CHALLENGES OF CARING FOR CHILDREN WITH MENTAL DISORDERS: EXPERIENCES AND VIEWS OF CAREGIVERS ATTENDING THE OUTPATIENT CLINIC AT MUHIMBILI NATIONAL HOSPITAL

By

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A dissertation Submitted in partial Fulfilment of the Requirement for the Degree of Master of Mental Health Nursing of Muhimbili University of Health and Allied Sciences.

Muhimbili University of Health and Allied Sciences

November, 2010

1.0 Certification

The undersigned certifies that he/she has read and hereby recommends for examination of dissertation entitled ***Challenges of Caring for Children with Mental Disorders: Experiences and Views of Caregivers Attending the Outpatient Clinic at Muhimbili National Hospital,*** in partial fulfilment of the requirements for the degree of Master of Science in Mental Health Nursing of Muhimbili University of Health and Allied Sciences.

SIGNATURE .....

Dr. Anne Outwater

(Supervisor)

Date.....16 Mar 2010.....

2.0 Declaration and Copyright

I, **Ambikile Joel Seme**, 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……Ambikile…… Date……16/11/2010……

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3.0 Acknowledgement

The mighty God, who helped me throughout in the process of working in this dissertation, deserves many thanks. He gave me strength and wisdom as driving forces for the entire work. I also express my sincere gratefulness to all people who made it possible for this work to be accomplished. Not all who were helpful have been mentioned here but let them know that whatever they did, little or big, has led the successful completion of this work.

Thanks to the Embassy of Germany in Tanzania who sponsored my master degree through DAAD program, of which this dissertations is part of.

To start with personally, I would like to thank my main supervisor, Dr. Anne Outwater for her close supervision, constant encouragement, and valuable advice that she provided right from the beginning stage of developing the proposal up to the completion of this work. Among things I will always remember was her quick response to my work whenever I submitted to her for review. Thanks should also go to the dean of School of Nursing, Dr. Khadija Malima for her contribution to research idea formulation, paper writing skills, and critical thinking, which were practically very helpful for this dissertation. My class mates, especially Masunga Kidula Iseselo, did a good job.

My sincere gratitude should also go to the staff of Muhimbili National Hospital who gave me permission to conduct the study and facilitated getting respondents. Lastly, but not least, my warm appreciations should go to all respondents who gave their precious time to participate in the study.

4.0 Dedication

This work is dedicated to my beloved mother, the late Enele Seme, who played a very big role in laying a foundation for my academic life. Although she didn't get the opportunity to go to school, she always encouraged me to pursue education so that I could achieve the highest possible level.

5.0 Abstract

Background

It is estimated that world-wide up to 20% of children suffer from debilitating mental illness. Mental disorder that pose a significant concern include learning disorders, hyperkinetic disorders "{ADHD}, depression, psychosis, pervasive development disorder, attachment disorders, anxiety disorders, conduct disorder/anti-social personality, substance abuse and eating disorder. Living with such children can be very stressful for caregivers in the family. Caregivers, parents and guardian play an important role in helping children grow to their full potential. Therefore, determination of challenges of living with these children is important in the process of finding ways of helping or supporting caregivers to provide proper care for their children

Objectives

The main objectives of this study were to explore the psychological, social, and economic challenges parents/guardians experience when caring for mentally ill children and ways they use to address or deal with these challenges.

Methodology

A qualitative study design using in-depth interviews and focus group discussions was applied. The study was conducted at the psychiatric unit of Muhimbili National Hospital in Tanzania. Two focus groups discussions and 8 in-depth interviews were conducted with a convenience sample of caregivers who attended the psychiatric clinic with their children. Fifteen respondents were interviewed, 11 being biological mothers of children, 3 biological fathers, and 1 biological grandmother. All interviews were digitally audio-taped and transcribed, and a note book was used to take field notes. Data analysis was done using content analysis in the original language. Translation into English was made for what was included in the dissertation report. Ethical clearance was obtained from Research and Publications Committee of Muhimbili University of Health and Allied Sciences and permission to conduct the study was obtained from Muhimbili National Hospital.

Results

The study revealed psychological, social, and economic challenges caregivers endure while living with mentally ill children. Psychological and emotional challenges included being stressed by caring tasks, having worries about the present and future life of their children. They had feelings of sadness, and inner pain or bitterness due to the disturbing behaviour of the children. They also experienced communication problems with their child due to the child's inability to talk. Social challenges were inadequate social services for their children, stigma, burden of caring task, lack of public awareness of mental illness, lack of social support, and problems with social life. The economic challenges were poverty, child care interfering with various income generating activities in the family, and extra expenses associated with the child's illness.

Conclusion and recommendations

Caregivers of mentally ill children experience various psychological, social, and economic challenges. Professional assistance, public awareness of mental illnesses in children, social support by the government, private sector and NGOs are important in addressing these challenges. This can be done through hospital and community programs so that caregivers receive the support they need in caring for mentally ill children.

More research is needed in order to understand the issues of sharing the burden of care in families of mentally ill children. Also exploring challenges caregivers experience in relation to health care services for their children is important due to concerns they raised about the care they received.

6.0 Acronyms and Description of Quotes IDs

ADHD	Attention Deficit Hyperactive Disorder
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision. (A classification system of mental disorders published by the American Psychiatric Association {APA} that includes all currently recognized mental health disorders.)
FGDs	Focus group discussions
IEC	Information, Education, and Communication
MNH	Muhimbili National Hospital
NGOs	Non Governmental Organizations
WHO	World Health Organization
ID10430JAi/ F10508JAi	Represents a quote from the participants; ID stands for in-depth interview and F for focus group discussion. The following two digits in each case stand for the year of interview, the next one digit is for the month and the other next two digits for the date. The following capital letters (JA) stand for initials of the name of the modulator and the last small letters (i or ii), if any, stands for whether it was the first or second interview/discussion done on that same day. **Example:** ID10430JAi means in-depth interview conducted in the year 2010 on April 30th. The modulator was Joel Ambikile and it was the first in-depth interview on that day.

Table of Contents

1.0 Certification ii

2.0 Declaration and Copyright iii

3.0 Acknowledgement iv

4.0 Dedication v

5.0 Abstract vi

6.0 Acronyms and Description of Quotes IDs viii

1.0 Chapter One: Introduction 1

1.1 Background 1

1.2 Problem Statement 2

1.3 Rationale of the Study 3

1.4 Main Objective of the Study 3

1.4.1 Specific Objectives 3

1.5 Conceptual Framework 4

2.0 Chapter Two: Literature Review 7

3.0 Chapter Three: Methodology 14

3.1 Design 14

3.2 Setting 14

3.3 Study Population 14

3.4 Unity of Analysis 14

3.5 Sampling Procedure 15

3.6 Data Collection Instruments 15

3.7 Data Analysis 15

3.8 Ethical Considerations 16

4.0 Chapter Four: Findings 17

4.1 Description of the Population 17

4.2 Preamble of findings 17

4.3 Psychological and Emotional Challenges 18

4.3.1 Disturbing (distressing) thoughts and associated emotional responses 18

4.3.2 Unavoidable Situation 21

4.3.3 Communication Problems 22

4.4 Social Challenges 22

4.4.1 Inadequate Social Services for Children with Mental Disorders 22

4.4.2 Stigma 25
4.4.3 Caring Task (Burden) in the Family 26
4.4.4 Ignorance about Mental Disorders in Children 27
4.4.5 Social Support 27
4.4.6 Social Life 28
4.5 Safety Issues 28
4.6 Economic Challenges 29
4.6.1 Poverty 29
4.6.2 Interference with Various Activities 30
4.6.3 Extra Expenditures 31
4.7 Measures to Address Challenges 31
4.7.1 Seeking Professional Help 32
4.7.2 Seeking Spiritual Help 32
4.7.3 Other Measures 33
4.7.4 Parents' need to have someone to talk to 33
5.0 Chapter Five: Discussion 34
5.1 Psychological and Emotional Challenges 34
5.2 Social Challenges 36
5.3 Economic Challenges 39
5.4 Measures to address challenges 40
5.5 Limitations 40
6.0 Chapter Six: Recommendations 41
7.0 Chapter Seven: Conclusion 42
8.0 References 43
9.0 Appendices 46
9.1 Appendix I: Informed Consent Form (English) 46
9.2 Appendix II: Informed Consent Form (Swahili) 48
9.3 Appendix III: FGD Guide 50
9.4 Appendix IV: FGD Guide – Swahili Version 51
9.5 Appendix V: In-Depth Interview Guide 52
9.6 Appendix VI: In-Depth Interview Guide – Swahili Version 53
9.7 Appendix VII: Basic Quantitative Data 54
9.8 Letter: Approval of Ethical Clearance 55
9.9 Letter: Permission to Conduct the Study 56

Table of Figures

Table 1. Caregivers' Demographic Data and Children's Particulars..... 18

1.0 Chapter One: Introduction

1.1 Background

The onset and chronic presence of mental illness in the family can be a stressful event or a crisis for the family members [1]. Moving from a crisis to recovery in such families has been found to be influenced by their interactions with mental health professionals. Families that have ongoing contact with the mental health professionals are more likely to recover from the crisis and cope with the situation compared to families that do not seek professional help. Therefore mental health professional support in families with a member suffering from severe mental illness is of vital importance.

Home based treatment program for children and adolescents with mental disorders appears to be an effective and sustainable strategy for meeting mental health needs in this group [2]. These programmes would also be cost effective in countries where the health system is overburdened with infectious diseases and where psychiatric inpatient-care is limited, such as in poor resource countries such as Tanzania. However, the success of such interventions requires compliance of patient and parents, and support from highly skilled therapists.

