COLLEGE OF MEDICINE

Assessing the Psychological, Social and Economic Effects of Caregiving on Caregiver of Mentally Ill Older Patients Accessing Services at St John of God Hospital, Mzuzu

By

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(BSc. Mental Health Nursing)

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DECLARATION

I, **FYNESS CHIKOPA,** declare that this dissertation is my work except where acknowledgements have been made and that it has not been or will not be presented to any other university for a similar or any other degree award.

Signature :

Date : 31st December 2020

CERTIFICATE OF APPROVAL

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DEDICATION

I dedicate this dissertation to my daughter, Tracy, who did not receive the motherly care the time she needed it most since I was away from home due to studies.

ABSTRACT

Introduction: Currently, in Malawi, there is scarcity of data on studies conducted on the psychological, social and economic effects of caregiving on caregivers of mentally challenged patients, who are also older persons above 60 years of age. Mentally challenged refers to all elderly suffering from any type of mental illness. A number of caregivers are affected psychologically, socially and economically due to their caregiving role, which affects quality of care, while little is done in managing these effects. Therefore, the study sought to identify psychological, social and economic challenges that affect the care-givers to inform the development of appropriate strategies.

Objectives: The study sought to describe how the psychosocial and economic effects of caregiving on caregivers of mentally ill older patients affects the quality of care of mentally ill older patients and documenting recommendations to address psychosocial and economic effects of caregiving on caregivers of mentally ill older patients.

Methods: The study employed a cross-sectional design and qualitative research method. In-depth interviews were used to gather information from caregivers of older mentally ill patients and health workers who assist these elderly clients at St John of God Mental Health Clinic. A semi-structured interview guide was used by the researcher to acquire information from the respondents. A total of 22 people participated in the study; 14 caregivers and 8 health workers. All the participants were above 18 years of age. The caregivers were 14; 8 females and 6 males, respectively. The health workers were 8; 3 clinicians and 5 nurses. Data collection was done from 22nd October to 20th November, 2020. Data was analysed using thematic analysis. Ethical clearance to conduct the study was obtained from the College of Medicine Research Ethical Committee (COMREC).

Results: Female caregivers were more depressed than male caregivers. The caregivers experienced stigma and discrimination and were isolated in their communities because they cared for the older mentally challenged patients. Caregivers were also faced with financial problems, which affected the quality of health care provided to the patient by the caregivers since the caregivers were affected. Recommendations were made to ensure caregivers provided quality care, including provision of support to the caregivers by the relatives; the health workers to provide mental health education to prevent stigma and discrimination in the community and the government to ensure that mental health service is available in all their health facilities**.**

Conclusion: Caregivers face social, psychological and economic problems during their provision of care to mentally ill older patients. There is need to provide comprehensive management of caregivers in order to alleviate these problems for the patient to receive quality care.

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ACRONYMS AND ABBREVIATIONS

COMREC : College of Medicine Research Ethics Committee

SES : Social Economic Status

PI : Principal Investigator

WHO : World Health Organization

SJOG : St John of God

CHAM : Christian Hospitals Association of Malawi

CHAPTER 1: INTRODUCTION AND OBJECTIVES OF THE STUDY

1.1 Background

The world population of aged persons is increasing in every country [1]. In Africa, the number of the aged population is expected to grow faster. In 2005, there were 34 million people aged 60 and above, and the number is projected to increase to over 67 million by 2030 [2]. The population aged 60 years above is projected to increase between 2017 and 2050 from 69 million to 226 million [1, 3]. In Malawi, population of older people aged 60 years and above is 891,805 [3, 4]. Studies have shown that decline in cognitive function starts from the age of 50 and accelerates after the age of 65years [5], and cognitive decline increases with age. This has made family members to provide support to the older persons, mostly with activities of daily living. Those who provide care are called caregivers. A caregiver is someone who provides more than 6 months of care and regularly responsible for taking care of patients more than other immediate or non-immediate family relative rather than a health professional [6]. Caregivers can be informal or formal; formal caregivers are paid for providing the care, while informal caregivers are not paid for the services they render.

Caregivers play a great role in the older people's life as they help them in a number of tasks. Studies conducted in America found that 2.7 to 36.1 million informal care-givers provide care to older disabled adults [7]. The caregivers are potentially at increased risk for adverse effects on their well-being and their every aspect of life including their health, their quality of life, relationship and economic security [7]. However, individual consequences for individual caregivers vary depending on the individual and contextual characteristics [8].

Currently, studies conducted by WHO found 35.7% - 42.5% caregiver burden globally [62] and in Malawi, there is scarcity of data on studies conducted on the psychological, social and economic effects of caregiving on the caregivers of mentally ill patients who are also older persons above 60 years of age. A number of caregivers are affected psychologically, socially and economically due to their role in caregiving, which can affect the quality of care and little is done in managing these effects. Therefore, this study sought to identify psychological, social and economic challenges that affect the care-givers, which can inform the development of appropriate strategies.

1.2 Definition of Operating Terms

Old age is defined as the advanced years of life, especially in human life, often thought of as being those years after 60 or 65 and characterized by a marked decline in strength and vigour [14].

Stigma is defined as stereotypes or negative views attributed to a person or a group of people when their characteristics and behaviours are viewed as different from or inferior to social norms [15].

A caregiver is someone who provides more than 6 months of care and regularly responsible for taking care of patients more than other immediate or non –immediate family relative rather than a health professional [6].

1.3 Statement of the Problem

A number of studies have been done to assess the psychological, social and economic challenges associated with mental health, focusing on mentally challenged patients as an affected party. In Iran, 50% of caregivers reported financial problems and psychological distress due to the role of caregiving [63]. However, in Malawi there is scarcity of data of the caregiving role on caregivers of older mentally ill patients. Despite caregivers spending much of their time with the patient, little is known about how caregivers' role of caregiving affects them psychologically, socially and economically. The caring for mentally challenged older patients brings more burden to the caregiver as old age and mental illness are challenging situations in their own rights. This affects the quality of care provided to the patients. However, caregivers are not assessed comprehensively when they visit the hospital with their patients by the health worker to detect any caregivers' burden on health. There is need to assess the impact of caregiving on caregivers, focussing on those who look after mentally challenged older persons to inform the development of appropriate strategies.

1.4 Literature

Literature review was conducted to locate the gap in the body of knowledge conducted to convey to the reader what is currently known regarding the topic. A number of articles were reviewed from the databases such as Google Scholar, PubMed, Pyschnet and general searches. I used the following key-words: caregiving, caregiver, psychological impact, social impact, economic impact and older patients. Articles were filtered depending on the years they were published, such as being more than 10 years, not relevant to the topic, and if the only available is the abstracts.

1.4.1 Effects of Caregiving On Caregivers

Caregiving affects caregivers psychologically, socially and economically. A systematic review done in older patients with dementia revealed that care- giving has an impact on the quality of relationship between the caregiver and the care recipient [13]. The caregiving role in older clients who are mentally challenged will pose a great impact on the caregiver. A study conducted in rural Ghana found that care-givers of mentally challenged patients face psychological, social and economic impact [29]. This places a great burden on caregivers of mentally challenged older patients, since the old age on its own is a burden and being mentally challenged adds to the prevailing challenge of age, thereby adding more burden to the caregivers' services.

1.4.1.1 Demographic Factors

Social demographic factors of caregivers also play an important role in caregiving. Studies conducted in low- and middle-income countries found that prevalence of caregiving was higher in women than men and in older age group ranging from 60-69 years [33]. Another study conducted in South Africa was in agreement with the previous study that demographic factors like age, educational level and level of income of the caregiver had an impact on caregiving [35]. However, another study conducted in Malaysia on caregivers caring for clients with dementia found that there is no relationship between demographic factors and care-givers burden [34]. Therefore, the study will help to find out if there is relationship between demographic factors and caregiver burden.

1.4.1.2 Psychological Effects

Caregivers may be affected psychologically in their role of caregiving in many ways such as being stressed, depressed and having anxiety. Psychologically, the caregiver is stressed and may have symptoms of anxiety and depression [10]. The psychological impact can affect the caregiver's quality of life.

Stress

A study conducted in the United States of America found that caregivers experience stress in their role of caregiving [19]. The study also revealed that new care-givers experience greater stress than those who are old in the role of caregiving as they may struggle to cope with their new responsibility. Findings of a study conducted in Ghana revealed that stress was more common in caregivers, both family caregivers and psychiatric nurses which may impact their physical health [22]. A study conducted in Malawi found that 41.2% caregivers who were mothers of children with disability were distressed due to lack of psychological support and increased perceived burden of care [20]. Another study conducted in Beijing found that caregivers who were patients' parents were extremely worried about the future life of patients [30).

The findings of these studies show that caregivers experience stress when caring for the patients. However, the methodologies used by the studies from Ghana and Malawi were different; qualitative and quantitative methods were used respectively. The setting of the studies was also different. One was hospital based while the other was community- based. The present study findings show that in Malawi, a study was done on caregivers on patients with disabilities only, while the findings are caregivers with dual diagnosis patients adding on the already caregiver burden present.

Depression

A study conducted in Pakistan compared depression in caregivers and non-caregivers and the results showed that the caregiver's role of care-giving was putting them more at risk of depression [21]. Caregivers are distressed as they are providing care to their patients. A study conducted in Brazil indicated that depressive symptoms are an important source of distress for caregivers [23]. The caregivers have changes in their moods, activities of daily living and behaviour. This may affect the care recipient in the quality of care to be provided.

