Participants explain as below:

*"I frankly think the services provided are not that bad, they are good. The patient gets the medicines according to the appointment dates, you just have to attend. After using the medication, the patient's condition improves: they help a lot". (Brother, 37yrs)*

*"Personally I see the doctors' attitude to my patient is not bad because since then the medications he is given are working because he has improved... during the visit he is supposed to be seen by doctor for at least 15-30 minutes but recently it isn't so." (Sister 48yars)*

The views above of a sister to the patient show that the duration of time the doctor spends with the patient has reduced.

Most participants reported that there is an increased waiting time. They explain as below:

*"I arrive here at few minutes to 7 till 8 we haven't meet the doctor, and even after seeing the doctor, it takes long to take the medications from the pharmacy". (Brother 52years)*

*"About service really one thing that burdens me here is the cue to getting medicines because patients have become many currently". (Parent 43years)*

One participant raised a complaint that recently patients stay long in the ward without fast improvement. He explains as below:

*"There is something I would like to talk about in relation to the mentally ill patients in the wards; patient does not improve fast as stays in the ward. One of the challenges that we face in this area is when the nurse says, this patient must be given a certain injection and as for we relatives, we do not know who authorizes a patient to be given such medicine, is it nurse or*

*doctor? Most of the time it's hard to know when the doctors go for rounds..." (Brother, 39years)*

However other participants denied having encountered such incidences of health staff asking for tips. The following participant explains:

*"To be honest, we can't avoid these small tips. There are some people who give tips without being asked to. They just feel like giving something, after a good service may be..." Brother, 39years)*

#### **6) Rehabilitation services**

No participant has ever had his or her patient in a rehabilitation area.

*"I think it would have been a very good service; firstly, it helps the patient to recover and return to his/her former self. And secondly the patient contributes to the national economy. Moreover the patient gains skills for life that s/he can use even when they heal completely..." (Uncle 43years)*

A few participants admitted that they have ever heard of the services though they attributed their patients' failure to enrol to lack of money that is required to subscribe before enrollment and limited vacancies at the rehabilitation areas.

*"I heard about those, but they were talked of money, you must contribute a certain amount of money in order to subscribe, wheew! Realistically, most families cannot afford that and therefore it's easier for them to stay with their patient and go for free services." (Brother 26years)*

## 7) Caregivers' needs

### To the government:

Some participants would like the government through the social welfare sector to help in solving the misunderstandings that result among family members in the care of the mentally ill patient resulting in one person being the sole caregiver of the patient.

*"...we need support, I personally would like to ask that these relatives should be called and asked what their problem is. I don't think that their problem is money, because the medication is free! Could it be the small amount of bus fares to come and fetch the medications..."*

*(Brother 34years)*

Also the government was called upon to strengthen the rehabilitation centres.

*"So I would like to ask the government to strengthen the rehabilitation centers where patients with relief and skills can use them to earn a living..."* (Parent 53years)

*"We who stay in the village for example ask that these mental health services that exist here be extended to the village where we stay and we be provided with transport means to his place in case we bring a patient..."* (Mother 58 years)

### To Muhimbili National Hospital:

Some participants requested the hospital to remove pre- requisite of having a referral letter from Mwananyamala, Temeke or Amana hospital for mentally ill patients since it is a waste of time. The following participant explains:

*"...my request is, for the mentally ill patients; whenever their conditions get worse and we bring them back to Muhimbili, we should be attended to quickly ....because I once brought my*

*patient late at night restrained with ropes, but they told me that I should leave with my patient. I had hired a Datsun (a pickup) knowing that the patient's condition has changed; he is hostile, beating people and the entire sort; so we tied him with a rope and brought him to Muhimbili. We found a certain lady at the reception at around 8p.m., she never gave us any medications....When we even came with documents from Amana (a referral hospital) it didn't help..." (Parent 58years)*

The view of the above parent suggests the hospital should admit patients that are aggressive and dangerous to stay with at home.