Parents and guardians play a major role in helping children grow and develop to their full potential. As children grow in the families they most significantly depend on their parents/guardians for basic needs and support including food, shelter, education, protection and care at all times but especially during life difficulties and times of crisis. In a cultural setting where extended families form a larger family, their involvement in child rearing is also acknowledged since mental disorders in childhood/adolescence can be chronic and very disturbing, requiring proper attention, help and support from caregivers [3]. Thus, parents/guardians and relatives living with children with mental illness have additional responsibilities and roles to care for them as they do for other healthy children. In this study 'children' means any male or female persons not more than twelve years of age, and a 'parent' is a biological mother/father or anybody who assumes that role. The importance of families for the growth and development of children and the role they play as determinants of whether the child will receive mental health services can not be overemphasized [4].

From the past until now the WHO mental health programme has not given due weight to child and adolescent psychiatry as compared to adults and the elderly [3]. Yet from a demographic and epidemiologic point of view, mental disorders in children and adolescents represent an important area that needs proper attention. It is estimated that up to 20% of children and adolescents suffer from debilitating mental illness[5].

There are various ways in which child and adolescent mental disorders can be considered. One way is looking at these disorders in a priority manner based on their frequency of occurrence, degree of impact, therapeutic possibilities, and long term care effects [3]. From this perspective, child and adolescent mental disorders that pose a significant concern include learning disorders, hyperkinetic disorders {ADHD}, depression and its associated suicide. Others include psychosis, pervasive development disorder, attachment disorders, anxiety disorders, conduct disorder/anti-social personality, substance abuse and eating disorders.

1.2 Problem Statement

Data from high income and low income countries show that the prevalence of children and adolescents with diagnosable mental disorders ranges from 15 to 20% [6, 7]. Regardless of this magnitude, most of these children and adolescents do not receive any help [7], and this may have a negative impact in their adult life. On the other hand, in most low income countries like, Tanzania, children and adolescents with mental illness usually live with their families in the community. Those who have access to mental health services are mainly treated on an outpatient basis regardless of whether the condition is acute or chronic. Parents, guardians or other family members are the ones who take care of them at home most of the time. Despite this trend, very little is known about the challenges that parents/guardians and family members face in caring for mentally ill children/adolescents in a Tanzanian context. On the other hand in developed countries, children in home-based foster care experience high rates of mental health problems but only a minority receive professional help for their problems [8]. It is acknowledged that children with mental disorders have worse health-related quality of life than children with no disorders [9]. If nothing is done about this situation these children/adolescents are most likely to face negative health and life consequences in their future. Therefore there is a need to learn about the current situation of care for these children and adolescents with mental illness. Exploring these challenges is a significant

initial step in understanding the current situation before further steps are taken. Moreover, new ways of mental health interventions have been developed within the last two decades and this underscores the need to define the challenges faced when caring for children with mental disabilities so that appropriate interventions are implemented. Some of these new developments are concerned with caring for children in their world which is commonly known as community based services. This is known as "wraparound" in USA, "child empowerment" in Tanzania, and "parent support" in Australia [7].

1.3 Rationale of the Study

Parents/guardians as main family care takers play a vital role in caring for mentally ill individuals including children and adolescents. Learning the challenges they face in caring for children and adolescents with mental illness is the first step in identifying good ways of improving support for such caregivers. It is crucial that children receive appropriate care and support at home and during the outpatient visit to the hospital in order to meet their mental health needs. The scarcity of published studies on this area in Tanzania, underscores the importance of this study to contribute towards better understanding on the challenges faced when caring for mentally ill children. The results may be useful in providing specific information for interventions to improve service provided by caregivers at home and by care providers at outpatient psychiatric clinic.

1.4 Main Objective of the Study

The main objective of this study was to explore challenges parents/guardians experienced when they cared for their mentally ill children

1.4.1 Specific Objectives

The specific objectives of the study were:-

1. To identify the psychological problems parents/guardians faced by living with a mentally ill child in the family
2. To identify the social problems parents/guardians faced by living with a mentally ill child in the family
3. To identify ways in which child mental illness interfered with economic activities in the family
4. To determine ways through which parents\guardians dealt with or addressed these challenges.

1.5 Conceptual Framework

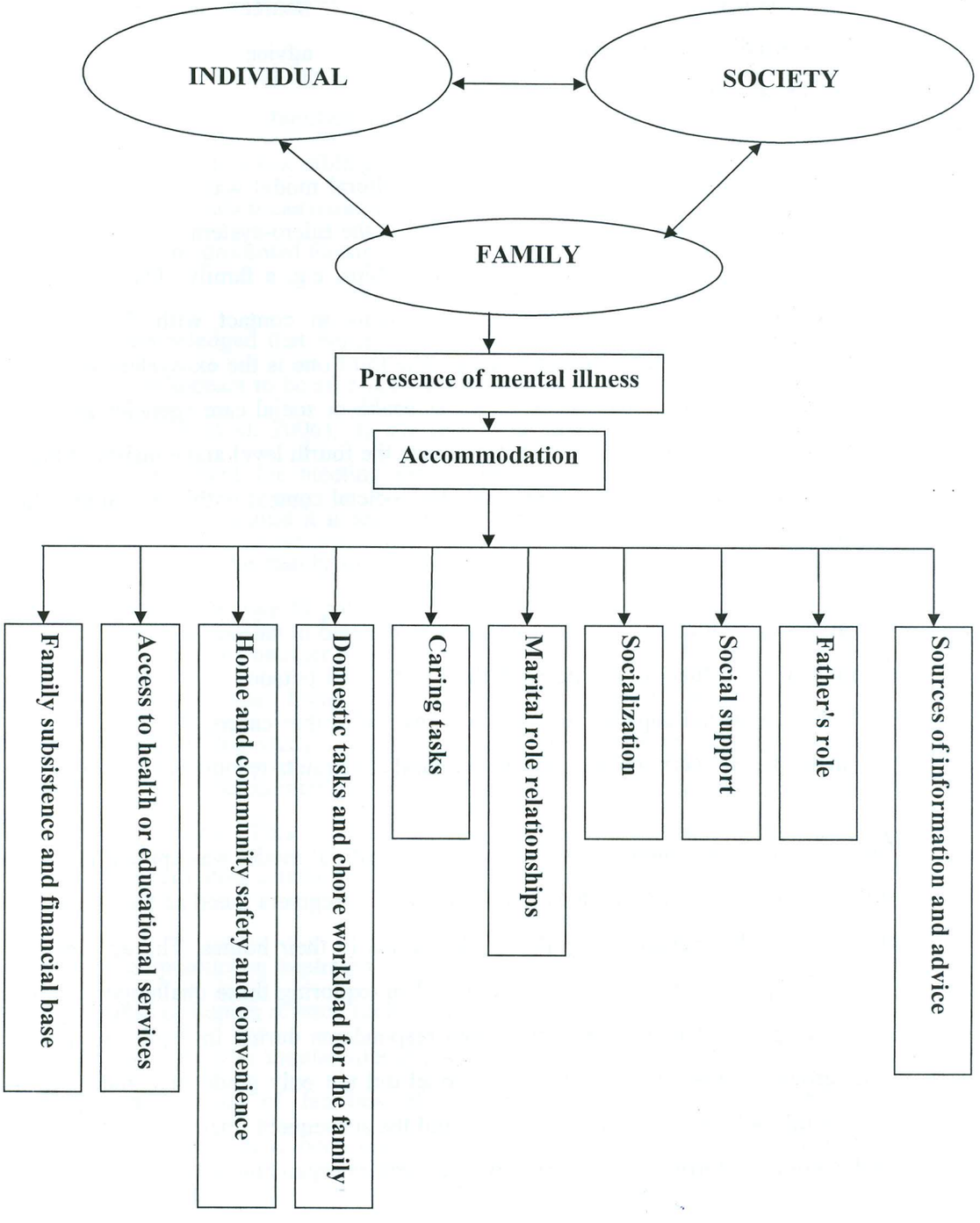
This study was guided by the eco-cultural model [10]. Although this model dealt with intellectual disability, the author acknowledged that many of its concepts and conclusions could be applied to a range of chronic disabling conditions. In fact, intellectual disability is one of the manifestations of mental illness. Thus, this model was very relevant and was applied to this study since mental illness is among chronic disabling conditions that can affect family life dynamics. For this reason, and for the purpose of this study, the phrase 'intellectual disability' was replaced by the phrase 'mental illness' in this model.

This model which was developed by Gallimore and his colleagues [11], builds on the 'social ecology' model which was developed by Bronfenbrenner {1979}. The eco-cultural model asserts that individuals and families do not live in isolation but in the context of a wider relationship within the society. The individual and family functioning are affected by the way they relate with the wider context of the community which also exerts influence over them and vice versa. Such relationships can include work flexibility, which may require adjusting work to incorporate the care-giving responsibilities, and how mental health services can support the person with mental illness living with the family. [10]

The eco-cultural model suggests that families must respond in different ways to pressures that come upon them in order to maintain a meaningful and daily routine of family life. These responses are referred to as 'accommodations' and occurs not only within the family but within the wider social context, thus forming an eco-cultural 'niche'. The family is considered here as possessing adaptive behaviour. This model shows that the process of accommodation is common to all families, and particular accommodation variables have been identified in relation to families of a person with mental illness. These variables include:

I. Family subsistence and financial base
II. Access to health or educational services
III. Home and community safety and convenience
IV. Domestic tasks and chore workload for the family

DIAGRAMMATIC REPRESENTATION OF THE ECO-CULTURAL MODEL



KEY

The arrows means "leads to" or "affects"

V. Caring tasks
VI. Socialization
VII. Marital role relationships
VIII. Social support
IX. Father's role
X. Sources of information and advice.

The social ecology model, on which the eco-cultural model was built, consists of four main levels of systems. The first system level is the micro-system which represents the patterns of activities and interpersonal relationships, e.g. a family. The second system level is the mesosystem and represents systems in contact with the family, e.g. neighbours, health workers, workplace etc. The third one is the exosystem which stands for the wider organizational systems such as health or social care agencies and operates more at the level of policy. The macrosystem is the fourth level and consists of the wider cultural, religious, economic systems; sets the societal context within which the illness is constructed.