All the studies from Pakistan and Brazil used quantitative study designs and had interviewed 2 groups each; the control and non-control group. Again, all the studies from Pakistan and Brazil took place at a hospital setting. The studies show that caregivers are at higher risk of depression than non-caregivers. However, the present study findings will provide a vast experience of caregivers' burden since the researcher will be able to assess the care-givers burden.

Anxiety

Anxiety is state of having fear. A study conducted in Korea revealed that caregivers had anxiety because of losing self-identity as they are caring for the patient [24]. This may be so because the caregiver may not be able to do the things they are used to, due to their caregiving role. Similarly, a study conducted in Spain found that caregivers of older adults were having anxiety [25]. This was characterized by self-blame and denial. The same study also found that the prevalence of anxiety was 21.4% in caregivers of patients with stroke and 43.6% in caregivers of a patients with dementia [25].

In both the above studies, the participants were the caregivers of older patients. However, they used different study methods; qualitative and quantitative methods. The study from Korea had all participants as female caregivers. The findings of the studies found that anxiety was high in caregivers. All the studies involved the caregivers of older adults. The present study findings will be rich in caregiver burden of care since the caregiver is caring for elderly, which brings caregiver burden and has added another cause of burden, which is mental illness. The caregiver will therefore have a true reflection of caregiver burden. Also, the present study findings combined both sexes of caregivers, which will give a representation of what is on the ground as caregivers are of all genders.

1.4.1.3 Economic Effects

Caregivers face financial difficulties in their role of caregiving. For a care-giver to provide quality care to the patients, there are many things that need to be present that may need good financial support. A study conducted in Canada among the caregivers of patients with Alzheimer's disease found that a caregiver had high economic burden than those caring for patients with the mild or moderate disease [26]. This was so because they required more finances to help with medication, physician attention and hospital encounters. This agrees with a study conducted in Sub Saharan Africa that found that the caregiver's economic burden depended on the duration of illness, severity of symptoms and socio-economic status of both the caregiver and the patient [11]. Another study conducted in Ghana found that caregivers had to take finances from their savings to assist the care recipient and could not afford to buy some of the things to assist the patient because of the expense of providing the care. A study conducted in Alberta found that 40.3% of family caregivers agreed that caregiving was causing them to dip into their savings [9]. Economically caregiving affects the caregiver in many ways through direct and indirect costs [11]. This leaves the caregiver with financial difficulties. In addition, 87% of care-givers indicated that caregiving was expensive [27]. Another study conducted in Canada found that caregivers who were working could quit their jobs or lose their work to fulfil their role as a caregiver [28].

A number of studies found that caregivers face financial problems during their care provision and that females had a high financial burden. However, there were differences in the caregivers' characteristics. A study from Canada used two groups of caregivers; one with a patient with mental illness and another without a patient with mental illness while the other studies were caregivers of patients with mental illness. Also, another study only used systematic approach to collect data. The present study findings had one group; caregivers of mentally challenged older patients. The earlier phrases claim that the socioeconomical findings are expected to be the same like in other studies in light of caregivers' expected experiences since the nature and characteristics of the patients will be the same.

1.4.1.4 Social Effects

Caregivers may be affected socially in many ways in their role of caregiving such as isolation and being stigmatised either by the public or self.

Stigma

A study conducted in Ethiopia found a prevalence of caregivers' perceived stigma of 89.3% [16]. The study also found that female caregivers' perceived stigma was higher than male caregivers' perceived stigma. This might be because the role of caring and social burden of caring for the female is more burdensome increasing their vulnerability to perceived stigma. The study also found that there was increased perceived stigma to caregivers who were not married than those who were married. This could be due to a lack of intimate social support to share stressful feelings, low self-esteem and weak coping skills among non-married women. Also, another study in Southern Ethiopia found that 36. 97% of caregivers felt shameful and embarrassed about their patient's illness, and the study also found that 38.63% of caregivers were worried that other people would discover about their patients' mental illness [17].

Socially, the caregivers have to reduce their responsibility to other key relationships, and this may result in stigma from the public and self. The caregivers' self-stigma may affect the patient’s treatment seeking behaviours and adherence. The care-givers may shift away from the social key relationships to caregiving task. The relationships with other family members may be neglected as caregivers’ main focus is directed to care provision [12].

A study conducted in Ethiopia found a stigma and discrimination prevalence on caregivers of 89.3% [59]. This was associated with being female, rural residency, lack of social support, long duration of the relationship with patient and being unmarried. The studies found that social stigma is high in caregivers and there are a number of factors contributing to these findings including poor social support. Though the findings show the presence of stigma and discrimination to caregivers, the studies used different research designs which included qualitative and quantitative. Again, the caregivers were caring for patients with different types of mental illness. The present study findings used a different methodology from the Ethiopian study in which quantitative method was used. This shows that the present study findings could add different perspectives on stigma experience reported by the caregivers. This could add more information on how to deal with the stigma since the qualitative provides open- ended questions, and a number of themes will come out of the study. The quantitative and qualitative study design complement each other and when used together they help in triangulation of the findings.

Isolation

The care- givers could experience changes in relationship which include the spouse, children and other close friends. These changes could affect social support and other activities resulting in isolation [18]. A study conducted in India reported social isolation experiences among caregiver of the patient with mental illness. On the other hand, the caregiver feels the society does not sympathise with them, and people lack understanding of their limitations and problems [16]. A study conducted in Turkey reported an increase in caregivers' social isolation as the care burden increases [48]. Studies conducted in South Africa found that social isolation in caregivers has prevented them from attending social events such as funeral and church services [38].

The studies' findings show that caregivers were isolated in their communities. All the studies used qualitative research methods. However, the studies were conducted in different countries. The present study findings are of greater importance as the method used was purposive sampling which helped to gather information from eligible caregivers which is different from South Africa which used systematic random sampling which might end up missing respondents who would have greater information.

1.5 Justification of the Study

The findings of this study could inform Malawi health professionals in designing interventions to address the local needs of the caregivers. Also, the documentation of the study findings could inform the development of policies to address the needs of families of caregivers and minimize the barriers caregivers encounter in the process of care provision for the older and mentally challenged patients. This could, in turn, improve the quality of care provided to mentally challenged older persons.

1.6 Objectives

1.6.1 Broad Objectives

The broad objective of this study was to describe the psychological, social and economic effects of caregiving on caregivers of the mentally challenged older patients accessing services at St John of God Hospital, Mzuzu**.**

1.6.2 Specific Objectives

Specific objectives of the study included the following:

a. To describe the psychosocial and economic effects of caregiving on caregivers of mentally challenged older patients.
b. To describe how the psychosocial and economic effects of caregiving on caregivers of mentally challenged older patients affects the quality of care of mentally challenged older patients.
c. To document recommendations to address the psychosocial and economic effects of caregiving on caregivers of the mentally challenged older patient.

1.7 Conceptual Framework

The study used a caregiver impact conceptual framework that analyses the interaction between care-givers role and care-givers burden in three dimensions which are psychological, economic and social. The framework borrowed some information from three models namely the family caregiver model, revised conceptual model on caregiver and Neuman's systems model. This is so because all the three models show interaction between the caregivers and patient characteristics [55]. There are also external factors that affect the care-giving process either positively or negatively. The presence of social support from the community to the caregiver results in quality care to the patient. The patient demands and behaviours affect the caregiver and patient outcome. The caregivers who perceive little disruption in their daily schedule reported low levels of depression [55].

The revised conceptual model on caregiver burden [56] also contributes to the framework. There are a number of factors that affect the care-giving role and these include family and personal relationships, social life, finances and mental health. These are factors that will produce positive or negative outcomes to both caregivers and patients. Financial problems increase caregiver burden ending up in poor quality care such as missing review dates and this may lead to patient relapsing.

Also, some inputs for the framework are taken from Newman's systems model [57]. The model helps to organise and direct the caregiving activities with the client as a central focus [57]. It identifies individual responses to stressors in all variables of the model. The model views a human being as an ever-changing system that is in a mutual interaction with the environment. The model suggests that the client system has to be addressed holistically because the variables affect each other. [57]. This is the same with the patient; when one variable is affected, the whole system is also affected. The variables include physical, psychological, socio-cultural, developmental and spiritual. When the caregiver is affected financially, they are also affected, which also affects their role of caregiving.

In the conceptual framework of the caregiver impact, other concepts have been taken from the conceptual model of the caregiving process and burden [59]. The model shows that the caregiving process and the care- giver burden are connected. There are a number of factors that contribute to the outcome of the role of caregivers. These include social support, social-economic status (SES), stress management and family function. This also applies to the caregivers of the mentally challenged older patients and shows that SES, patient characteristics such as aggressive behaviours, the severity of mental illness and the intra psychic factors, such as the coping strategies, the social support have been associated with the psychological/physical outcome of the primary caregivers [58].