The caregivers request the health professionals to be patient to them. The participant below explains:

*"So I request nurses to serve mentally ill patients knowing that they are mentally ill and we caregivers are human and we are not perfect, please be patient with us..." (Father 53 years)*

#### To the Fellow Caregivers:

A number of participants called upon their fellow caregivers that is, relatives to rise up and support them in the care of patients

*"So I would like to call upon my fellow caregivers to change our attitude, binging condolences when a patient has died does not help, participate when the patient is alive such that you help the patient..." (Father 53 years)*

## Chapter 6: Discussion

This study establishes that majority of patients reported experiencing negative symptoms of mental illness (being moody, unpredictable, being withdrawn, or uncommunicative). Qualitatively, similar results were found; majority of the caregivers experienced psychological distress that had different expressions for example among others feeling sad, stressed, tired or feeling punished. These feelings seemed to be more pronounced during the acute phases of the illness where the patients were very aggressive and energetic necessitating the caregiver at times to hire people to restrain them and take them to hospital. This is in agreement with the findings of a study done at the same hospital on caregivers of mentally ill children that revealed that caregivers had psychological stress, sadness, inner pain and bitterness<sup>30</sup>. Similar findings were reported in a study done in Kenya where among other behaviours, physical aggression and refusal to go to hospital caused a lot of effects on the relatives<sup>6</sup>. Likewise, such moments during the onset of the crisis are stressors of the entire family for example experiencing a strong sense of helplessness and loss of control, fears for their own and other relatives' safety, and a lot of disruption to the household<sup>15</sup>.

Majority of the caregivers reported that patients often had misunderstandings with the family members though the latter never had problems with understanding the former's illnesses. This is in line with the findings of another study that showed that there was an effect on the relationship of the patient and caregiver<sup>35</sup>. The family members had misunderstandings among themselves. The caregivers were left to solely take care of the patient due to several possible reasons among them being: differing with the caregiver on the line of treatment, lack of funds for transport to the hospital, and getting tired of helping the primary caregiver due to the chronicity of the illness. These findings are similar to those in one study that showed that despite the patients' denial of relatives, the latter were ready to continue offering care<sup>33</sup>. In Ireland, family members had separations and loss of contact just as it was found in our study but the difference is that in our study, the proposed cause wasn't stigma of the illness<sup>18, 21</sup>.

Majority of the caregivers were often unable to perform their usual economic generating duties due to the care of their patients. They reported that the patients were often dependent on them for a living. This involved frequently providing money to the patient for upkeep, payment of debts or compensation of damages caused by the patient. These expenditures in addition to the costs of transport affected the economic status of the caregiver though majority of them reported that they had no difficulty accommodating or looking for money in caring for the patient. This means they were working so hard with the limited time and opportunity to run their day to day activities and also care for the patient. Similar results were found in a study done in Kenya where by most patients were dependent on the relatives economically and family finances suffered the greatest impact due to the patients' mental illness<sup>6</sup>. A study done in Canada also supports our findings that is, over half of caregivers paid out-of-pocket expenses for transportation costs, such as gasoline, taxis, or public transit while caring for someone diagnosed with a mental illness<sup>5</sup>. Another study done among first time caregivers which are a higher percentage of our study population had similar findings where the caregivers had financial constraints especially with the direct costs in caregiving<sup>38</sup>. These findings are different from a study done to assess the likelihood to ask for help among women caregivers that showed that slightly more than half needed help while caring for the patient<sup>36</sup>.

Majority of the caregivers reported that they believed the hospital structure was functioning well and the health professionals' attitude toward them and the patients was good. However, they complained of long waiting hours, shorter time with the doctor, and long cue towards the pharmacy to pick drugs. These findings do correspond with those found earlier at the same hospital<sup>30</sup> though they differ from the findings of a study where the caregivers blamed the health professionals for not telling them the progress of their patients<sup>15</sup>.

Rehabilitation services are suggested to be an important factor in Majority of the participants did not know about the rehabilitation services but after being informed they liked the service

and wished their patients were enrolled in such a scheme. However, knowing about a service does not always mean availability. According to another study, caregivers knew about the services but reported that they lacked such services and thought they are very helpful in reducing their stress while caring for a mentally ill patient<sup>15</sup>.