Caregivers of children with mental illness may respond in various ways in the process of adapting to the situation {living with the mentally ill person}. They may change jobs, establish new social support networks, or link with other carers. The accommodations they make depend very much on the eco-cultural constraints/resources available to them.

The concept of 'accommodations' from the eco-cultural model was applied in this study in the efforts to explore the challenges/difficulties caregivers faced as they took the role of caring for the mentally ill children/adolescents in their homes. The accommodation variables explained in this model were useful in exploring these challenges. They were applied in probing more information from respondents during in-depth interviews and focus group discussions. Therefore this model did not only guide this study, but was a very useful tool for developing objectives and the subsequent interview guides that were used to collect information from caregivers as well as organizing data analysis.

2.0 Chapter Two: Literature Review

A recent study has revealed that many challenges and stresses are faced by persons with mental illness and their families [12]. Some of these challenges include financial constraints, negotiating roles, sibling stress, and isolation. This being the case, it is vital that health professionals understand these difficulties so that the health and well-being of their patients can be promoted through the use of patient/family-centred care approaches.

Since it is acknowledged that home based treatment for children and adolescents with mental disorders appears to be an effective treatment setting when compared to inpatient treatment (Schmidt et al, 2006), its use should be advocated for in order to create a conducive environment for meeting mental health needs and reduce morbidity and disability. This is so because it is less expensive, takes place in a familiar environment, and has a more effective family involvement. However, this type of treatment requires motivation and compliance of patients and parents, and highly skilled therapists. This idea is also supported by another study which was comparing the effectiveness of treating autism in children between home based behavioural therapy and standard school-based interventions [13]. This study revealed that children who were exposed to intensive intervention were higher in intelligent quotient (IQ) at the time of follow-up than children in the standard group. This evidence supports the ideas that home-based treatment is more effective than other standard school based approaches.

Evidence based practice in treatment of mental health disorders is emphasized just as it is with other areas of human science such as medicine. Since families assume major roles in supporting relatives with mental illness [14], key literature themes with respect to the experiences and needs of families of individuals with mental illness have been determined [15]. They have been found to be: family stigma; family/caregiver burden; information exchange and referral; family stress, coping, and adaptation; family support; crisis response; and family psycho-education.

It has been stressed that in order to obtain the best outcomes for clients with mental illnesses, the needs of their families must also be assessed and addressed. One basic need is information which can be provided by health professionals. Nurses can play an

important role in teaching clients and families many skills including problem solving, parenting, coping with daily living and personal and family stressors, and effective communication. Referring families to appropriate outside resources can provide them with a means of continuing support [16].

A systematic review of studies in the treatment of child and adolescent mental disorders has shown that effective treatment should involve working closely with parents [6]. This includes teaching parents how to implement behavioural modification procedures and contingency management strategies in the child's natural environment. This evidence, for instance, points out that parents should be taught how to control and modify environmental contingencies to increase the occurrence of a desired behaviour. Such support for parents is usually provided by health professionals who are knowledgeable in this area of behaviour modification.

Regardless of the known roles of parents in treating mental disorders in children many studies have revealed challenges that parents and other caregivers face in caring for children with mental disorders. In Australia, when care givers were asked about the challenges they faced most often, they mentioned the social psychological problem of "being consumed" as a major problem [17]. This was experienced when the family member was officially diagnosed with a mental illness. By "being consumed", respondents meant that their integrity, identity, self-esteem, and self-equilibrium were threatened. This was experienced in two phases which were (1) disruption to the established lifestyle and (2) sustained threat to self-equilibrium. In the first phase, preoccupation with not knowing what was wrong with the family member consumed their time and this impacted on their ability to accomplish planned life goals. The second phase was associated with concerns about the commitment made to care for the individual, feelings of grief and loss, personal cost of caring, the need to manage future crises, and the need to prioritize the patient's needs. The other concern in this phase was disruption of the caregivers to achieve their own goals/dreams.

This caregivers' experience of being consumed does not differ from similar studies which were conducted in Egypt [18], Botswana [19], and Nigeria [20]. Caregivers in Botswana suffered embarrassment that was associated with the ill relative being verbally abusive and undressing publicly, but later on they learned how to live with the ill relative and

of knowledge, the greater the burden experienced. The burden experienced was supervision, worrying, tension and urging. Nevertheless, this study could not establish whether knowledge of schizophrenia caused the burden.

A study in Nigeria [20] showed that differences in marital status can influence the perceived burden by caregivers. In this study, caregivers of patients who were divorced or separated significantly experienced more routine burden and financial distress as compared to caregivers of patients who were married. Financial burden was experienced more by caregivers who were unemployed than by those who had a job. It is possible that the financial burden was less for caregivers who had a job because they had an income. Furthermore, this study showed that an intact family and financial stability were associated with fewer burdens experienced by caregivers.

In South Africa, the integration of mental health services into primary health care and the shift towards community- and family-based care for chronic mental disorders has been associated with increased burden on households. The major problem with mental health service provision which has been reported by households is the way clinics are organized to provide care [26]. In this study, common problems experienced by family members of people with chronic mental disorders when they went to collect medication were the long queues and waiting time. This interfered a lot with other important activities they had.

Caring for an individual with a mental disorder can by itself result in poor physical and mental health of the caregiver [27]. With regard to old age, parents of adult children with bipolar disorder have a more compromised profile of physical and mental health as compared to those without such children. These parents experience more difficulties in marriage and work life. However, this study could not find any significant differences in levels of psychological well-being and social resources in later life.

In a study which was conducted in the United States [28] externalized and internalized behavioural problems in children with mental disorders were found to be associated with parents' distress. In this study externalized behavioural problems meant the child having symptoms of hyperactivity, hyperirritability, impulsivity, self-abuse, fighting, destructiveness, and disobedience at home or school. Internalized behavioural problems meant that the child had symptoms of anxiety and depression, fearfulness, loneliness,

social withdrawal, and compulsive or suicidal thoughts. Externalized behavioural problems in children were more correlated with subjective parental distress and had a stronger impact on parents as compared to internalized problems. Parent's subjective distress in this study referred to the degree parents were affected intra-personally, such as through fear, worry, or guilt related to their child's mental health problem. Conversely, internalized behavioural problems in children were more highly associated with objective distress in parents than externalized problems. Objective distress related to the degree parents' lives were disrupted, such as through family or work disruption or lack of time for leisure activities.

With regard to perceived personal control (general sense of having the intrapersonal resources to deal with stressors), parents with higher levels of control were significantly less distressed as compared to those with lower levels when their child's behavioural problems were less severe. But this became a different story when there was a dramatic increase in the child's internalized problems. Therefore regardless of their degree of perceived control, parents of children with high levels of internalized problems needed support. The researcher observed that the majority of caregivers who participated in this study were biological mothers (81%). This was followed by adoptive mothers (8%), grandmothers (7%), and 1% each stepmothers, foster mothers, biological fathers, and adoptive fathers. However this study had some limitations in that it used a convenience sample which could not be representative of the study population. Also bias was likely to have been introduced by collecting information from one primary caregiver who was most likely to be a mother. Maybe, if more fathers participated in the study the perceived personal control could be different.

Lack of recognition of the multiple needs of children and families by the health care field was mentioned to be one of the major challenges experienced in child and adolescent mental health in the United States [29]. The interrelatedness of problems in mental health including health, education, substance abuse, delinquency, teen pregnancy, and vocational domains was said to be not considered in the health care field. Factors that impact on mental health in children and adolescents are important to consider if significant improvement to mental health services is to be made. Determining multiple needs of children and families by health care providers in Tanzania is one of the areas that should be explored since not much in known about it.

Other challenges faced in the United States were inadequate financing system to support home-based care, and improper practices by private for-profit psychiatric hospitals which provided substandard care when patient's insurance problems arose [29]. It was also explained that lack of partnership between the private and public organizations escalated mental heath problems in the community. Regardless of being a high income country, United States still faces challenges of allocating adequate funds to child and adolescent mental health. Government funding to mental health of children is decreasing [30]. The consequences include parents being left with few treatment options; the juvenile justice system bulging with children in need of treatment and placed in wrong places; school system frustrated by unacceptable behaviour of children who need treatment. Drug and alcohol use and suicide risk have remained risks for adolescents. This is an example of what inappropriate fund allocation by governments can do to child and adolescent mental health. One can ask the question that, if this is the situation in a high income country like United States, what should be expected in low income countries like Tanzania, where poverty is among the biggest problems in the health care system?

Mental health services in Tanzania, for instance, are free of charge as declared by the government that provides funding for health care. However, the researcher's observation is that government investment in mental health including child and adolescent psychiatry is minimal to an extent that presence of essential drugs like atypical (second generation) antipsychotic drugs in hospitals is not common. While patients in many countries are now using atypical antipsychotic drugs that have fewer side effects [31], most patients in Tanzania are still using typical (first generation) antipsychotic drugs that have many side effects. However for patients who are insured and those who can afford to buy newer drugs the situation is different.

When it comes to professional support, a study in the United States revealed that health professionals had very limited contact with families of the mentally ill [32]. A wide range of services needed by the families were not covered and the most frequently reported services were provision of emotional support and helping families to cope with specific situations. Very few health professionals reported providing family therapy, teaching identification of early warning signs of relapse, including family in client's treatment, or referred family to support group. Regardless of all these weaknesses, health professionals

still believed that families were satisfied with the service they provided. In Tanzania, the professional support for families of the mentally ill is likely to be even more complicated by many obstacles such as an inadequate number of mental health professionals, issues of accessibility (infrastructure) and poverty.