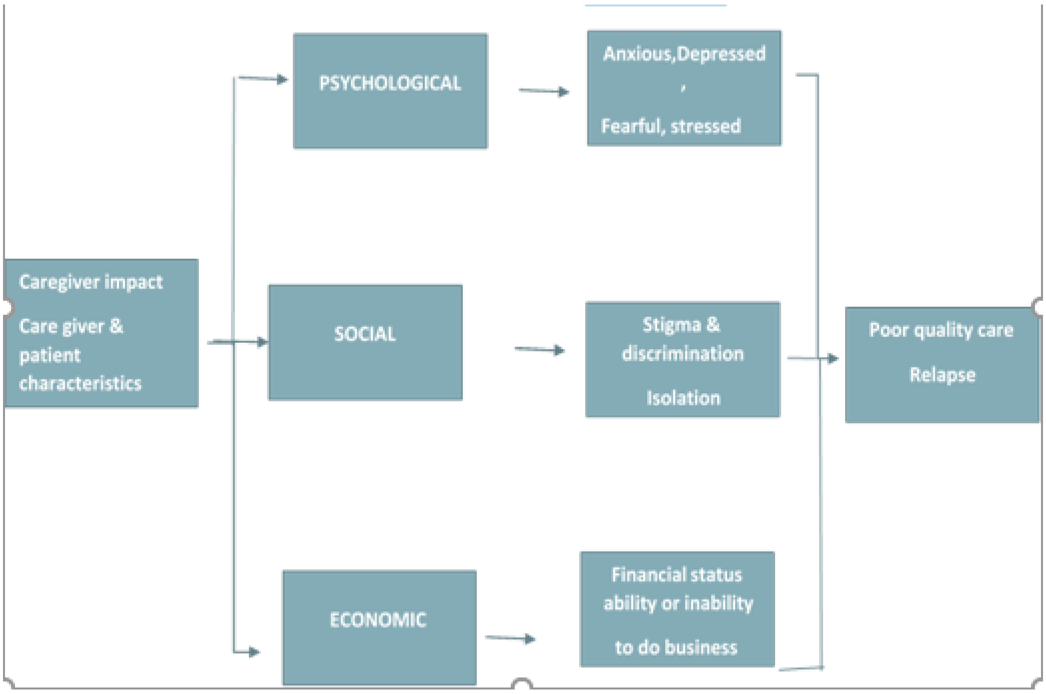

Figure 1: Caregiver Impact Conceptual Framework

The conceptual framework above, shows that caregiving leads to psychological, social and economic challenges. In the framework, the role of caregiving affects the caregiver psychologically, socially and economically. There are a number of factors affecting the role of caregiving. The factors may affect the caregivers positively or negatively. These include the caregiver characteristics such as old age, unemployment, poor relationship with relatives and poor social support. The patients' characteristics include aggressiveness, inability to carry out activities of daily living and poor support from relatives. These result into stigma and discrimination, depression and financial problems to the caregiver which ultimately affects the quality of care for the patient. The effects of the role of caregiving may include good mental health, good quality of care, relapses and ability to do business.

CHAPTER 2: METHODS

2.1 Type of Research Study

The study employed a cross-sectional study design using qualitative research methods. This study involved describing and explaining the psychosocial and economic effects of caregiving on caregivers of mentally challenged clients. The information was obtained directly from those experiencing the phenomenon under investigation and where resources and time were limited [36]. The qualitative research method explored and explained the impact of caregiving on the caregivers, answered the research questions through the caregiver experiences, and understood the meaning from the experiences [60]. The caregivers were able to express their views through the participants being able to answer the questions about their experience [61].

2.2 Study Place

The study was conducted at St John of God Hospital in Mzuzu city. St John of God hospital is located in Mzimba District in the northern region of Malawi. Mzimba district has a population of 936,250 people [14]. St John of God Hospital provides mental health services to the northern region people, including the districts of Nkhata-Bay, Likoma, Rumphi, Chitipa and Karonga. A total of 310 patients are seen on monthly basis. The users of the services at the hospital pay user fees. The older patients visit the hospitals with their caregivers.

2.3 Study Population

The study population comprised of two groups namely the caregivers of mentally challenged older patients and health workers assisting the patients.

2.4 Study Period

Data collection was conducted from 22nd October to 20th November, 2020.

2.5 Sample Size and Sampling Technique

A total of 14 caregivers of the patients who were aged 60 years and above were interviewed. The caregivers come with their patients for reviews and supply of medication on monthly basis. The second group comprised health care workers who interact with the caregivers to assess the health workers' perceptions of the psycho-social and economic impact of caregiving on the caregivers. The care givers comprised males and females of different age groups in the ranges of 18-45 years, 46-60 years and above 60 years. Again, different numbers of years caring for the mentally challenged older clients were taken on board. Health workers comprised those providing services to the mentally challenged older clients. These were nurses and clinicians, and those who had been working at the mental health clinic for more than 6 months. On health workers, the number interviewed were eight; 6 males and 2 females translating to 5 nurses and 3 clinicians.

Purposive sampling was used to select respondents. The purposive sampling identified and selected information rich cases related to the study's area of interest [40]. This helped to gather more information from the participants, enabling the investigator to achieve the study's intended objectives. The saturation point was reached from both sets of participants who are health workers and caregivers, after observing that there was repetition of information coming out from the participants.

2.6 Inclusion Criteria

a. Adult caregivers of older patients of 60 years above.

b. Caregivers who spent most of her/his time with the older patient.

c. Caregivers who were willing to provide informed consent.

2.7 Exclusion Criteria

a. Caregivers accompanying the older patient who were very sick.

b. Caregivers of older patients who were less than 18 years of age.

2.8 Data Collection Method

The researcher used in depth interviews. These are one to one interviews, where an interviewer interacts with a respondent. The in-depth interviews generated more information and allowed the freedom to explore additional points [41]. These were administered to the caregivers of the mentally challenged older clients and the health care workers who interacted with the caregivers of the older clients. The interview guide with open ended questions was used to interview the caregivers on the psychosocial and economic impact of the caregiving role (Refer Appendix F1). Another interview guide was used to interview health workers on their perceptions of the psychological, social and economic impact of caregiving of the caregivers of mentally challenged older clients (Refer Appendix G).

A research assistant interviewed the caregivers of the mentally challenged older clients, while the Principal Investigator (PI) interviewed the health workers. All the interviews were audio-recorded. The research assistant was trained on the interview guide, data collection and management process, including the study's ethical considerations. Pre-testing was done with one caregiver and one health worker to identify any anomalies, and corrections were made. This was done at our admission unit, where a caregiver visited a patient above 60 years and with a health worker who was on duty. The interviews were done at the St John of God Clinic.

When they came to the clinic for reviews of their client, the caregivers fulfilling the inclusion criteria for the study were provided with information about the study and informed consent was sought from them. The care-recipients were advised to remain at the reception to wait for their guardian when they were being interviewed to avoid confusing the care recipients. This has been the standard practice during studies. The health workers were also provided with information about the study and informed consent was obtained. The appointments were booked for the interview to prevent disturbing their duties.

The confidentiality was maintained during the interviews. The interviews lasted for 30 - 40 minutes per individual and were done in a room where privacy was assured. All the interviews were recorded.

2.9 Data Analysis and Management

Thematic data analysis was used [31]. This is one method of analysing qualitative research. After data collection, the team -principal investigator, research assistant and an independent team member, followed steps for thematic analysis on a daily basis [32]. The team familiarised itself with the data by listening to the recordings several times and going through the field notes. The PI then asked two people who were conversant with Tumbuka language (that was used during interviews with caregivers) to transcribe the audios verbatim into English. After transcription, the team went through the transcribed texts and made notes after reading the transcripts. Then, the team developed a chart consisting of all participants with their identity numbers. The team went through the transcribed texts and then came up with codes from each transcript. The team went through the transcripts of every participant highlighting the phrases and sentences to match with the codes. New codes were added in the process. The team looked at the codes identified and their patterns and started to come up with themes. Several codes were combined into a single theme. The team looked at the themes critically and found that some were not matching and were discarded whilst other themes were also created. The team reviewed the themes to ensure that they were representing the data. Cross-checking with the themes was done to prevent missing important information and other themes were changed for better terminology. Then each theme was defined to show the meaning of each theme's meaning and naming of the theme. Then the PI started writing a report of the findings.

2.10 Study Limitations

Some mentally challenged older patients came alone without caregivers. Some caregivers of the mentally challenged older patients came with the patients who were very sick mentally. Turn up of caregivers of mentally challenged older patients was poor due to the Covid-19 pandemic. The PI had few days to collect and analyse data due to the late onset of data collection. This was so because COMREC delayed giving feedback on approval of the proposal. It may also be difficult to generalise the results because the study was conducted at only one hospital, which asks for user fees. However, the study's themes covered may be applicable to similar settings as qualitative methods are not necessary aimed at generalizing but to obtain an in-depth understanding of the subject matter. The study can also act as a springboard for further research focusing on public health facilities which are free at the point of service.

2.11 Ethical Considerations

Permission

The Ethical approval to carry out the study was sought from the College of Medicine Research Ethics Committee (COMREC) (**Refer Appendix A).** The Director of Services at the St John of God Hospital granted the authorisation to conduct the study at the institution **(Refer Appendix B & C)**.

Voluntary Participation

Participants were not forced to participate in the study. Adequate information was given to the study participants and a consent form was read to or read by each participant depending on their literacy levels. The participants gave written consent before conducting interviews. The consent forms were in English and Tumbuka **(Refer to Appendix E1 & E2)**.

Risk to Respondents

No invasive procedures were used to ensure that there was no harm to the study participants.

Confidentiality

Confidentiality was maintained throughout the study. The questionnaires had no names and only codes were used. After collection of information, questionnaires were kept in a locked cupboard for safety. Audio files were saved in a password - protected computer.

Compensation

Participants were informed that there would be no compensation for participating in the study. This was so as the care-givers participated in the study on the day of their patient reviews.