Majority of the caregivers through the caregiving role have often learnt more about themselves, contributed to others' understanding of the illness, grown in strengths in coping with illness and made valuable contribution to the household. These findings are similar to the other studies<sup>22</sup> which suggest that caregiving role has positive impact.

Caregivers in this study raised a number of needs that they wished the responsible parties would meet to help in the care of their mentally ill patients. The caregivers emphasized on the need for the government through the social welfare to help in solving the misunderstandings that arise among family members towards caring for the patient. They suggested to the hospital management to use a letter from the local government other than that from the referral hospitals as it is currently because some of them live far away from those hospitals and usually get no treatment during acute phases while at those hospitals. They also called upon their fellow relatives to rise up and help them in the caregiving role to reduce on the burden of care. Some needs are common to the latin population<sup>37</sup>. These findings are far different from other studies probably because of the difference in culture, mental health service structure and referral systems<sup>15</sup>.

Limitations of the study:

One limitation of the study is the possibility of an element of bias due to the sampling technique. However, this was minimized during data collection where the researcher was impartial. Also, sampling error could not be estimated due to the sampling technique being convenient sampling. Lastly, the validity of the E.C.I tool's Kiswahili translation has not been tested in our setting.



## **Chapters 7: Conclusion and recommendations**

Caregivers of mentally ill patients experience psychological distress and suffer physical, social and financial strains due to the different roles they play while caring for their patients. Due to the chronicity and repetition of the episodes many family members drop the caregiving roles and leave the care to one person or a few who seem to be closer to the patient hence increasing the ir burden of caregiving. Caregiver needs should be addressed. Government through social welfare sector should help in solving family conflicts that arise from the care of mentally ill patients. Government should also improve rehabilitation services. MNH should revise the referral rules of MNH patients that are aggressive.

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## Chapter Eight : Appendices

### Annex 1. Consent for Study

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

**DIRECTORATE OF RESEARCH AND PUBLICATIONS**



### CONSENT FORM

ID No .....

Greetings,

My name is Dr Atutta Robert, I am a Master's student (Master of Public Health), at the School of Public Health and Social Sciences, Muhimbili University of Health and Allied Sciences, Dar es Salaam – Tanzania, P.O. Box 65001, Dar es Salaam – Tanzania

#### **STUDY TITLE**

EXPERIENCES AND NEEDS OF CAREGIVERS OF MENTALLY ILL PATIENTS AT MUHIMBILI NATIONAL HOSPITAL

#### **WHAT PARTICIPATION INVOLVES**

This study is aimed at exploring the experiences and needs of caregivers of mentally ill patients. If you agree to participate in the study you will be requested to sign this consent

form and then a questionnaire shall be given to you, please answer the questions with my guidance and when you are done you will give it to me. You are free to withdraw your consent to participate in the study at any point in time without any prior notice and absolutely no harm will happen to you for not participating.

### **CONFIDENTIALITY**

All information collected for the purpose of this study shall be confidential. No identifying information for you or your patient shall be used for in the study.

### **RISKS**

There may be emotional risks associated with discussing issues around your patient, and that is regretted. You will spend about 20-30 minutes of your time, but there are no other risks anticipated in participating in this study

### **BENEFITS**

This being a purely academic study, there may not be direct benefit to you from participating in this study however findings may be used by planners and policy makers in addressing your needs towards the care of Mentally ill patients.

### **WHO TO CONTACT**

In case of any further questions concerning this study you may contact the Principal Investigator Dr Atutta Robert, phone number..... (Master's Student –Master of Public Health, School of Public Health and Social Sciences, Muhimbili University of Health and Allied Sciences, P.O.Box 65001, Dar es Salaam - Tanzania) or the Dr. Atutta's supervisor Ms. Lusajo Kajula, phone number 0784 721174 (Lecturer, Department of Psychiatry– School of Medicine, Muhimbili University of Health and Allied Sciences, P.O. Box 65001, Dar es Salaam – Tanzania). If you ever have further questions about your rights as a participant – please don't hesitate to call Prof. Mohammed Aboud, Chairman (Research and Publications Committee, MUHAS. P.O.Box 65001, Dar es Salaam – Tanzania, Tel +2552150302-6);



**CONSENT**

Do you have any questions? Do you agree to participate in the study?