Suggestions from a study in Zimbabwe indicated several ways in which the communities could be helped with care provision issues to families with mentally ill individuals [23]. These include financial assistance, food and clothing, home-based care, and rehabilitation. On the other hand, several demands were described by caregivers at personal, family, and community levels [19]. The most prominent demand was lack of resources. Families were impoverished and lived below the poverty line characterized by food insecurities and inability to provide material commodities for their ill members. Most communities didn't have any programmes for mentally ill people. Caregivers also expressed emotional and social demands as their mentally ill relatives were difficult to control, and the environment was not supportive due to presence of negative factors that facilitated relapse such as alcohol drinking and smoking cannabis. This interplay of social problems makes it difficult for families to effectively provide care for their relatives in the home. According to the researcher's experience, such negatives factors that were associated with relapses in Zimbabwe can also be observed in communities in Tanzania. Several studies have been conducted in African countries about the challenges families face by living with individuals with mental illness, but none from Tanzania have been published to date.

3.0 Chapter Three: Methodology

3.1 Design

This was a qualitative study that used focus group discussions (FGDs) and in-depth interviews. FGDs were conducted to gain insight as to what issues needed to be explored in the in-depth interviews.

3.2 Setting

The study was conducted at the Psychiatric Unit of Muhimbili National Hospital (MNH) in Dar es Salaam, the economic centre and fastest growing region of Tanzania. MNH is the only national government referral hospital with the highest specialized health services. It is a place where patients with complicated health problems from all over the country can be found. The psychiatric unit is one of the departments in the directorate of clinical services. Unlike other departments, it only caters for patients who are referred from the three districts of Dar es Salaam namely Ilala, Kinondoni and Temeke. Psychiatric services at this unit are provided into two major forms depending on age. The first form of service is provided for adults who receive either inpatient or outpatient care. More serious patients from this unit are referred to Mirembe Institute located in Dodoma region which is a specialized national hospital for psychiatry. Secondly, there is child and adolescent care which is usually provided on the outpatient basis. A special day has been reserved in a week (Thursday) for children and adolescents to be seen by health care providers. According to the records obtained at the unit, about 30 children and adolescents were seen every week.

3.3 Study Population

Respondents were parents/guardians who brought their children to attend the outpatient psychiatric clinic at Muhimbili National Hospital on Thursdays. This was the day in the week when children and adolescents were brought to the psychiatric unit for treatment.

3.4 Unity of Analysis

Two focus group discussions (FGDs) and 8 in-depth interviews were conducted. The first FGD was attended by 5 respondents (all were mothers) and the second one consisted of 6 respondents (3 fathers and 3 mothers). Eight in-depth interviews were conducted with 7 biological mothers and one grandmother. Among them, 4 were mothers who participated in the first FGD. Since no more information was obtained from them, participants from

the second FGD were not included in in-depth interviews and only new participants were involved. Conducting in-depth interviews was stopped when no more information could be obtained from caregivers. The purpose of using FGDs was to help get general information and ideas that were further explored during in-depth interviews.

3.5 Sampling Procedure

Convenience and purposive sampling methods was used. Respondents were recruited through the identified child and adolescent nurse counsellor working at the psychiatric clinic. They were asked to participate in the study during the waiting period before they could be seen by the doctors. An appointment to come back for interviews was given to them on the day of their choice. Since the purpose of this study was to get reliable information about the experience of parents/guardians living with mentally ill children, criterion-based purposive sampling method was employed. The inclusion criterion was a parent or guardian who had lived for at least six months with the mentally ill child. This was considered adequate period for having reasonable experience. Parents/guardians who met this criterion and consented were included in the study.

3.6 Data Collection Instruments

In-depth interviews and focus group discussions were conducted to gather data on psychological, social and economic challenges caregivers faced in living with children with mental disorders. A semi-structured interview guide was used to interview respondents. All interviews were digital voice recorded and a note book was used to take filed notes. During FGDs the moderator (researcher) led the discussion and kept the conversation flowing while the research assistant was recording the interviews and taking some notes. Basic quantitative data were also collected from respondents after conducting the interviews. All interviews were transcribed verbatim. The quality of the interview was ensured by making sure that respondents who were interviewed met the inclusion criterion i.e. being a real caregiver who had lived with the mentally ill child for not less than six months.

3.7 Data Analysis

Analysis of data was done by using content analysis in accordance with qualitative analytical framework which consisted of the researcher reading and re-reading the text, manual coding in the margins, and through memos, synthesizing and grouping of data in relatively exhaustive categories [33]. Data was analysed in the original language

(Swahili) in order to minimize the possibility of losing the original meaning of concepts. Translation into English was done for what was included in the report. Trustworthiness of data collected was ensured by taking the following actions: credibility was increased by employing two methods of data collection i.e. use of FGDs and in-depth interviews. Raw data and research findings were presented to colleagues for critique (peer debriefing). The issue of dependability was dealt with by ensuring that all data and documents which were used during data collection and analysis are kept safe and are available upon request. Moreover, dependability and confirmability were checked by allowing research supervisors to audit each stage of analysis process and the results.

3.8 Ethical Considerations

The ethical approval of the study was obtained from the Research and Publications Committee of Muhimbili University of Health and Allied Sciences and permission to conduct the study was obtained from Muhimbili National Hospital. Confidentiality was guaranteed as follows: (a) for their anonymity, participants were identified by numbers; (b) for in-depth interviews, confidentiality was guaranteed, but with FGDs this could not be completely ensured due to involvement of more than one respondent. Nevertheless respondents participating in FGDs were informed that the discussion was confidential; (c) participants were informed on their right to decide to continue with or quit the study. Written informed consent was sought from all participants prior to interview sessions; (d) The audio folders, transcripts, and written notes containing the participants' information are kept well in a safe place and only the researchers has access to them and they will be destroyed later after completion of the study.

Interviews served as a psychologically relieving moment for participants. However also it was possible that participants, influenced by the sensitive nature of the data needed from them, could be emotionally traumatized. Although this did not happen, the researcher was prepared to link participants to senior mental health personnel at MNH psychiatric unit for further management in case of any psychological or emotional problems that needed attention as a result of the interviews.

4.0 Chapter Four: Findings

4.1 Description of the Population

Fifteen respondents participated in the study, 8 through in-depth interviews and 11 in FGDs (5 females participated in both). Those who participated in in-depth interviews were all female while 3 males and 8 females participated in focus group discussions. Respondents ranged between 26 and 60 years old, with the majority in their 30s. Their children's age ranged from 3 to 12 years. Ten respondents were married, 3 were widowed, one was separated, and the other was single. All were biologically related to a child with mental disorders. Eleven were mothers, 3 fathers, and one was a grandmother (who had become the primary caregiver after the mother had died), and for this reason all caregivers will be referred to as parents in this study. Most respondents had primary education (9), one had secondary education, two were university graduates, and the rest (3) had never gone to school. Most of them (8) were home mothers, 3 were doing petty business, and the rest were an engineer, a vehicle mechanic, and a caterer and decorator. Mental disorders suffered by their children included autistic disorders (n=5), attention deficit hyperactive disorder (ADHD) (n=3), seizure disorders (including epilepsy) (n=11), and mental retardation (6). Children's diagnoses were taken from their files at the clinic since their parents were not able to tell exactly what the child was suffering from. Most of these children had two disorders at the same time (co-morbidity). Demographic data is shown in Table 1.

4.2 Preamble of findings

According to the objectives of this study, psychological, social and economic challenges that respondents experienced in caring for children with mental disorders were determined. Since data analysis was done in the original language (Swahili), quotations in this section have been translated into English.

Table 1. Caregivers' Demographic Data and Children's Particulars

ID. NO	SEX	AGE	MARITAL STATUS	TYPE OF CAREGIVER	LEVEL OF EDUCATION	OCCUPATION	CHILD'S AGE(YRS) /SEX	CHILD'S DIAGNOSIS
ID10501JAii F10424JAi	F	33	Married	Mother	STD VII	Home Mother	10/F	Autism
F10424JAii	F	37	Married	Mother	STD VII	Home Mother	11	Mental retardation
ID10501JAi F10424JAiii	F	33	Widow	Mother	STD VII	Home Mother	7/F	Seizure disorder & ADHD
ID10430JAi F10424JAiv	F	36	Single	Mother	STD VII	Petty Business	9/F	Seizure disorder & Mental retardation
ID10430JAii F10424JAv	F	60	Married	Mother	None	Home Mother	8/M	Autism & Seizure disorder
ID10502JA	F	51	Widow	Grandmother	STD VII	Home Mother	3/F	Seizure disorder & Mental retardation
ID10503JA	F	33	Married	Mother	None	Petty Business	10/F	Epilepsy & Learning disability
ID10504JA	F	39	Married	Mother	Form IV	Catering and Decoration	11/F	Autism & Seizure disorder
ID10506JA	F	42	Married	Mother	Bachelor's Degree	Police Officer	5/M	ADHD & Seizure disorder
F10508JAi	M	38	Separated	Father	STD VII	Vehicle mechanic	11/M	ADHD & Mental retardation
F10508JAii	F	26	Widow	Mother	None	Home Mother	8/M	Seizure disorder & Mental retardation
F10508JAiii	M	38	Married	Father	Bachelor's Degree	Engineer	5/M	Autism
F10508JAiv	F	37	Married	Mother	STD VII	Home Mother	12/M	Epilepsy & mental retardation
F10508JAv	M	45	Married	Father	STD VII	Petty Business	9/F	Mental retardation & Epilepsy
F10508JAvi	F	40	Married	Mother	STD VII	Home Mother	11/M	Autism & Seizure disorder

4.3 Psychological and Emotional Challenges

Four major themes emerged from the study that explain the psychological and emotional challenges that parents experience in the everyday life of caring for the mentally ill child. These were: disturbing thoughts, emotional disturbance, unavoidable situation, and communication problems.