2.12 Trust Worthiness of the Study

The study ensured trustworthiness throughout the study period. This involved ensuring credibility, confirmability, dependability and transferability. The study ensured credibility by doing peer debriefing to have an external check on the research process. Also, the researchers were familiar with the study project and study setting [37]. Pre-testing of the interviews was done to the caregiver who visited the above 60 years patients at the admission unit and the nurse on duty, respectively, to identify any anomalies. Two independent people conversant with Tumbuka language were used to transcribe the audios. The transcripts were done for each respondent. Confirmability was observed through conducting team meetings and discussing the codes. The meeting was attended by the principal researcher, assistant researcher and an independent member.

Reflection and feedback were given to the researchers through written and oral format [38]. Dependability was ensured through audit trail [39]. The audit trail is the record track keeping of the step-to-step process of the study. This was done by documenting clearly the research process, records of raw data, field notes and transcripts. This allows the observer to trace the course of research step by step. Transferability was observed by ensuring that data saturation had been reached, which might generalise findings of similar settings.

CHAPTER 3: RESULTS

3.1 Participants' Social Demographic Profile

This section presents social demographic profiles of respondents. Below are tables for caregiver and health worker respondents.

3.1.1 The Caregivers

Fourteen caregivers were recruited in the study, 43% were males and 57% were females. Mean age for caregivers was 41 years and mean duration of care was 8years. For more demographic details see the **Table 1**.

Table 1: Demographic Details of Caregivers

Id	Gender	Age	Relationship With the patient	Duration For caring for the patient	Marital Status	Educational level	Employment
1	F	43	Son	8 years	Married	Secondary	Unemployed
2	M	45	Cousin	10 years	Married	Secondary	Self employed
3	F	28	Parent	6 years	Married	Primary	Unemployed
4	M	34	Aunt	8 years	Married	Tertiary	Formal employment
5	M	33	Parent	8 years	Married	Secondary	Farmer
6	M	62	Brother	6 years	Married	Secondary	Retired
7	F	45	Parent	6 years	Married	Primary	Volunteer
8	F	49	Parent	10 years	Married	Tertiary	Formal employment
9	F	32	Parent	6 years	Separated	Primary	Small scale business
10	F	51	Parent	10 years	Divorced	Secondary	Small scale business
11	F	47	Parent	8 years	Never married	Secondary	Small scale business
12	F	28	Parent	6 years	Married	Primary	Small scale Business
13	M	33	Parent	6years	Married	Primary	Small scale business
14	M	42	Parent	9 years	Married	Secondary	Formal employment

3.1.2 The Health Workers

Eight health workers were recruited in the study. 75% were males and 25% were females. The mean age of the health workers was 39 years. The mean duration of care by the health workers was 8 years. 62.5% of the health workers were nurses and 37.5% were clinicians. Below are other demographic details for the health workers. **See Table 2.**

Table 2: Demographic Details of Health Workers

Id	**Gender**	**Age**	**Duration caring for the patient**	**Marital status**	**Cadre**
1	M	43	16 years	Married	Nurse
2	M	33	6 years	Married	Clinician
3	M	28	3 years	Single	Nurse
4	M	48	9 years	Married	Clinician
5	F	36	7 years	Married	Nurse
6	M	39	11years	Married	Clinician
7	M	46	4 years	Single	Nurse
8	F	42	10 years	Married	Nurse

3.2 Roles of Caregivers of Older Mentally Challenged Clients

Findings of the study revealed that the roles of caregivers were providing basic necessities, providing emotional support, providing financial support and ensuring drug adherence.

3.2.1 Providing Basic Necessities

All the caregivers interviewed in the study indicated that the role of the caregiver of the mentally challenged older client is to provide the client with basic necessities in life. These include food, assisting with bathing, assisting with cleaning beddings, assisting with taking a bath and staying with the client in a clean environment.

One of the caregivers had to say this regarding their roles:

> *"As a care giver, we make sure that their beddings are clean, we provide food and sometimes due to mental illness they pace up and down so we closely monitor them to ensure they are safe. We always check on them to make sure they are not assaulted by other people."* **Caregiver 1**

Another caregiver had this to say:

> *"Firstly, when I wake up in the morning, I make sure I give her water to take a bath. Then I provide her breakfast and give her lunch and supper and make sure that the environment is clean".* **Caregiver 11**

The health workers also had the same perceptions on the roles of caregiver as provision of basic needs. A health worker had this to say:

> *"The basic needs of the client have to be met by the caregiver. The client has to be fed, has to be assisted in taking a bath and with toileting"* **Health worker -5**

3.2.2 Provide Emotional Support

The caregivers and health workers mentioned that emotional support is one of the roles of caregivers of mentally challenged older clients. The emotional support was provided through chatting with the client, keeping company or staying with the client and showing love.

A caregiver explained that:

> "*I take time to chat with her in order to help her psychologically.*" **Caregiver 4**

Another caregiver also narrated her roles of a caregiver saying:

> "*I stay with the client, chat with him telling different stories about our home and relatives which help the client to forget the problems he is having regarding his illness.*" **Caregiver 6**

The health workers also had this to say regarding the roles of care givers of mentally challenged older clients:

> *"The caregiver should chat with the client and understand them* and not side lining *them. They are also human beings."* **Health worker 8**

3.2.3 Ensure Adherence to Medication

All the caregivers and health workers interviewed revealed that one important role of caregivers of mentally challenged older clients was to ensure adherence to medication. One of the care givers had to say:

> *"I ensure that I try to look for money to take the client to hospital, to take medication daily so that the client should not miss the review dates."* **Caregiver 10**

Another caregiver had this to say:

> *"I take him to the hospital to take medication so that he should be well. At home I observe him when taking medication to ensure that he has taken them."* **Caregiver 3**

Another health worker had this to say:

> *"I expect that a caregiver should help the client to comply with treatment and monitor drug side effects".* **Health worker 6**

3.3 Psychological Effects of the Role of Caregivers On Mentally Challenged Older Patients

3.3.1 Anxiety

The majority of caregivers showed that they had anxiety symptoms during their provision of care to mentally ill older patients. The caregivers experienced fears and worries. Worries and fears were experienced by (n=12) and (n=5) respectively. They narrated that they had worries because of the patients' behaviours like doing things that they were not supposed to do. For example, beating up people. They were also fearful because they were afraid of what would happen to their patient with the behaviours they were portraying. One participant had to say:

> *"I am worried because my patient is verbally aggressive and becomes angry on others. People will not understand him that it's out of illness* and so I am afraid that they may not understand him resulting in beating each other. He may get injured in the process." **Care giver 8**

Another participant added:

> *"I have fears when the patient is alone in his bedroom because I don't know what is happening to him. He may overdose himself with the medications that we were given at the hospital since they are also kept there."* **Care giver 12**

The health workers also expressed their experiences that caregivers are worried and fearful during their provision of care. One health worker had this to say:

> *"Most caregivers are worried about the behaviours their patients portray* and their *failure to provide the basic needs of the patient."* **Health worker 4**

The findings of the study on anxiety showed that females n=8 were the ones having more worries and fears than males n=5 and n= 1 did not show any signs of anxiety. The findings also revealed that those caring for a parent had anxiety symptoms more than those with other relationships. The relationships of the patient and the caregiver was n=10 parent; n= 1 son; n=1 aunt; n= 1cousin and n=1 brother.

3.3.2 Depression

Out of n=14 caregivers, n=4 experienced depression during their provision of care. Most of them were depressed because they could not understand why their relatives were suffering from mental illness and the symptoms one was showing that made them to feel sorry for them and have guilty feelings. One of the caregivers said:

> "*Yes at one point I was depressed because I was very worried with the symptoms my mother was showing, like failing to walk, failing to talk and sleeping too much."*
> **Caregiver 4**

The findings of the study revealed that both male and female caregivers had the same level of depression due to their role of caregiving. There was n=2 with depression in male and female caregivers, respectively. It was not clear if the findings were related to the respondents' educational levels. The educational levels of the respondents with depression were n=2 had primary education and n=1 had tertiary and secondary educational levels.

3.3.3 Stressed

Out of 14 caregivers who participated in the study n=6 reported to have been stressed in the process of caring for the older mentally challenged patients. They reported that the situations they were going through caring for the patient made them to be stressed. One participant had this to say:

> *"I am very concerned and disappointed most of the times due to the patient's behaviours. For example, he does things that are irritating and does not follow instructions."* **Caregiver 8**

Another caregiver narrated her reason for being stressed that she was not able to meet the patient's basic needs. She had this to say:

> *"I don't know what to do? What will the client eat when there is no food?"* **Care giver 12**

Out of the n=8 health workers who participated in the study, n= 6 reported that caregivers are stressed. Most of them reported that the reason was the behaviours of the patients like being physically aggressive. A health worker had to say:

> "*The caregiver reported that they are tired of the burden of care due to patients' behaviours like aggressive behaviours and says cannot withstand the behaviours anymore."* **Health worker 1**

The findings of the study revealed that female caregivers were more stressed than male care givers as they are providing their care. Four (n=4) females were stressed and two (n=2) males were stressed.

3.4 Social Effects

Out of n=14 care givers who participated in the study n=10 reported to have experienced stigma and discrimination. Out of care givers who reported stigma and discrimination n=4 were males and n=6 were females. The caregivers complained that they were being associated with witchcraft because of their patients' behaviours and for not being involved in community development activities. Another participant reported:

> *"Neighbours ask me why my patient is quiet during the day and talkative during the night. And they keep on saying my patient is practising witchcraft together with me."* **Caregiver 9**

Still on witchcraft accusations, another participant had this to say:

> *"My patient is viewed as a witch by the community because of her behaviours and they accuse me of practising witchcraft as well because I provide care to someone who is older and behaves strangely. Due to these beliefs, many people stopped vising our home."* **Caregiver 8**

Seven n=7 respondents reported social isolation n=1 male and n=6 females. This shows that female caregivers were more isolated than male caregivers.