1. Yes....., 2. NO.....

Signature of research assistant.....Date.....

**Annex 2: Kiswahili Translation: Consent**

**MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES**

**DIRECTORATE OF RESEARCH AND PUBLICATIONS**



**FOMU YA KUKUBALI KUSHIRIKI**

ID No .....

Salaam,

Jina langu ni Dk. Atutta Robert, ni mwanafunzi wa Shahada ya Uzamili (Uzamili katika Afya ya Jamii) kutoka Chuo Kikuu cha Afya na Sayansi ya Tiba Muhimbili, S. L. P. 65001, Dar-es-Salaam - Tanzania

**UTAFITI JUU YA:**

**UZOEFU NA MAHITAJI YA WATOAHUDUMA KWA WAGONJWA WA AKILI  
KATIKA HOSPITALI YA TAIFA MUHIMBILI**

**USHIRIKI UNAHUSISHA;**

Utapewa utangulizi juu ya utafiti huu, aidha na mimi mwenyewe au mmoja wa watafiti wasaidizi wangu. Iwapo utakubali kushiriki katika utafiti huu, utahitajika kusaini fomu hii na kasha utapewa dodoso, utajibu maswali kwa mwongozo wa mtafiti msaidizi wangu au mimi mwenyewe, na utakapomaliza, utanirudishia dodoso mimi au msaidizi wangu. Unaweza

kuacha kuendelea kushiriki katika utafiti wakati wowote bila notisi na hautafanywa kitu chochote.

## **USIRI**

Taarifa zote zitakazokusanywa kwa ajili ya utafiti huu zitakuwa siri na zitatumika katika kazi za kitaaluma tu. Hakutakuwa na matumizi yoyote ya majina katika utafiti huu.

## **HATARI**

Isipokuwa kwa muda utakaotumika kujaza dodoso (takribani dakika 20), hakuna uhatarishi unaotegemewa au vinginevyo katika ushiriki wako kwenye utafiti huu.

## **MANUFAA**

Kwa kuwa huu ni utafiti wa kimasomo, hakutakuwa na manufaa ya moja kwa moja kwako kwa ushiriki wako, hata hivyo matokeo ya utafiti yanaweza kutumika na wanamipango na watunga sera katika uboreshaji wa huduma kwa wagonjwa wa akili.

## **MAWASILIANO**

Ikiwa una maswali zaidi kuhusu utafiti huu unaweza kuwasiliana na Principal Investigator Dk. Atutta Robert ( Mwanafunzi – Shahada ya Uzamili, Chuo Kikuu cha Afya na Sayansi ya Tiba, S. L. P. 65001, Dar-es-Salaam – Tanzania) au Msimamizi wa Utafiti Lusajo Kajula (Mhadhiri, Kitengo cha Magonjwa ya Akili, Chuo Kikuu cha Afya na Sayansi ya Tiba, S. L. P. 65001, Dar-es-Salaam – Tanzania. Na iwapo una swali lolote juu ya haki zako kama mshiriki – tafadhali usisite kuwasiliana na Prof. Mohammed Abood, Mwenyekiti (Kamati ya Utafiti na Uchapishaji, MUHAS. S. L. P. 65001, Dar-es-Salaam – Tanzania, au kwa simu namba +2552150302-6)

## **MAKUBALIANO**

Baada ya kusoma fomu hii ya makubaliano na baada ya kujibiwa maswali yako yote, Je, unakubali kushiriki katika utafiti huu?

1. Ndiyo.....
2. Hapana

Sahihi ya mtafiti msaidizi.....Tarehe.....

### Annex 3: Questionnaire in English

#### Socio-Demographic

1. What's your patient's age?
2. What is your patient's sex?
  - a) Male
  - b) Female
3. What is Age?
  - a) 30 or younger
  - b) 31 to 49
  - c) 50 to 64
  - d) 65 or older
4. Sex
  - a) Male
  - b) Female
5. What is your Marital status?
  - a) Single
  - b) Married
  - c) Divorced
  - d) Widowed
  - e) Cohabiting
6. What is your level of Education?
  - a) Never went to school
  - b) Attended primary
  - c) Attended secondary
  - d) Attended college/ university

7. What is your occupation?

- a) Student
- b) Peasant
- c) Formal employment
- d) Informal employment
- e) Businessman/woman
- f) Other (specify).....