4.3.1 Disturbing (distressing) thoughts and associated emotional responses

A number of respondents revealed having disturbing thoughts about living with a mentally ill child. They expressed being stressed by the explicit behaviour of the child that caused problems not only for the parent but also to people nearby such as neighbours. Behaviours of the children that were of particular concern to parents were being aggressive, destructive, restless or hyperactive, making noise, and lack of proper eating skills. A father of a child with autistic disorder explained:

> *"It is very true, it's a problem, there is a problem because the way he is you can clearly see that he completely does not fit in the community. His actions are*

different and, of course, not accepted by other people. You may decide to go with him to some place, for example if you look at the appearance of my own child you may think he is just okay. But his actions are so disgusting (kukera) that you can't go with him anywhere; to church or so, he just has to remain at home, it's really a problem". {F10508JAiii}

A mother of a child with ADHD and seizure disorder cried when she was explaining how hopeless she felt:

"..... When the child is hungry, because those pills induce hunger, she eats to the extent that I sit down and wonder how it's going to be. When she is hungry she picks a plate from the bowl and brings it to you, which means she is hungry..... And where we stay there is a man from Pemba who makes snacks, so early in the morning she stands at the gate showing the plate, sometimes I sit down and shed tears, sometimes I don't have even a hundred shillings... I don't have front or back (Sina mbele wala nyuma) ." {ID10501JAi}

Note: 'Sina mbele wala nyuma' is a Swahili saying which people use to explain a desperate situation.

Worrying about the future life of the child was another form of disturbing thought that some parents experienced due to the inability of the child to accomplish personal and social needs such as self-care and education. They showed these concerns because the child could not do certain developmental tasks expected at specific ages such as feeding, toileting, bathing, and dressing themselves, as expressed by a mother of a child with autistic disorder:

"Truly, what I am afraid of is that it will be more difficult later in life. This is what makes me fail to sleep all the days, I keep thinking only about that and my husband and I quarrel about that everyday. Just imagine, now you have to wash her since she soils herself with faeces and urine, now when she grows up it will become a very big task, it will really become a big task. ... since I already know because I move around and see my colleagues who also have such children but who are grown up, the way they complain. And when I see the child's condition about which this person is complaining, it's not like the one I have; she is at least better. Now how will it be with my child, who can not do anything? My greatest concern is after menarche (kuvunja ungo); what I am thinking of is after menarche and this is a big test". {ID10501JAi}

Parents were also disturbed by the complexity of caring responsibilities that demanded a lot of work and being available most of time to meet the daily needs of the child. The issues about how to handle the child and ensure security if the parent died was expressed by one father of a child with mental retardation and epilepsy:

> *"I accept to be meek and gentle because I know it is God who has intended for the matter to be like this, but it's a big burden to me because that child is always restless. He can not even sit down with others for a minute, he likes seeing himself wandering and he feels good. So in the process of wandering he gets lost, and there we are staying near the road. Therefore the mother doesn't do anything other than looking after (kumwangalia) the child all the days of her life for two years now, and we don't know what will happen in the future."* {F10508JAv}

A mother of a child with ADHD and seizure disorder said,

> *"Until now I don't know how my child's condition will be if, let's say I die. This is because I don't have any sister, mother, or father who can take care of my child in that condition .....let's say I die now, I don't think she will be in a better condition..."*{ID10501JAi}

Living with a mentally ill child was described as emotionally distressful by parents. Varying degrees of emotional distress were experienced which included having feelings of sadness and inner pain or bitterness. Parents experienced these negative emotions due to disturbing behaviour of the children, extra care-giving responsibilities, family and social problems caused by the child, and people's perception about families having a mentally ill child.

Some parents were sad and grieving for several reasons: the situation of having a mentally ill child in the family (child's condition), the chaotic or disturbing behaviour of the child, and the anticipated problems related to care-giving responsibilities in the future. A sad mother of a child with autism explained:

> *"I really somehow grieve (sononeka), I just accepted it (having a mentally ill child), but I really grieve because I really suffer (pata shida) a lot from this child...now when I look at this child with disability and the challenges of care, it makes me grieve..."* {ID410501JAii}

Sadness caused by having a child with mental disorder was even more intense for the couple as expressed by a mother about a boy who was their only son:

> *"And that Mzaramo (husband from Zaramo tribe) as I told you does not have another child, he is the only child and he has problems, and this makes him (the*

husband) very sad as he wondered what kind of spell found him...and for me he is the only male child, and my soul keeps hurting. I thought I got a man (son), you see, all others are females, and the man himself is like that. Now we are having two situations; his mind is not okay, and we have already got a loss. The way he is there is nothing remaining". {ID10430JAii}

Inner pain {described by participants as bitterness, disgust (kukerwa), hurting heart (moyo kuuma), feeling bad (kujisikia vibaya), and burning soul (roho kuungua)} was another form of emotional response that parents expressed. Circumstances that led parents to experience these feelings were the child depicting strange behaviour, not being able to go to school, being mistreated by people, and stigma. A mother of a child with ADHD and seizure disorder explained:

"Now what makes me feel bitter, I mean it would be better if my child was studying, if I could manage" {F10424JAiii}

Another mother of a child with seizure disorder and mental retardation described:

"But, I mean, you know, as a parent, it really hurts in the soul (unaumia nafsi) (Another respondent supports this comment by saying 'absolutely'). She may touch somebody and that person may react, "get your child into the house". Why should I take her into the house? Doesn't she deserve to stay outside or watch? It really hurts in the soul." {F10424JAiv}

However one mother (a caterer and decorator) of a child with autism and seizure disorder acknowledged the child being not a problem:

"...that child on my side does not give me trouble (shida) because she takes her medicine as usual, the challenge I face is may be the house girls. You know I can not stay home, I have to go out." {ID10504JA}

4.3.2 Unavoidable Situation

Parents described living with or having a mentally ill child as a disturbing but unavoidable situation. They had to accept it since they had no any other alternative. They viewed their caring duty for the child as very difficult and distressing. This was stated by some participants when they were responding to the question about how they generally viewed the situation of having a mentally ill child at home. One mother of a child with autistic disorder said,

"Really I have accepted it because I have already been given, but it's a big task, it's a very big task to care for a child with mental disability". {F10424JAi}

Another mother of a child with mental retardation and seizure disorder emphasized:

> *"...yes we have been disgusted (tunakerwa), but God has already planned it for you, and you have no any other way".* {F10508JAii}

4.3.3 Communication Problems

The inability of the child to express needs was another source of psychological and emotional distress associated with living with mentally ill children. This resulted in failure of parents to understand the child especially when he/she had problems. Sometimes when the child went out, he/she was mistreated by other people and returned home crying. When he/she was asked by the parent to explain what happened he/she couldn't explain, as expressed by a father of a child with autism:

> *"The challenge I face is that that child can not express his needs ... Sometimes he may be sick and you don't know, he just cries, when he has problems he just ends up crying. Now you don't know why he is crying, and sometimes when you touch him and feel that he is hot then you may guess that this could be malaria and take him to hospital. But when he has like stomach ache you can't understand, you just see him crying,..."* {F10508JAiii}

Still another mother of a child with seizure disorder and mental retardation lamented:

> *"Difficulties like when he gets a fever, for such a child you may not even know where he is having a problem. You just take him as, what you can do; you just have to take him to the hospital to be examined to know what he is suffering from."* {ID10502JA}

4.4 Social Challenges

Caring for a child with mental illness was found to be associated with many social challenges. Social services, stigma and caring responsibilities were areas which posed major concerns for most parents. Other important issues included a lack of public awareness, social support, and social life.

4.4.1 Inadequate Social Services for Children with Mental Disorders

Inadequate social services for children with mental disorders was the most challenging issue for parents. They were concerned about education for the child and to a lesser degree hospital care.

The most distressing aspect was inability of the child to acquire education due to an inadequate number of schools. Parents spent a lot of time looking for schools that could

accommodate the child as explained by a mother of a child with mental retardation and seizure disorder:

> *"...I was told to take her to Uhuru Mchanganyiko (primary school for children with various disabilities); I went there because she has mental and visual problems. When I got there they told me they would not accept the child and that I should take her to Mtoni special school (another school for disabled children). Until now, when I go to Mtoni special school they tell me there is no vacancy. There are no school opportunities for these children or their schools are very few, you see"* {F10424JAiv}

Sometimes, parents who took the child to the very few available special schools for children with disabilities in Dar es Salaam, were told that no vacancies were available. The major reason for refusal of the child was self-care problems such as being unable to feed or attend the toilet by himself/herself. Some parents who tried to take the child to ordinary schools found him/her being rejected, as said by a mother of a child with mental retardation and seizure disorder:

> *"With school it's like that, I took my child to school. They told me that the child should first learn to wash hands and to go to the toilet. They said that I should teach her all that and bring her back when she has managed..."* {F10508JAii}

A mother of a child with ADHD and seizure disorder also had the same experience:

> *"There are schools, but the children are rejected because they can't take care of themselves, you see. It's not that there is no school, schools are there but they reject them..."* {F10424JAiii}

Another single mother of a child with mental retardation and seizure disorder said,

> *"She doesn't go to school, I took her to an ordinary nursery school but the teachers told me they could not manage her and that I should take her to their (special) schools. I told them I was looking for a school for her and I still had not found one so I asked them to stay with her. After some time they rejected her, and said they could not stay with her there; really it's a problem."* {F10424JAiv}

Some parents whose children were lucky to be recruited in the special schools were experiencing other problems. Some of their children could not understand anything that was taught at school, while others had transport problems especially because of the traffic congestion in the city of Dar es Salaam. Others could not take their children to school because they could not afford bus fare, as explained by the mother of a child with autism and seizure disorder:

"She goes to school but she doesn't understand..... she just goes to school but there is nothing she understands at school" {ID10504JA}

Another mother of a child with autism and seizure disorder added:

"The first difficult thing about it is that I haven't found the school. Money is needed, as he (the child) is supposed to stay there (at school) because we can not afford for him going and coming back since we are not able to. Schools like Buguruni require having money." {ID10430JAii}

Special schools in Dar es Salaam only allowed children from other regions to stay in the hostels. Children from Dar es Salaam could only attend school during the day. Consequently, parents who were living far from these schools could not take the child to school due to transport problems. As a result many mentally ill children were not attending school and this was a challenging situation for most of the parents, as expressed by a mother of a child with ADHD and seizure disorder:

"She (the child) doesn't go to school; I took her to Mtoni and Kijitonyama; at Kijitonyama they said I could not manage because I was staying very far. They told me children were brought to school by their parents at 6:00 or 6:45 am, you see, and at 12:00 pm they picked them back..." {ID10501JAii}

Another concern about education was raised regarding lack of continuity in the school programs for children with mental disorders. After primary education the child could not go for further education since there were no such schools and this was perceived to be something that would increase the burden of care for parents in the future. One mother of a child with autism and seizure disorder said,

"I can foresee a future problem about education because when they grow older they are brought back home. Now how does the child stay home 24 hours when they are brought back!"... They no longer attend children when they reach 14 or 15, and there is no where to take these children". {ID10504JA}

With regard to health care services, parents were generally satisfied with services at the MNH psychiatric Unit, as expressed by the mother of a child with epilepsy and learning disability:

"The service she (the child) receives is really good, they do their best at the hospital...I am satisfied with this service." {ID10503JA}

However parents complained about: long waiting periods before they were seen by the doctor, spending too little time with the doctor, out of stock medications, lack of speech

therapist in the country, and lack of proper facilities such as the toilets. A mother of a child with seizure disorder and mental retardation complained:

> *"With hospital services, for example it is very far where I come from, you can arrive there (at the clinic) may be at 8:00 AM. From that time you may see the doctor may be at 11:00 AM. So it really becomes a problem because you sometimes leave home before the child had tea. Now you stay there with the child until 11:00 AM, it becomes a problem...I would like that if we just get there we should be seen early, then we leave. Sometimes you may stay there for a long time and because of hunger the child starts troubling you, it really is a problem. ... I was not happy with that thing, the toilet, it should have been the floor toilet (choo cha chini) (as opposed to sitting on type) the normal one, that would have been good".* {ID10430JAi}

A mother of a child with ADHD and seizure disorder commented:

> *"And when we come to the hospital there should be a long time for the doctor to ask you questions and be satisfied from the three months (last clinic date) and see what should be done...now the child has reached the stage to start learning. And to learn with that condition he needs an expert who knows children's problems so that he can learn well and be good. Now in this country of ours especially even in a hospital like Muhimbili there are no experts who can teach children how to talk called speech therapists. For that reason it's a problem, it's a problem because I just teach him in a normal way."*{ID10506JA}

4.4.2 Stigma

In this study living with mentally ill children was found to be associated with stigma. Parents were troubled by the mentally ill child being mistreated, discriminated against and segregated in the community. Sometimes the child was told words that made him/her feel bad. Parents were laughed at and told bad things about the child.

The child was mistreated by people in various ways. Sometimes he/she was labelled and made fun of at school, considered to be useless and even rejected by the parent because of the disability. A mother of a child with epilepsy and learning disorder explained:

> *"...My child is in primary school, she goes to school and comes back complaining that she is being called a crazy person (tahira). She really feels bad (anajisikia vibaya) and when she comes to the hospital she tells her doctors..."* {ID10503JA}

Parents were sometimes held responsible for the child's behaviour. They were thought to be spoiling the child by not being strict enough when the child was behaving strangely. Furthermore, some parents were told they had caused the child to become mentally ill as a means of getting rich and becoming successful in life. A father of a child with ADHD and mental retardation explained with sadness:

> *"Let me add to what I have said. It is true, according to the prevailing situation when people see those children the majority of them say we have caused them to become sick as way of getting money and becoming successful in life."* {F10508JAi}

At one occasion this father had a terrible confrontation with a woman (a neighbour) when his child destroyed her radio:

> *"That woman stood in front of the police officer and said, 'I never asked him (the father) to bear a crazy child. What I want is my radio...'"* {F10508JAi}

4.4.3 Caring Task (Burden) in the Family

For most families the burden of caring for the mentally ill child was found to be mainly borne by the mother. Mothers complained about the role that fathers played in everyday care of the child. They expressed that some fathers were only supporting the child financially and others did not care at all. The grandmother who was taking care of the child with seizure disorder and mental retardation whose mother was dead commented:

> *"...Now the burden of care is upon me. The father doesn't love her (the child) very much. Sometimes you may tell him that you have a problem with the child and he will tell you to just wait. Now that's just like totally not being involved in the care of the child."* {ID10502JA}

Mothers were generally not satisfied with the fathers' involvement in the care of the child as expressed by the mother of a child with autism and seizure disorder:

> *"...since it's the two of us who brought the child on earth cooperation is important, even if she has a disability she belongs to us. You can't run away from her, what will you do? Will you hit her with a club? What will you do? It's impossible, so you have to accept the fact that this is my child, who does not just belong to the mother."* {ID10504JA}

The other thing that was revealed in this study was that two mothers were actually left by their husbands. One mother of a child with seizure disorder and mental retardation was left because the father claimed he could never have a mentally ill child since there was no

history of mental illness in his clan. The other mother of a child with epilepsy and learning disability was forsaken by her husband because she gave birth to two children with the same mental illness.

4.4.4 Ignorance about Mental Disorders in Children

Ignorance about mental disorders was found to be common in the community. The child with mental illness and parents suffered stigma and mistreatment out of ignorance. Parents explained that some people were surprised and others laughed at the child when they saw him/her showing abnormal behaviour, as explained by the mother of a child with autism and seizure disorder:

> *"The public should understand these children. If you go with her to some place everybody is surprised, you know, even the child wonders why they get surprised at her. They really don't understand and I don't know how. They think it's something that does not exist..."* {ID10504JA}

4.4.5 Social Support

The majority of parents in this study expressed their concern about not receiving the needed support from neighbours and people in the community. Some people could not even give help when they found the child in a critical condition like having seizures. One mother of a child with autism complained that people sitting in the commuter bus would not help her by giving her a seat when she was standing with the child on her back.

> *"I have to carry the child from home, board the bus ...somebody in the bus may see you carrying the child while you are standing without even letting you sit."* {F10424JAi}

In order to avoid conflicts with neighbours, parents tried to control the child's environment depending on the severity of his/her behaviour. Sometimes they asked neighbours not to leave their utensils outside or doors open so the child would not tamper with their properties or go into their houses. It was not always easy to get this support from neighbours, as explained by the father of a child with ADHD and mental retardation:

> *"So I asked her (the neighbour) to close the door of her house when she went out to talk with other women so that my child could not go in and open... she answered that she had freedom and was paying for the house."* {F10508JAi}

4.4.6 Social Life

The social life of parents was found to be disrupted by the presence of a mentally ill child in the family. Sometimes parents avoided going with the child to social gatherings such as church because of the child's disturbing behaviour. Parents also experienced conflicts in the community and sometimes were even accused when the child destroyed somebody's property. This created tension and resulted in lack of peace especially with people like neighbours. Sometimes the love life of a mother was affected for reasons related to having a mentally ill child. One woman of a child with ADHD and seizure disorder who avoided having another child with a new partner in case she was overwhelmed by caring responsibilities explained:

> *"...Who knows? He (the partner) went to see his friends there... they said to him, "How can you stay with a woman and just take care of her child? After all she (the child) is crazy, and so on. She doesn't want to have a child with you, I don't know what!" Then that person (the partner) ran away from me, we were staying in the same room.*" {ID10502JA}

4.5 Safety Issues

It was noted that the mentally ill children were vulnerable and suffered mistreatment from people by being beaten, pushed, and burned. The child who could not speak seemed to be more vulnerable since he/she could not mention a person who was responsible for the cruel action when parents wanted to know. A woman of a child with ADHD and seizure disorder said,

> *"...may be she (the child) goes and touches somebody's property, or in doing so she makes somebody's water dirty. The owner will come out with anger and will beat the child with a fist in the head or pinch her knowing that the child will not say. The child comes back crying and when you ask her she doesn't understand you."* {F10424JAiii}

These children were also reported to be at risk of being physically and sexually abused such as being burned or raped as explained by a woman of a child with seizure disorder and mental retardation:

> *"...for example, one day I left my child with the house girl. She dared to take the spoon that she was using for frying and applied it on the child's skin. When I came back I found the child with scars wounds on the body.....there is another child in the neighbourhood who is also disabled. That day her mother went to the*

field in the morning leaving the child still asleep with instructions to follow her to the field. When that child got out to follow her mother there was a man nearby who called her into his house and did to her a very bad thing (shedding tears), just last week...he raped her. We really need to be very close to these children. The issue of being raped makes us to be with them so that they don't suffer such actions" {F10424JAiv}

4.6 Economic Challenges

Apart from psychological, emotional, and social challenges parents were experiencing, they also expressed several economic problems that either were a result of living with a mentally ill child or hindered provision of proper care to him/her. Three major themes emerged that explained how living with a mentally ill child interfered with economic activities of the families. These were: existing poverty, interference with various income generating activities, and extra expenditure due to the illness.