One participant had this to say:

> *"We are not involved in community developmental activities because we care for mentally challenged older patients*." **Caregiver 3**

Health workers reported similar challenges as caregivers. All health workers n= 8 who participated in the study reported that caregivers experienced stigma and discrimination. One of the health workers reported:

> “*Caregivers reported that they are believed to be practising witchcraft and using charms given to them by the client. Also, they are not involved in community activities because they are caring for mentally challenged older patients.*

The health worker also said:

> “*The care givers cannot marry from other family members of the community because the family members believe the caregivers are going to have mental illness.”* **Health worker 4**

The findings of the study revealed that female caregivers (n= 6) faced stigma and discrimination more than male caregivers (n=4). And also, n= 1 males and n=6 females showed the caregivers are isolated. These findings showed that female caregivers were more isolated than male caregivers. The findings also showed that the caregivers had poor social support from other members of the community.

3.5 Economic Effects

3.5.1 Financial Problems

All n=14 caregivers who participated in the study reported to have financial problems. This was observed through lack of money to buy basic needs, lack of money to use for transport to go to the hospital for reviews and lack of money to buy medication. A caregiver had this to say:

> “*I get assistance from other family members though it’s not enough as the client will need money for transport to take her to the hospital and to buy medication since we have to pay for medication and buy food of his preference.*” **Caregiver 14**

Another caregiver agreed that some family members assisted them with money to support the patient which was not enough to meet their expenses. The caregiver had this to say:

> *“I do not have money for transport when going to the hospital, we walk though it’s a long distance.*” **Caregiver 3**

All health workers n=8 who participated in the study reported that care givers do not have enough money to use for transport to the hospital, buy medication and to provide the patient with basic needs. One health worker had to say:

> *“*Most *of the caregivers report that they do not have money to buy medication and for transport, they walk long distances on foot.*” **Health worker 1**

The findings of the study revealed that all caregivers faced financial problems at one point.

3.5.2 Inability to Do Business

The caregivers n=6 reported that they were not able to do business. They revealed that patients could not be left alone. The caregiver spends most of the time caring for the patient, used their business capital to assist the client with basic needs and cannot be able to participate in income generating activities because of the nature of illness of the patient. A care giver had to say:

> *"I have no time to do business as I spend my time with the patient, monitoring his movements as he keeps wandering about and I have to search for him when he is missing.*" **Care giver 3**

Another care giver said:

> *"I stopped doing business because I used the capital to search for the patient when he went missing. I had to hire a vehicle"*. **Care giver 1**

Four n=4 health workers who participated in the study reported that caregivers were unable to do business because they had used the capital for buying patients' basic needs, and could not leave the patient alone as there was nobody to stay with the patient. A health worker said:

> "*The caregiver had to divert her money for business to provide basic needs of the patient.*" **Health care 3**

The findings revealed that both male givers and female care givers were not able to do business because they were caring for their patients.

3.6 Effects of the Impact on Provision of Quality Care

The findings of the study from all the participants; health workers and caregivers revealed that the psychological, social and economic impact of caregiving of mentally challenged older patients had affected the quality of care of the patients. One of the caregivers had to say:

> "*The care provided to the client will not be adequate when the care giver has financial problems. As a result, the client will not have all the basic necessities. This will result in a patient having poor health due to lack of food resulting into nutritional problems. The patient will also not be able to pay for medication and transport due to lack of money. Eventually, the patient may not visit the hospital to collect medication as scheduled and this will lead to poor drug compliance causing patient to relapse"*. **Caregiver 8**

The respondents reported that caregivers may also end up providing the care with emotions because they are stressed up and depressed, resulting to poor quality care. A health worker reported:

> *"Lack of performance by the caregiver and stress of the caregiver will lead to low immunity, resulting into an unhealthy condition by the caregiver and failing to make good decisions regarding caregiving.*" **Health worker 6**

Other health workers reported that due to psychological impact on the caregiving role, the caregiver may not concentrate on their work as a care giver which will also affect the care.

On the quality-of-care effects, nurses and clinicians reported the same things that would affect care like compromised quality due to issues of stressors and increased relapses due to lack of transport money to go to the hospital. However, the clinicians were looking more on the effects on care affecting the physical well-being while the nurses looked on the psychological effects of the care giver on the care of the patient.

3.7 Respondents' Recommendations

There were a number of recommendations from the study respondents, both the caregivers and the health workers. The recommendations were in four categories namely: what relatives should do, what health workers should do, what non-governmental organisations should do and what the Ministry of Health should do. The caregivers recommended that relatives should provide emotional, material, physical and financial support. Health workers should ensure availability of mental health services to all through mobile outreach clinics, should provide psychosocial services, conduct home visits, provide free medication, reduce user fees and ensure availability of medications. Health workers should also conduct health education to communities on care of the mentally challenged older patients and caregivers, and prevention of stigma and discrimination to caregivers of mentally challenged older patients. Non-Governmental Organizations should provide financial support to the caregivers through providing capital to caregivers to start business. They should also provide caregivers with transport money and free medication. The Ministry of Health should ensure availability of mental health services to all through availability of financial, material and human resources. It should also provide psychosocial services through mobile outreach clinics and mental health clinics in all districts and health centres. Above all, the ministry should ensure availability of medications.

Health workers recommended that relatives should support the caregiver materially, socially, economically and emotionally. The health workers should provide psychosocial services to caregivers in order to relieve them from caregiver burdens. They should also collaborate with government and other stakeholders responsible for the elderly to lobby for mental health services for the caregivers and their patients and conduct mental health awareness in the community to prevent stigma and discrimination to mentally challenged older clients and their caregivers.

The health workers further recommended that the Ministry of Health should update mental health policies to ensure that mental health services are allocated adequate budget and more mental health professionals are trained. The ministry should also collaborate with other stakeholders like social welfare to have open days for the elderly and should establish the positions of psychosocial counsellor in government hospitals to provide comprehensive psychosocial services to the patient and the caregivers. The Ministry of Health should ensure that research is being conducted on caregivers of mentally challenged older patients to develop interventions depending on evidence.

The health workers recommended that Non-Governmental Organisations should work in collaboration with all stakeholders dealing with the elderly and caregivers and with the government to lobby for mental health centres of the elderly and their caregivers in the community, to advocate for the mentally challenged older patients and their caregivers and formulate support groups for the caregivers to share their experiences and help to learn from one another.

One of the caregivers had this to say:

> *"I would ask the relatives to support us, caregivers, by visiting the client and chat with them, assisting us with money to buy the patient basic needs, to pay for transport when going to the hospital for reviews since it's too far and to pay for medication every monthly visit. The health workers should provide health*

> *education to the members of the community about mental illness and how the community should be treating them and their clients. The health workers should give us medication for free. I would ask the government to ensure availability of mental health services to be nearer to us in our communities and to ensure availability of medications for the patients. I would also ask Non-Governmental Organizations to assist us with capital to start businesses and they should lobby for health centres to be nearer to the patients".* **Caregiver 5**

A health worker had this to say:

> *"The relatives should be committed to assisting the caregivers by providing financial, emotional and material support. The health workers should provide mental health education in the community to prevent stigma and discrimination to caregivers and the patient. Government should ensure there is a post of psychosocial counsellor in the Ministry of Health to provide psychosocial counselling services to the caregivers, should establish mental health clinics at all district hospitals and health centres, should also have trained mental health professionals in these settings and should ensure collaboration with other stakeholders responsible for the elderly. Also, government should update the mental health policies to suit with the current situation. The Non-Governmental Organisations should assist caregivers with income generating activities".* **Health worker 4**

The recommendations made by the caregivers and the health workers were the same. However, the health workers added more on things that have to be done in order to invest more on mental health in order for everyone to access the services. This showed that both the caregiver and the health workers were concerned with the caregiver burden being faced by the caregivers of mentally challenged older patients.

CHAPTER 4: DISCUSSION

The study confirmed that caregivers of mentally challenged older clients experience psychological, social and economic impact of caregiving.

4.1 Psychological Impact

On psychological impact, the study findings from previous studies [42] state that female caregivers experience more burden than male caregivers. This agrees with the findings of the present study, where women are more stressed than males. This is so because it is the female care- giver who is mostly with the patient, so the caregiver is more exposed to stressors that are present due to financial difficulties, disease progression and patient's symptomology [42]. According to Malawian culture, it is believed naturally that women are caregivers. Saudi Arabia study findings are in agreement that care- giver burden is high in caregivers caring for close relatives such as parents, son/daughter, siblings and spouses [45]. In our findings the close relative was the parent. A parent plays a great role to a child, so if sick everything is affected leading to stress to caregivers.

The findings of the study on depression in caregivers do not agree with other study findings from Malaysia, which showed that depression is more in female caregivers than male caregivers [43]. The findings of the present study showed that there was no difference between male and female caregivers in terms of depression. This is not in line with other study findings, which say that female caregivers are more depressed than male caregivers. A study with a more representative sample may clarify experiences of depression among male and female caregivers in Malawi. As reported by other studies, reasons that make a female caregiver to be more depressed include closeness to the patients than males since males are much like bread winners. Males are not close in contact with the clients and female caregivers spend most of their time with the patient. The caregivers need to help each other in providing care to the patient whether female or male. Caregivers should be in close contact with the patient and spend more time equally in order to prevent others being more depressed than others.