8. What is your Religion?

- a) Christian
- b) Muslim
- c) Buddhist
- d) Pagan
- e) Others (specify).....

9. What is your relationship with the patient?

- a) Spouse
- b) Parent
- c) Sibling
- d) Relative
- e) Neighbour
- f) Others (specify).....

10. Do you stay with the patient in the same household?

- a) Yes
- b) No

11. How much do you earn per month on average?

- a) < 60,000
- b) 60,000-99,000
- c) 100,000-199,000
- d) 200,000,-299,000
- e) >500,000

12. Have you ever taken care of a mentally ill patient other than this one?

- a) Yes
- b) No

13. For how long have you taken care of this patient?

- a) Less than 2 years
- b) 2 to 5 years
- c) 6 to 10 years
- d) More than 10 years

14. How many hours do you spend caring for the patient in a week?

- a) Less than 1 hour
- b) 1-4 hours
- c) 5-8 hours
- d) 9-16 hours
- e) 17-32 hours
- f) More than 32 hours

## **Experience of Caregiving Inventory Questionnaire**

### Negative

1. Difficult behaviours
  - a) Patient being moody ( *Never, Rarely, sometimes, often, nearly always*)
  - b) Unpredictable( *Never, Rarely, sometimes, often, nearly always*)
  
2. Negative symptoms
  - a) Being withdrawn( *Never, Rarely, sometimes, often, nearly always*)
  - b) uncommunicative( *Never, Rarely, sometimes, often, nearly always*)
  
3. Stigma
  - a) Any feeling of the stigma of having mentally ill relative( *Never, Rarely, sometimes, often, nearly always*)
  - b) Any difficulty in explaining patients illness to others( *Never, Rarely, sometimes, often, nearly always*)
  
4. Problems with services
  - a) How health professionals do not take you seriously( *Never, Rarely, sometimes, often, nearly always*)
  - b) How hospital and mental health services work( *Never, Rarely, sometimes, often, nearly always*)
  
5. Effects on the family



- a) How patient gets on with family members( *Never, Rarely, sometimes, often, nearly always*)
  - b) How members do not understand the illness( *Never, Rarely, sometimes, often, nearly always*)
6. Loss
- a) What sort of life the patient might have had( *Never, Rarely, sometimes, often, nearly always*)
  - b) Whether the patient will ever get well( *Never, Rarely, sometimes, often, nearly always*)
7. Dependency
- a) Being able to do things you want to do( *Never, Rarely, sometimes, often, nearly always*)
  - b) Patient's dependency on you( *Never, Rarely, sometimes, often, nearly always*)
8. Need for back up
- a) Difficulty looking after money( *Never, Rarely, sometimes, often, nearly always*)
  - b) Setting patient up in accommodation( *Never, Rarely, sometimes, often, nearly always*)

Positive

9. Positive personal outcomes
- a) I have learnt more about myself( *Never, Rarely, sometimes, often, nearly always*)

b) I have contributed to others' understanding of the illness( *Never, Rarely, sometimes, often, nearly always*)

10. Good aspects of the relationship with the patient

a) Grown in strengths in coping with the illness( *Never, Rarely, sometimes, often, nearly always*)

b) Makes a valuable contribution in the household( *Never, Rarely, sometimes, often, nearly always*)

## **Annex 4: Kiswahili Translation of Questionnaire**

### **DODOSO**

#### **TAARIFA ZA MDADISIWA**

1. Una umri gani?
  - a) 30 au chini
  - b) 31 hadi 49
  - c) 50 hadi 64
  - d) 65 au zaidi
2. Jinsia
  - a) Mme
  - b) Mke
3. Hali yako ya ndoa....
  - a) Mseja
  - b) Oa/Olewa
  - c) Tengana
  - d) Mjane/Mgani
  - e) Ishi pamoja
4. Kiwango chako cha elimu....
  - a) Sijasoma

- b) Elimu ya Msingi
- c) Elimu ya Sekondari
- d) Elimu ya Chuo/Chuo Kikuu

5. Unajishughulisha na nini

- a) Mwanafunzi
- b) Mkulima
- c) Ajira rasmi
- d) Ajira isiyo rasmi
- e) Mfanyabiashara
- f) Nyingineyo (taja).....