4.6.1 Poverty

Poverty was revealed by parents as being responsible for their inability to meet certain important needs of the mentally ill child. Most parents were home mothers or house wives (mama wa nyumbani) who did not have any means of earning income and depended solely on their partners; those who didn't have partners expected to get help from other people. This was a problem if they could not get the help they needed. Many of them (including fathers) could not manage buying drugs for their children when they did not receive them at the hospital. They also could not afford bus fare to attend the clinic with their children on the day of their appointment. A mother of a child with autism explained:

"...From here you may go to the hospital's drug unit...you may find that you get only one type of drugs while you have a prescription of two or three drugs... If you go to a (private) pharmacy you find that it's 500 shillings (US$ 0.36) per pill. Now with our income in this situation; house rent, water bills, everything, transport charges, you may reach a point where – I once spoke with my mouth, and may God forgive me, that instead of giving me these problems he should have taken him (the child), I reached that point..." {F10508JAi}

Sometimes parents were compelled to borrow money for bus fare from their neighbours or other people in order to attend the clinic as expressed by a mother of a child with autism:

"The one I depend on is him (the husband). Now there comes a time when he doesn't have (the money). Since we have house tenants I can tell them to give me the money like I did on the previous day when I came (to the hospital), I had 1000 T-shillings (US$0.71) which I borrowed from a house tenant". {F10424JAi}

4.6.2 Interference with Various Activities

Daily life and activities of parents in this study were very much affected by the presence a mentally ill child. Much time was spent looking after the child and as a result they were not able to do other important activities such as business. Income generation in the family was affected and this further escalated family's poverty as explained by a mother of a child with seizure disorder and mental retardation:

"Care responsibilities for such children are very cumbersome; you need to stay with them for a very long time so that you watch over them from morning till evening. Your activities will be limited only to the home environment; you can't go out for activities to earn a living apart from being home." {F10424JAiv}

For couples, interference with various activities by the child did not only affect one parent who remained home to look after the child, but it was a concern for the other in one way or another. A father of a child with mental retardation and epilepsy said,

"Sometimes I {the father) have to go even to fetch water because she {the mother} can't leave the child to go and fetch water. So I have to stop income generating activities in order to go and fetch water, if we run out of it. When I am back then I can rush to Kariakoo (market) to get certain commodities or to any other place. Therefore my performance has not been good because that child has been a burden in the family". {F10508JAv}

Some parents had to stop doing petty businesses due to high demand of care giving responsibilities of the child and having no one to stay with the child during business time. This negatively affected family income generation, and increased poor living conditions as explained by a mother of a child with autism and seizure disorder:

"I used to sell buns and pillows of cotton from Urafiki (factory) in the streets, you see. But now there is nothing I do because as I am telling you, if you leave him (the child) alone he roams about and as a result, as I have told you, we picked him at the police station where he slept..., the obvious challenge is just as I am saying, I don't have anybody to stay with the child... so when you are busy with

business you may come back and find that the child is not there. Where will you go to look for him?". [ID10430JAii}

4.6.3 Extra Expenditures

Family economy was further affected due to the child's illness-related extra expenses that parents incurred. These illness-related extra expenditures included hospital-related services such as bus fair to attend the clinics, and buying drugs. Going to see traditional healers and witch doctors was another reason for extra costs for parents, as expressed by a mother of a child with epilepsy and mental retardation:

> *"I struggled to see traditional healers, I struggled very much; I started keeping pigs solely for the purpose of meeting the child's needs. I just kept on providing care by selling pigs at 80,000 shillings (US$57) and taking the money to traditional healers, but up to this time I say traditional healers are useless...."* {F10508JAiv}

Moreover, some psychiatric drugs induce hunger; therefore some extra expenses were incurred by parents due to the child's increased food intake. A mother of a child with seizure disorder and mental retardation complained:

> *"I don't know if he (the child) has worms because all the time he wants to eat. There was a time I thought he had worms and took him twice for check up but it was negative. But now I am telling you (today) at 7.00 AM I woke up and bought him 4 buns, a piece of fried cassava and one cup of a drink. The moment you (the researcher} called me his sister was preparing tea, ehe! (amazed), I told them to go and buy buns so that each one could get 3 of them before I left. There you should not only consider yourselves but you have to include him (the child). As a result I ate two buns and he ate three, leave alone those he ate in the morning..."* {ID10430JAii}

Other extra expenses incurred were school-related such as travel expenses spent in search for the right school for the child. Child's destructive behaviour due to the illness sometimes caused parents to pay for property that the child had destroyed.

4.7 Measures to Address Challenges

Parents expressed various ways they used in order to address the challenges they were facing by living with a mentally ill child. A variety of coping mechanisms were employed in different situations depending on what seemed to be helpful to the parents.

4.7.1 Seeking Professional Help

Parents were aware of the importance of professional assistance for the sick child and were determined to continue attending the clinic. Most of them didn't understand the nature of the disorders the child was suffering from although they knew the importance of medication for controlling behaviour. They could not even mention the name of the disorder the child was suffering from. One mother whose child is afflicted with autism and seizure disorder expressed:

> *"It is the hospital, it's the hospital that has helped her (the child) to be honest. If it was not for the hospital her condition would have been worse. I have done everything I could; I have not stopped going to the hospital since she begun having the problem. It is 11 years now she is on medication..."* {ID10504JA}

4.7.2 Seeking Spiritual Help

Spiritual help was found to be helpful for most caregivers of children with mental disorders. Two major ways through which they received spiritual help were through religion and seeing a traditional healer. Religious help was obtained by seeing religious leaders, attending gospel crusades or church in order to be prayed for, and by caregivers themselves fasting and praying to God. A mother of a child with ADHD and seizure disorder explained:

> *"...what I really do apart from receiving treatment from the hospital is to fervently pray to God, yah. And I believe that every time I pray to God I succeed very much. I do that very much (laughs)"* {ID10506JA}

Caregivers sought traditional healers for the purpose of treating the child and revealing the cause of illness as expressed by a mother of a child with ADHD and seizure disorder:

> *"...when she (the child) got sick she became unconscious, could no longer sit, or speak, or see, she became just like a statue. When I took her to traditional treatment she became better."* {ID10501JAi}

Another mother of a child with autism and seizure disorder said,

> *"...I thought my colleague (a co-wife) did something bad to my child, but she didn't do that it was just God. ...yes, the witch doctors told me that she didn't do anything but it was just God and they told me to take her (the child) to the hospital, that's why I came here.* {ID10430JAii}

4.7.3 Other Measures

In order to deal with the challenges of caring for the mentally ill child, there were other measures that other parents took. These included training the child to do what she/he could not do such as toilet training and speaking, involving other family members such as siblings in the care of the child, and seeking information about the child's disorder from sources like the internet. Due to the nature of some disorders and the behaviour displayed by the child some caregivers tried to control the child's environment. Parents who had children with seizure disorders tried to keep their children from being close to dangers such as fire, pits, and climbing trees. When it was possible, the caregiver tried to rent a house in which the family could stay alone without interference by other people so as to avoid problems that could be caused by the behaviour of the child. They also listened to the advice from people who had a success story about living with a mentally ill child.

4.7.4 Parents' need to have someone to talk to

With all these challenges parents expressed a need to have somebody to speak to. When they did have somebody to talk to they felt relieved. The focus group discussions and in-depth interviews served as psychological relief for them because they had the opportunity for somebody to listen to them. After a focus group discussion one respondent who had a child with autism gave a comment which was supported by the rest:

> *"Just having somebody listen to you like this makes you feel better".* {FN10508JA}

This was also the case at the end of an in-depth interview with another respondent whose child is afflicted with ADHD and seizure disorder:

> *"Thank you very much Mr. Joel (the researcher), I am also happy because I have at least had someone to listen to me, I have never had such opportunity...".* {ID10506JA}

5.0 Chapter Five: Discussion

The purpose of this study was to explore psychological, social and economic challenges of living with children who have mental disorders, and to learn various ways caregivers (parents, in this case) used to address or deal with these challenges. The findings of the study revealed various psychological, social and economic challenges that parents experienced in living with a mentally ill child. Some of the key themes found in the peer review literature (family stigma; family/caregiver burden; information exchange and referral; family stress, coping, and adaptation; family support; crisis response; and family psycho-education) with respect to experiences and needs of families of individuals with mental illness [15] also emerged in this study.

The results of this study showed that families living with mentally ill children went through similar adaptations described in the eco-cultural model [10] which guided this study. Although this model was earlier used for people with intellectual disability, it was found to be very relevant when it was applied to children with mental disorders in this study. Just as the model asserts, caregivers in this study were affected at individual, family, and society levels. All the accommodation variables described in the model (indexed as I to X) were reflected in the findings of this study.

Therefore, the universality of the eco-cultural model which was developed in the United States of America was revealed in this study just as it was suggested by its author. All accommodation variables described in this model that affect families living with a person with disability were present in the very different situation in Tanzania. Therefore it is true that the model can be applied to a range of chronically disabling conditions and that the consequences of living with a child with mental disability are similar in disparate environments.

5.1 Psychological and Emotional Challenges

A number of psychological and emotional challenges were experienced by parents. They were stressed by living with a mentally ill child and considered it an unavoidable situation since it was a big burden for them and developed worries about the future. These concerns are similar to what was found in the United States [22] where mothers of children with serious mental illness had concerns about the future of their children due to

the child's special needs, erratic or worsening of behaviour and long term consequences. Similar stressful experiences were also reported by parents of children with autism [34], and intellectual disability [35, 36].

Parents in this study experienced feelings of sadness, and inner pain or bitterness due to disturbing behaviour of the children, extra caring responsibilities, family and social problems caused by the child, and people's negative perception about families having a mentally ill child. In a previous study in the United States [22], emotional strain was expressed differently by mothers of children with serious mental illness as having fears, frustrations, and guilt in dealing with the child's behaviour and attitude.

Communication problem with their children caused by inability to speak was another source of psychological and emotional distress for parents. The situation was further aggravated by lack of speech therapists in the country. Parents of children with Asperger syndrome (autistic disorder)/nonverbal learning disorder in the United States [37] had similar communication problem concerns. Mothers of children with developmental disabilities and challenging behaviour in United Kingdom [38] also complained about lack of speech and language therapists. Therefore lack of speech and language therapists is a problem experienced not only in a low income country but also in high income countries.

The above challenges were experienced as families were going through adaptive processes in domestic tasks and core workload for the family, caring tasks, and socialization, described in the eco-cultural model as accommodation variables IV, V, and VI respectively [10]. These findings did not differ very much from what was found out in the United States where externalized and internalized behavioural problems in children with mental disorders were associated with parents' distress (having fear, worry, or guilt related to their child's mental health problem) [28]. Parents in this study also experienced distress associated with externalized and internalized behavioural problems in their children though these terms were not directly applied.