Anxiety was also present in the caregiver respondents, which is in line with study findings from Malaysia, where more family caregivers were worried during the provision of care [42]. In the present study, the caregivers were worried about the behaviours of their patients, like beating people. The level of anxiety of caregivers is related to the signs and symptoms of the disorder and the patient's behaviour more than the psychotic diagnosis [50]. This shows that not all diagnosis of psychiatric illness causes anxiety. However, the behaviours and signs and symptoms contribute to anxiety symptoms. Another study from Pakistan found that the caregiver's role of caring for patients with mental illness had a high level of depression and anxiety [52]. The findings of the study from Pakistan agree with the findings from the present study. However, the Pakistan study compared the depression and anxiety between caregivers of different types of mental illness. Still more, findings from the present study and that conducted in Pakistan agree that any caregiving role is associated with depression and anxiety.

4.2 Social Impact

The caregiver's relationship with the community, neighbours and friends is affected because they care for the mentally challenged older patients. The findings of the study revealed that more caregivers experienced stigma and discrimination. The findings are in agreement with study findings from India, which indicated that caregivers were treated differently from others [44]. This was shown in the study that stigma and discrimination would affect the relationship of the caregivers with others and the caregivers' emotional well-being. Many caregivers were not involved in community activities and were isolated by their neighbours. The stigma and discrimination were closely linked to the symptoms of illness and inability to participate in activities [44].

The findings of the present study also concur with the findings from Malaysia that the caregiver did not get support from other family members and could not attend other functions in their community [43]. This agrees with the study findings from Ghana which state that the caregiver could not attend any community activity as they spent most of their time looking after the patient [29]. The present study findings highlighted that most of the people could not attend community functions because they had to stay with the client which led to less interaction by the caregivers with other people to express their concerns on their role as caregivers. The role of caregiving is challenging and so the caregivers need to interact with other caregivers and members from the general community to be relieved from the caregiving burden. This can help them to provide quality care.

Another study from China found that caregivers faced stigma and discrimination [49]. This agrees with the study findings from the present study. The stigma and discrimination of caregivers will affect caregivers caring for the patient, resulting into poor care quality. The presence of stigma and discrimination shows that there is poor social support from the community, which will play a negative role in caregiving. The caregivers with high social support are likely to live in a friendly and open environment [49]. This will be so because the community members will be able to help the caregivers caring for the patient thereby relieving the care- giver from the burden of care. The caregivers will be involved in income-generating activities and development activities of the community. Furthermore, the community members will understand that the patients’ behaviours are due to old age and mental illness, which will prevent double stigma and discrimination. Such understanding will prevent the community from making accusations that the patient and caregiver are practising witchcraft together with the caregiver. The community members understand the patients' behaviour and support the caregiver when the need arises.

In addition, a study from Iran supports the idea of good social support to the caregivers. The study found that support from other social network decreases the care- givers' burden [51]. Social isolation was revealed during the study. The caregivers were isolated from other members of the community because they cared for mentally ill older patients. This finding agrees with findings from Nigeria, which showed that the caregivers expressed abandonment and isolation [53]. The caregivers were left alone with the patient and the community members could not visit them. Another study finding revealed that caregivers are more likely to be isolated [54]. These findings are in agreement with what the present study showed: that caregivers are isolated. This can negatively impact the caregiver as there will be nobody with whom to share concerns, resulting into high levels of depression.

4.3 Economic Impact

The study findings showed that many caregivers experienced financial burden during their care provision to the patients. The caregivers revealed that they did not have enough money to cater for the patients' needs. These needs include money to transport the client to hospital, buy medication, buy food of the patients' preference and basic patient needs. The findings agree with a study done in Tanzania that expressed financial concerns from caregivers. The findings revealed that caregivers had financial problems related to transport money to go to hospital as most people lived long distances from the hospital. Also, money to pay for medication was a challenge [46].

In Malawi, many caregivers rely on other family members to support them financially, though the money given is not enough. There is need for financial support for the caregivers since most of them do have income sources that are not enough to care for the patient. The study findings showed that many caregivers were not in formal employment, many were doing small scale businesses and some were not employed. This contributes to the caregivers' financial burden. The higher the income level the low the burden. These findings are consistent with the study findings from Ethiopia [47]. The caregivers need enough money to pay for the unexpected caregiving expenses. For instance, one caregiver had to pay for a vehicle hire to look for a patient who had gone missing.

In addition, the study findings from Alberta [48] found that 40% of the family caregivers could not afford little extras because of the expenses needed to care for the patients. Also, the role of caregiving was causing them to dip from their savings. This is consistent with the findings from the present study, where the caregivers had to use money that was saved for a certain purpose to provide care to the patients.

The study findings are in line with those from Malaysia which showed that the care-givers could not provide for the family due to financial difficulties [43]. The caregivers of mentally challenged older patients had financial difficulties as they could not do business due to lack of capital to start the business and used the money intended for the business to provide care to the patient. The caregivers spent most of their time caring for the patient instead of doing business. The financial problems faced by caregivers should be taken seriously as this will affect their provision of quality care to the patient. They should be supported through involvement in programmes that may help empower them financially to meet their financial expenses without problems.

Many caregivers do not have a reliable source of income. They mostly have to fend for their family daily. This is so because they have short term income sources which put them in a challenging situation where they cannot fend for the family. This means that the family will be affected in many ways. For example, there will be no food for the family including the patients. The client will not be taken to hospital for reviews and medications resulting in defaulting treatment. The present study findings are of greater importance as the method used was purposive sampling which helped to gather information from eligible caregivers and is different from a South African study which used systematic random sampling resulting in missing respondents who would have greater information. The present study findings will be rich with important information thereby standing a chance of the study findings to be generalized.

The present findings are in agreement with the caregiver impact conceptual framework that a number of factors contribute to positive and negative outcome. The factors include social, economic and psychological. Problems in the factors may lead to a number of problems to the client as the caregiver will not be able to provide quality care and as a result, the patient can relapse.

CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

5.1 Conclusion

In conclusion, study findings show that caregivers of mentally challenged older clients face psychological, social and economic burden emanating from their caregiving role to the patients. The findings of the study reveal that financially, the caregivers are affected as there are a number of things that are needed to support the patients throughout their illness that need monetary support.

The study findings also concluded that socially and psychologically the caregivers are affected during their provision of care to patients which will in the end affect their role of caregiving. Therefore, it is important to address the psychological, social and economic burden of caregivers to provide quality care. There is need for concerted efforts from different stakeholders to address the issue. These include government, non-governmental organisations and the community as a whole. All stakeholders need to take part to help caregivers cope with the burden of caring for mentally challenged older patients, thereby improving the quality of care provided to the clients.

5.1.2 Implications of the Study

5.1.2.1 Practice

As shown in the study, the caregivers' burden may contribute to the development of caregivers' mental health problems later in life. The mental health nursing services should focus on providing comprehensive mental health care to the caregivers to promote good recovery of the patients.

5.1.2.2 Research

The study investigated the burden in terms of social, economic and psychological on caregivers of mentally challenged older patients. The burden on the caregivers affects the quality-of-care provision. Regardless of the study limitation that the findings may not be generalised, these findings may apply to similar settings, keeping with qualitative research methodology, which focuses on an in-depth understanding of the phenomena. Therefore, these findings can act as a springboard for similar research to be conducted at national level, applying both qualitative and quantitative methods to comprehensively inform the government on the burden of caregivers of mentally challenged older patients and plan appropriate interventions.

5.1.2.3 Policy

The study revealed that caregivers spend money to transport the patient to hospital due to long distances and pay for medications. The study showed the need to provide specialized elderly mental health services in all the communities that are far away from the health facility.

5.2 Recommendations

5.2.1 Practice

The study recommends that hospital management must include psychosocial services to caregivers. The caregivers should be assessed holistically at each visit to the hospital with the patient to rule out any problems during their care provision and manage them accordingly.

5.2.2 Education

The study recommends that the Nurses Council and Medical Council should review the curriculum for mental health nurses. Clinicians and doctors should include caregivers' mental health assessment in their operations. This will help the health workers to identify caregivers' problems and manage them to promote quality care.

5.2.3 Policy

The findings show that caregivers are faced with the burden of adverse health and economic effects which mostly go unidentified due to lack of trained personnel. Therefore, there is need for mental health clinicians and psychosocial counsellors in all the health centres. Government should collaborate with other stakeholders that deal with the elderly to empower the caregivers through involvement in income- generating activities.

5.2.4 Research

Since the study was done at a CHAM hospital where people are expected to pay, many caregivers may opt to go to government hospitals. The study recommends that a similar research study be conducted at the national level at government hospitals to comprehensively inform the government on the burden faced by caregivers of mentally challenged older patients and plan appropriate interventions.

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APPENDICES

Appendix 1: Clearance Letter to the Ethics Committee

College of Medicine
P/Bag 360
Chichiri
Blantyre 3

03.02.2020

The Chairperson,
College of Medicine Research and Ethics Committee
College of medicine
P/Bag 360
Chichiri
Blantyre 3

Dear Sir/Madam

RE: ASSESSING THE PSYCHO-SOCIAL AND ECONOMIC EFFECTS OF CAREGIVING ON CAREGIVERS OF MENTALLY CHALLENGED OLDER PATIENTS ACCESSING SERVICES AT ST JOHN OF GOD, MZUZU.

I write to submit the above description and attached study procedures. I am a second-year student at College of Medicine pursuing a Master’s degree in Public Health.