6. Dini yako.....

- a) Mkristo
- b) Muislamu
- c) Mbudha
- d) Mpagani
- e) Nyingineyo (taja).....

7. Una uhusiano gani na mgonjwa?

- a) Mwenzi wa ndoa
- b) Mzazi
- c) Ndugu wa kuzaliwa
- d) Ndugu
- e) Jirani
- f) .Nyingine (taja)

8. Kwa wastani, una kipato cha kiasi gani kwa mwezi?

- a) < 60,000
- b) 60,000-99,000
- c) 100,000-199,000
- d) 200,000,-299,000
- e) >500,000

9. Umeshawahi kumhudumia mgonjwa wa akili zaidi ya huyu?

- a) Ndio
- b) Hapana

10. Umekuwa ukimhudumia mgonjwa huyu kwa muda gani sasa?

- a) Chini ya miaka iwili
- b) Kati ya miaka 2 hadi 5
- c) Kati ya miaka 6 hadi 10
- d) Zaidi ya miaka 10

11. Unatumia masaa mangapi kumhudumia mgonjwa kwa wiki?

- g) Chini ya lisaa limoja
- h) Masaa 1 hadi 4
- i) Masaa 5 hadi 8
- j) masaa 9 hadi 16
- k) Masaa 17 hadi 32
- l) Zaidi ya masaa 32

## **DODOSO JUU YA UZOEFU WA MHUDUMIAJI WA MGONJWA**

### **Hasi**

1. Tabia sumbufu (ngumu)
  - c) Mgonjwa ana hali za kununa/kukasirika
    - 1) Asilani,
    - 2) mara chache sana,
    - 3) wakati fulani,
    - 4) mara nyingi,
    - 5) karibu wakati wote
  - d) Asiyetabirika
    - 1) Asilani,
    - 2) mara chache sana,
    - 3) wakati fulani,
    - 4) mara nyingi,
    - 5) karibu wakati wote
  
2. Dalili hasi
  - c) Mwenye hali ya kujitenga
    - 1) Asilani,

- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

d) Asiyewasiliana/asiyezungumza

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

3. Unyanyapaa

g) Kuna hisia/hali yoyote ya unyanyapaa (kujisikia vibaya) kwa kuwa na ndugu mwenye ugonjwa wa akili

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

h) Kuna ugumu wowote katika kuelezea tatizo la mgonjwa kwa watu wengine

- 1) Asilani,
- 2) mara chache sana,

- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

4. Matatizo katika huduma

a) Jinsi wataalamu wa afya wasivyokuchukulia uzito.

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

b) Jinsi huduma za hospitali na kitengo cha magonjwa ya akili zinavyofanya kazi.

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

5. Athari katika familia

a) Mgonjwa anashirikianaje na wanafamilia

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

b) Namna wanafamilia wasivyoele wa kuhusu ugonjwa



- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

6. Hasara, Upotevu

a) Ni aina gani ya maisha mgonjwa angelikuwa nayo sasa?

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

b) Iwapo mgonjwa atakuja kupona

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

7. Utegemezi

a) Kuwa na uwezo wa kufanya vitu utakavyo

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,

- 5) karibu wakati wote
- b) Utegemezi wa mgonjwa kwako
  - 1) Asilani,
  - 2) mara chache sana,
  - 3) wakati fulani,
  - 4) mara nyingi,
  - 5) karibu wakati wote

8. Uhitaji wa msaada,
  - a) Ugumu wa kutafuta hela
    - 1) Asilani,
    - 2) mara chache sana,
    - 3) wakati fulani,
    - 4) mara nyingi,
    - 5) karibu wakati wote
  - b) Katika kuishi na mgonjwa
    - 1) Asilani,
    - 2) mara chache sana,
    - 3) wakati fulani,
    - 4) mara nyingi,
    - 5) karibu wakati wote