Provision of psychological and emotional support for caregivers of mentally ill children should be considered in order for them to have some relief from distress. One of the ways to achieve this is creating the environment for health professionals to be working closely

with caregivers to effectively treat their children's mental illness [6]. Working closely with caregivers can provide an opportunity for them to talk about their everyday challenges. Provision of information on how to manage the child can help parents to provide proper care and this can be done through support materials such as booklets, which was found to be very helpful to parents in another study [36]. Nurses can also play a role in providing social and emotional support by talking and being empathic to parents of children with mental disorders [22]. Relevant information for child care should be provided to parents in order to avoid dissatisfaction problems with health care services like the experience of mothers of children and young people with developmental disabilities and challenging behaviour in the United Kingdom [39] .

Therefore mental health services for children need to be modified in such a way that they should facilitate caregivers to be working closely with mental health professionals. Research evidence shows that this will facilitate recovery of families with mentally ill children from crises and coping with the situation [1]. But modifications to achieve such services require human and financial resources, which is another challenge by itself for a low income country like Tanzania. Mental health services for children with mental disorders should be a priority

5.2 Social Challenges

In this study, parents described social challenges they experienced by living with a mentally ill child. These were inadequate social services, stigma, burden of caring task, lack of public awareness of mental illness, lack of social support, and problems with social life.

Challenges of inadequate social services were basically about not having enough special schools and care centres for mentally ill children. Parents struggled to get schools for their children so that they could have the opportunity for education. Their children were often rejected at few available schools. This was also the case in the United Kingdom [39] where children with developmental disabilities and challenging behaviours suffered exclusion from schools. However the case was different from another study [34] in the same country (United Kingdom) where parents reported high proportion of their autistic children living in residential provisions including weekly boarding at the school. This entails the need for the government, private sector and non-governmental organizations to

consider school expansion programs for disabled people like children with mental disorders.

Parents in this study were actually advocating for boarding schools for their children so that they could have time to do other necessary activities in order to support the whole family. However, this is in contradiction with the existing evidence that home based treatment program for children and adolescents with mental disorders appears to be an effective and sustainable strategy for meeting their mental health needs [2]. Since the success of home based care interventions requires compliance of patient and parents, and support from highly skilled therapists [2], provision of professional support to such parents in their home environment could alleviate the burden of care. Respite services, which no parent reported receiving, might be helpful in this case since it is one of the perceived needs of families in dealing with challenging behaviour of children [40]. Other interventions such as establishing day care centres for these children could bring relief to caregivers as this would save much time spent on looking after them and in turn this precious time could be used for other productive activities. Systems such as hospitals and schools need to connect in evidence based practice [4].

Parents reported being stigmatized both within and outside the family. This did not differ from other studies in which stigma was experienced by caregivers and family members due to having a mentally ill person in the family [14, 24]. Just as it was explained in the world report [3], stigma was experienced at all levels of society. Public awareness programs about children with mental disorders at all levels of society is necessary in order to reduce stigma. People in society need to understand that mental disorders are present in children just as they are with other age groups.

Although parents were generally satisfied with health care services at the MNH Psychiatric Unit, they reported some serious problems with services organization, facilities and human resource. Similar problems were previously reported in the United Kingdom by mothers of children with developmental disabilities and challenging behaviour who were not satisfied with health care services. They complained of delays in service provisions, having to fight for or chase services, difficulty contacting services, poor coordination and high staff turnover. Other problems were lack of speech and language therapy, insufficient respite services, and poor information provision [39].

These mothers had more access to health information (books, internet and attending courses) as compared to parents in this study. This could have affected how the two groups perceived health care services. However, proper planning and organization of psychiatric services is important, whether one has more or less resources and this can contribute to service satisfaction by users.

In order to avoid long waiting periods by caregivers at the clinic before they are seen by doctors, there is a need for the staff at the clinic to consider reorganizing services provided. On the day of clinic caregivers usually attend health education sessions before they are seen by doctors. These sessions are run by nurses and they need to be client-centred and caregivers should be involved in the choice of topics to be discussed so that their needs can be addressed. According to the management team of the psychiatric unit there is shortage of human resources with all cadres. But mental health services can be improved through good organization of the clinic which can also make consumers of health care services enjoy the services. Improving facilities such as toilets needs to be to be done for services to be user friendly.

There is a serious need in our country to train people in speech therapy due to a great number of children who need the service in order to learn how to communicate. Sending people for studies to specialize in this area will be an important step that will serve this purpose in the future.

In this study mothers expressed being main bearers of the burden of care for mentally ill children. They were not satisfied with the father's role in the task of caring for the child although one father talked about carrying water and other things because the mother could not leave the child. But more research should be done on this to reach a more reliable conclusion. However it was obvious that most women who were married depended on their husbands financially. Their husbands were expected to go out to search for money. This could have resulted in the husbands' lesser participation in the direct care of the child and the mother (who mostly remained at home with the child) taking a bigger role. Furthermore, culture could have explained this phenomenon since traditionally mothers are the main care takers of children in Tanzanian context, and fathers rather play an indirect role, although this could be gradually changing now.

Lack of social support, social life challenges, and safety issues about the child were experienced by parents living with mentally ill children in this study. Parents did not receive support from neighbours and other people when they needed it even during the illness crisis of the child. Some mothers were left by their partners (lovers) and children were maltreated and even at risk of being raped. Similar previous experiences were revealed in United States [37] where parents had concerns about the child's adulthood and independent life. They had fears about the future dreams and career of the child, risk of the child being victimized (being bullied, teased; physical or sexual abuse), not being able to have a loving relationship outside the family, and not being accepted in the social life. A recent study in United States [4] has shown that child maltreatment occurs in all regions (states). These issues can be well addressed by public awareness programs. Promoting public awareness about mental illness in children can improve social support, social life and safety for caregivers and their children.

Various social adjustments were made by parents in order to live with the mentally ill child in the family. Here we see access to health or educational services, home and community safety and convenience, socialization, marital role relationship, social support, and father's role as social accommodations (variables II, III, VI, VII, VIII and IX respectively) of the eco-cultural model [10] which were made by families in this study.

5.3 Economic Challenges

The economic challenges that caregivers experienced in this study were mainly due to poverty, child care interfering with various activities such as business, and extra expenses associated with the illness. Similar poverty challenges were experienced by families of a child with intellectual disability in United Kingdom [41] when they were compared to families without such a child. Child care interfering with various activities corresponds with a study Australia [17] where caregivers experienced disruption to achieve their own goals/dreams.

Challenges due to poverty could be addressed by providing financial assistance, food and clothing [23]. But the best way to help these caregivers is to facilitate acquisition of adequate time for them to do their own income generating activities. This can be achieved by providing respite services and establishing day care centres for their ill

children so that they do not spent so much time looking after them at home, and by providing loans and perhaps training them to start some form of business. These are actually some of the ideas they suggested during the interviews, and the government, private sector, and NGOs could investigate the possibility of providing such economic support.

Family subsistence and financial base was also affected by the presence of a mentally ill child in the family. This corresponds with the first (I) accommodation variable of the eco-cultural model [10].

5.4 Measures to address challenges

Parents took various measures in order to deal with challenges they faced in living with the mentally ill child. They sought professional assistance from the hospital, spiritual help from their religious leaders and traditional healers, and involved other family members in child care. They also trained the child to do self-care, sought information from the internet, received advice from experienced parents, and tried to control the child's environment. These measures correspond with accommodation variables number III, V, and X (home and community safety and convenience, caring tasks, and sources of information and advice, respectively) of the eco-cultural model [10].

5.5 Limitations

The results of this study can not be generalized to the entire population since it only involved parents attending Muhimbili National Hospital which is located in the city of Dar es Salaam. All respondents except one came from within the city, and findings may have been different if respondents came from rural areas. Since convenience sampling was used and only one fifth of the respondents were fathers, the findings may be mainly representative of mothers' experience.

6.0 Chapter Six: Recommendations

Parents living with a child who is mentally ill need to work closely with health professionals so that they receive the support they need. Psychiatric clinics for these parents and their children should be designed in ways that they are user friendly. During the clinic hours parents should at least be given enough time to explain the progress of the child and other needs. There is a need to explore in detail challenges caregivers experience with mental health services because of concerns raised in this study which were not explored further.

Proper programs should be put in place to monitor the progress of parents and children and resolve any issues that may arise. This will provide the opportunity for parents to get the support they need in caring for mentally ill children. It is also high time to start training speech therapists in our country because of the need expressed by parents. In addition, much of the burden experienced by families living with mentally ill children could be alleviated by provision of respite care.

Just as it is with normal children, children with mental disorders and other disabilities should be given the opportunity to receive education. More special schools for such children should be built so that they are easily accessible. The government, private sector and non-governmental organizations can play a big role in achieving this.

Financial institutions should also consider giving small loans to parents so that they can start businesses that will not interfere with caring responsibilities.

Further research to investigate how the burden of care is shared among family members is needed as well. This could help in finding ways to help families balance caring tasks and avoid stresses that may arise from being overburdened with the caring tasks.

7.0 Chapter Seven: Conclusion

Caregivers of children with mental disorders experienced many challenges. These included psychological and emotional challenges such as stress, worries, sadness, grief, and bitterness. They also experience social problems such as inadequate special school for their ill children, stigma and lack of social support. Safety issues for their children and disruption in their social life are other challenges they face. Poverty and child care tasks interfered with their activities which increased the economic challenges they already had. Professional assistance, public awareness of mental illnesses in children, social and financial support by the government, private sector and NGOs are important in addressing these challenges.

Mental health nurses need to provide relevant care to clients and their families. Provision of psychosocial support to parents living with mentally ill children is necessary in order to meet their needs. Mental health nurses can accomplish this by offering counselling service to parents in order to address everyday challenges of care. Since most of mental disorders suffered by children are chronic, counselling sessions should be conducted on a regular basis (for instance twice or thrice a year) for continued support. Mental health nurses should also play a crucial role during clinic visits by providing support information to parents through health education, IEC materials, and proper organization of services at the clinic. Furthermore, mental health nurses need to assess the home environment of families living with mentally ill children and provide the needed support. To accomplish this, mental health nurses need to have adequate knowledge of mental disorders in children and how to support families.

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