My supervisor is Dr Lot Nyirenda has looked at my research proposal and authorized my submission to your committee for approval.

I am looking forward to your favourable consideration.

Yours Faithfully

Fyness Chikopa

(MPH STUDENT)

Dr Lot Nyirenda

Research Supervisor

Appendix 2: Request Letter to Research Site

College of Medicine
P /Bag 301
Chichiri
Blantyre 3.
6th May, 2020.

The Chief Executive Officer
St John of God hospital
P.O. Box 744,
Mzuzu.

Dear Sir,

APPLICATION FOR PERMISSION TO CONDUCT A RESEARCH STUDY IN YOUR ORGANISATION

I write to seek for permission to conduct a study in your organisation. The aim of the study is to assess the psychosocial and economic effects of caregiving on caregivers of a mentally challenged older patients in order to design interventions that will help to provide quality care to older clients.

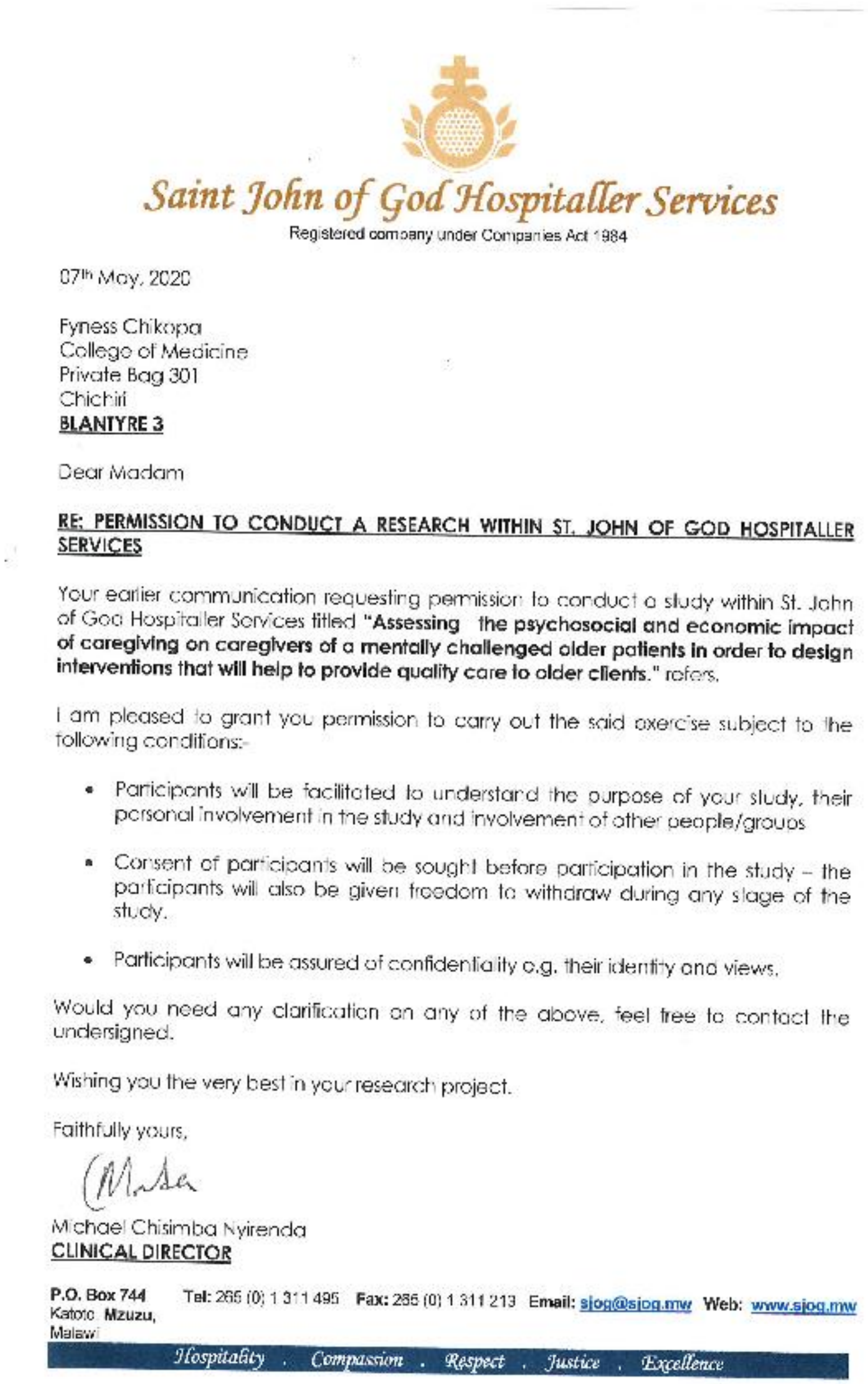
I am a final year student pursuing a Master's degree in Public Health at College of medicine. In partial fulfilment of the course, I am required to conduct a research study in any public health issue. And am expected to submit the research findings to the college. Attached is an introductory letter from the course coordinator for Masters in Public Health.

I will be grateful if this letter will meet your favourable prompt response.

Yours Faithfully,

Fyness Chikopa (MPH student year Two)

Appendix 3: Clearance Letter from Study Site



Saint John of God Hospitaller Services
Registered company under Companies Act 1984

07th May, 2020

Fyness Chikopa
College of Medicine
Private Bag 301
Chichiri
BLANTYRE 3

Dear Madam

RE: PERMISSION TO CONDUCT A RESEARCH WITHIN ST. JOHN OF GOD HOSPITALLER SERVICES

Your earlier communication requesting permission to conduct a study within St. John of God Hospitaller Services titled **"Assessing the psychosocial and economic impact of caregiving on caregivers of a mentally challenged older patients in order to design interventions that will help to provide quality care to older clients."** refers.

I am pleased to grant you permission to carry out the said exercise subject to the following conditions:-

- Participants will be facilitated to understand the purpose of your study, their personal involvement in the study and involvement of other people/groups
- Consent of participants will be sought before participation in the study – the participants will also be given freedom to withdraw during any stage of the study.
- Participants will be assured of confidentiality e.g. their identity and views.

Would you need any clarification on any of the above, feel free to contact the undersigned.

Wishing you the very best in your research project.

Faithfully yours,

Michael Chisimba Nyirenda
CLINICAL DIRECTOR

P.O. Box 744
Katoto **Mzuzu,**
Malawi
Tel: 265 (0) 1 311 495 **Fax:** 265 (0) 1 311 213 **Email:** sjog@sjog.mw **Web:** www.sjog.mw

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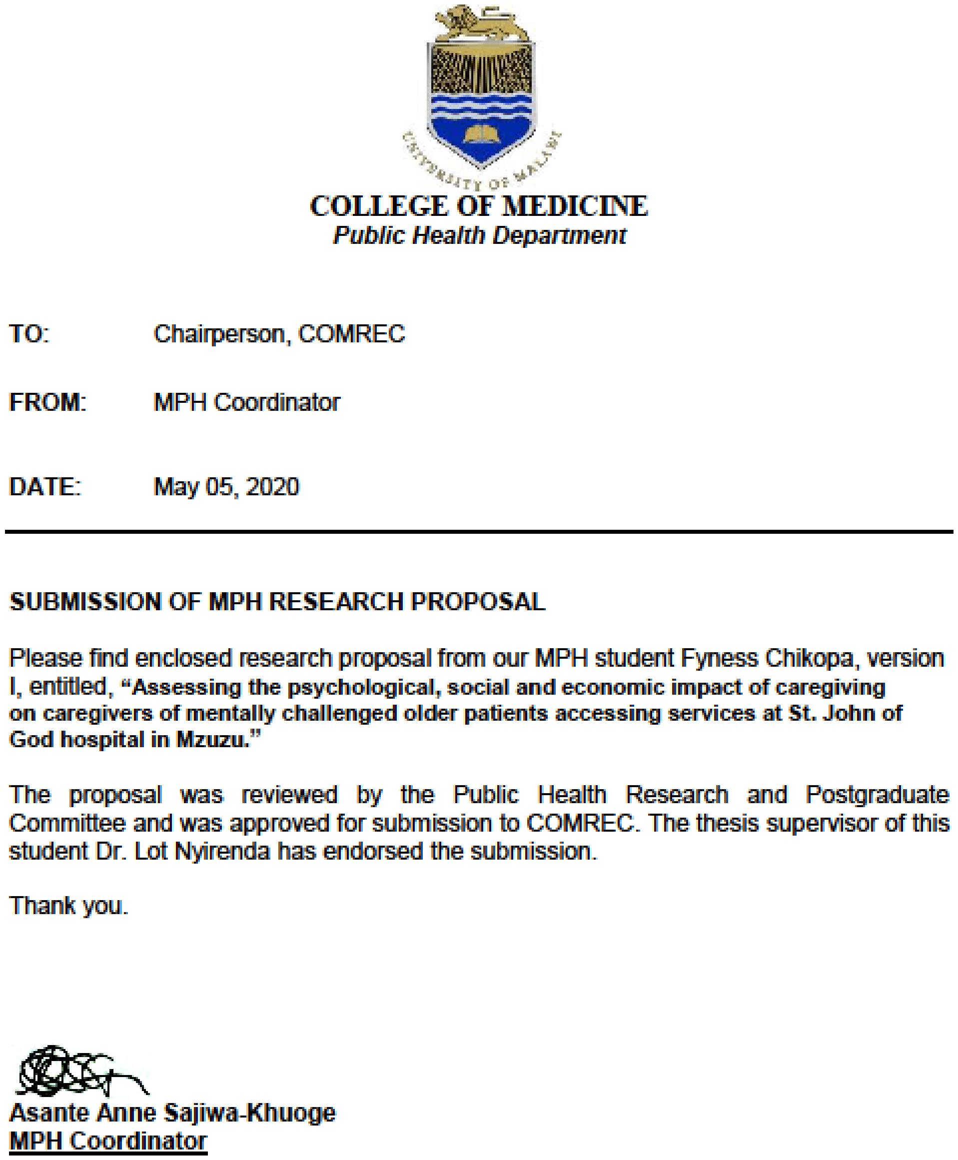
Appendix 4: Letter from MPH Coordinator to COMREC



COLLEGE OF MEDICINE
Public Health Department

TO: Chairperson, COMREC

FROM: MPH Coordinator

DATE: May 05, 2020

SUBMISSION OF MPH RESEARCH PROPOSAL

Please find enclosed research proposal from our MPH student Fyness Chikopa, version I, entitled, **"Assessing the psychological, social and economic impact of caregiving on caregivers of mentally challenged older patients accessing services at St. John of God hospital in Mzuzu."**

The proposal was reviewed by the Public Health Research and Postgraduate Committee and was approved for submission to COMREC. The thesis supervisor of this student Dr. Lot Nyirenda has endorsed the submission.