### **Chanya**

9. Matokeo binafsi chanya
  - a) Nimejifunza zaidi kuhusu mimi mwenyewe

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

b) Nimesaidia wengine kuelewa kuhusu ugonjwa huu

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

10. Namna nzuri za kuhusiana na mgonjwa

a) Umeongeza uwezo wa kukabiliana/kuchukuliana na ugonjwa

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

b) Hutoa mchango mkubwa katika kaya

- 1) Asilani,
- 2) mara chache sana,
- 3) wakati fulani,
- 4) mara nyingi,
- 5) karibu wakati wote

## **Annex 5: Interview guide for in depth interviews and focused group discussions:**

Experiences of caregivers of mentally ill patients

1. What is your relationship with the patient?
2. Please share with me the emotional impact of taking care of the mentally ill patient.
  - a) What are some of the emotions you feel in taking care of the patient?
  - b) How has the care of the mentally ill patient affected your emotions? Probe; how so?
  - c) Can you tell me how your relationship with the patient has become since they became mentally ill?

I would like to talk to you about the physical impact of taking care of the mentally ill patient.

- a) What are some of the physical challenges that you have faced in taking care of the patient?
  - b) Probe: please elaborate.
  - c) How has the care of mentally ill patient affected you physically? How so?
3. Please tell me the financial impact of taking care of your mentally ill patient. How has the care of your mentally ill patient affected you financially?
  4. Please share with me the experience of functioning of your family since you began caring for the mentally ill patient. How has the family affected by the existence of

your patient? What are some of the negative experiences that your family has gone through since you become caring for this patient?

#### NEEDS

1. May you please tell me the common concerns you have experienced during the critical phases of the patient's illnesses. What really bothers you when the patient becomes acutely ill?
2. In your opinion, what are the attitudes of mental health professionals towards you and the patient while accessing service at this hospital?
3. Please tell me about psychosocial rehabilitation services.

## **Annex 6: Kiswahili translation of the interview guides**

Uzoefu wa watoa huduma wa wenye magonjwa ya akili..

1. Una uhusiano gani na mgonjwa?
5. Tafadhali nishirikishe matokeo ya kihisia yatokanayo na kumhudumia mgonjwa wa akili.
  - a) Huwa unajisikiaje katika kumhudumia mgonjwa huyu?
  - b) Je, ni kwa namna gani uhudumiaji wako wa mgonjwa huyu wa akili umekuathiri kihisia? Kwa namna gani hasa?
  - c) Je, unaweza kunijulisha uhusiano wako na mgonjwa umekuwaje tangu alipopata kuwa na ugonjwa wa akili?  
.
6. Nitapenda kuzungunza nawe juu ya 'physical impact' za kumhudumia mgonjwa wa akili.
  - a) Ni changamoto zipi za kimwili umeshakumbana nazo katika kumhudumia mgonjwa?
  - b) Tafadhali fafana.
  - c) Je, suala la kumhudumia mgonjwa huyu limekuathirije kimwili? Kwa namna gani?

7. Hebu nieleze changamoto za kifedha/kiuchumi katika kumhudumia mgonjwa wako. Je, suala zima la kumhudumia mgonjwa huyu wa akili limekuathiri vipi kifedha/kiuchumi?
8. Tafadhali naomba unieleze uzoefu wako wa kuendesha familia yako tangu ulipoanza kumhudumia mgonjwa huyu wa akili. Familia yako imeathirikaje kwa uwepo wa mgonjwa wako? Je familia yako imepata athari (uzoefu hasi) gani tangu ulipoanza kumhudumia mgonjwa huyu?

#### MAHITAJI

4. Tafadhali naomba uniambie kinachokukera mgonjwa akiumwa.
5. Kwa maoni yako, unauonaje mtazamo wa wataalamu wa afya ya akili kwako wewe na kwa mgonjwa wako wakati wa kupata huduma katika hospitali hii?
6. Tafadhali naomba unieleze kwa ujumla kuhusu huduma za ushauri kwa watu wenye mgonjwa ya akili.