Thank you.

Asante Anne Sajiwa-Khuoge
MPH Coordinator

Appendix 5: Subjects Consent Form - English Version

COLLEGE OF MEDICINE

Informed Consent Form for Older clients assessing mental health services at St John of God hospital –Mzuzu and who I am inviting to participate in a research titled 'Assessing psychological, social and economic effects of caregiving on caregivers of mentally challenged older patients accessing services at St John of God, Mzuzu".

Name of Principle Investigator : Fyness Chikopa

Name of Organisation : College of Medicine

Name of Sponsor : Self

Name of Project and version : Public health Research project and version 2

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the study with you)**
- **Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form.

PART I: Information sheet

Introduction

My name is Fyness Chikopa, a second-year student at college of Medicine pursuing Master of Public Health. I am currently conducting a study on 'Assessing the psychological, social and economic effects of caregiving role on caregivers in older mentally challenged clients accessing services at St John of God Hospital, Mzuzu'. Caregivers plays a great role in caring the older mentally challenged clients mostly in their homes.

I am going to give you information and invite you to be part of this research. In case there may be other words you do not understand as I go through the information please ask me to stop, I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research

The reason for doing this research is to assess the psychological, social and economic effects of caregiving role on caregivers of older mentally challenged clients in order to improve the quality of care.

Type of research intervention

The research will involve answering questions from a questionnaire guide.

Participant selection

I am inviting about caregivers and health workers caring for clients above 60 years and are mentally challenged clients accessing their services at St John of God hospital to participate in the study.

Voluntary participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. Your refusal to participate in the study will not affect your ability to access services at this institution

Study procedures

About 30 caregivers and about 10 health workers of older mentally challenged clients above 60 years of age will be asked to answer the administered questionnaire on the day of their visit to the hospital. There will be no follow up visit to the hospital.

We do not anticipate any major risk from the study.

Duration

The research will take place over one month. During, the time we will meet you once and each interview will last for 45 minutes.

Risks

Potential benefits

There may be no direct benefit to you from the study. Information gained from the study will help us to assess the psychological, social and economic impact of caregiving role on caregivers and health worker challenged older people and design intervention to provide quality care.

Cost and compensation

There is no cost associated with this study and you will not receive payment for participation.

Confidentiality

The information that we collect from this research project will be kept confidential. You will be identified by a code. Your name will not be used in the study. The information about you that will be collected during the research will be put away and no one but the researchers will be able to see it. Only researchers will know what your number is and will lock that information up with a lock and key. The information will not be shared and be given to anyone except the supervisors and the Malawi College of Medicine Research Ethics Committee (COMREC).

Sharing the results

The knowledge that I get from doing the research will be shared through seminars, journals and in service trainings. The results will also be shared to COMREC and will be published in a peer review. However confidential information will not be shared.

Who to contact

If you have any questions you may ask them now or later, even after the study has started. If you wish to ask questions later you may contact me on **088 657 37 38** or **0999 442 812**.You can ask me any more questions about any part of the research study, if you wish to. And also, if you have any questions relating to your rights to participate or not contact COMREC members on this number **0888 11 89 93.** Do you have any questions?

PART II: Certificate of consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction.

I consent voluntarily to take part as a participant in this research.

Print Name of Participants: ____________________________________

Signature of participant: __________________________

Date: _________________________________

Day/Month/Year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness: ___________________________ **Thumb print of participant:**

Signature of witness: ___________________________

Date : ____________________________

Day/month/year

Statement by the researcher/ person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done: 1. Confidentiality

2. Voluntary participation

3. Potential benefits

I confirm that the participant was given an opportunity to ask questions about the study and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this informed consent form has been provided to the participant.

Print Name of researcher: ____________________________________

Signature of researcher/ person taking consent: __________________________________

Date: ____________________________

Day/month/year

Appendix 6: Subjects Consent Form - Tumbuka Version

COLLEGE OF MEDICINE

Kalata yakumanyisha kutolapo lwande cha awo wakusungilira wachekulu awo wali namatenda ghamuubongo na awo wakugwira tchito za vya umoyo kwa wachilala awo wali namatenda ghamuubongo awo wakugwira ku St John of God hospital ku mzuzu. Ndipo ni awo khuwachema kuti watolepo lwande mukafukufuku wakhuzana na umo kaghanaghaniro, kakhaliro na chuma cha awo wakusungirira wachekulu awo wanamasuzgo ghamuubongo vikukhuzira wusungiriri wawalwali awa awo wakupokera wovwiri ku St John of God ku Mzuzu.

Wakupanga kafukufuku: Fyness Chikopa

Malo gha sukulu : College of Medicine

Wakulipira masambiro : Ndekha

Ndina la kafukufuku na nambala yake: Public health Research project and version 1

Chipepara chakupepha kutolapo lwande chili na magawo ghawiri

- **Kulongosola vya kafukufuku (kugawa vyakafukufuku uyu kwa imwe)**
- **Kukhozgera kwakutolapo lwande (kwakusainila pala mwasakha mutolengepo lwande)**

Mupasikenge pepela langati ili

Gawo la kwamba: Vyakwambirapo

Pakwambira

Dzina lane ndine Fyness Chikopa, msambiri wa chaka chachiwiri ku College of Medicine, khupanga masambiro gha Masters Mu Public Health. Khupanga Kafukufuku wakhuzana na umo kaghanaghaniro, kakhaliro na chuma cha awo wakusungirira wachekulu awo wanamasuzgo ghamuubongo vikukhuzira wusungiriri wawalwali awa awo wakupokera wovwiri ku St John of God Hospital mumusumba wa mzuzu. Wasungiriri wakugwira ntchito yikulu chomene pakupwererera walwari wachilala awo wali namatenda ghaubongo muvikaya vyawo.

Nimupasaninge uthenga wakumuchemani kuti mutolepo lwande pa kafukufuku uyu. Pala pali vinyake ivyo mulekenge kupulikisha apo nimulongosoleleninge, chonde fumbani kuti nilongosole makola. Pala mulinamafumbo paumaliro munganifumba ine panji wanyane awo tikupanga nawo kafukufuku.

Chakulata cha Kafukufuku

Chakulata cha kafukufuku uyu chakuona umo kaghanaghaniro, kakhaliro na chuma cha awo wakusungirira wachekulu awo wanamasuzgo ghamuubongo vikukhuzira wusungiriri wawalwali awa mwakuti tisange thowa zakukwezgera panji kulutisha kapwererero pathazi.

Kovwirapo pa Kafukufuku uyu

Kafukufuku uyu ali namafumbo agho ghakwenera kuzgoreka

Wakwenerera kutolapo lwande

Nkhuchema wapwerereri na awo wakugwira ntchito za umoyo awo wakupwererera walwali wakwamba vyaka 60 (makhumi ghakhonde na limoza) and walwali awa wawe kuti wakulwala matenda ghamuubongo ndipo wakupoka wovwiri ku St John of God mumusumba wa mzuzu.

Kujipereka pa kafukufuku uyu

Kutolao lwande pa kafukufuku uyu khwakujipereka waka ndipo muli na chisankho chakutolapo lwande panji yayi. Kuleka kutolapo lwande kwini kuti kupangishenge kuti muleke kupoka wovwiri kuno chara.

Ndondomeko ya kafukufuku uyu

Wapwerereri makhumi ghatatu(30 caregivers) na wakugwira ntchito khumi(10 health workers) awo wakuwonerera wachekulu wa vilimika vakujupha vyaka makumi ghakhonde na limoza(60 years) ndiwo wafumbikenge mafumbo pa dazi ilo wizirenge kuchipatala. Pazamuwa kalondolondo waliyose yayi ndipo palije chakofya chilichose icho tikuyembekezera.

Kutalika kwa kafukufuku uyu

Kafukufuku uyu watolenge mwezi umodza ndipo tisanganenge namwe kamoza pera apo mukwenera kuzgola mafumbo kwa phindi zakukwana 45 (45 minutes)

Vwakupindura kwawakutolapo lwande

Palije chakupindura chilichose chakuoneka kwa awo wakutolapo lwande pakafukufuku uyu, ivo tifumbenge apa vitovwirenge kusanga chakulata cha kafukufuku uyu nakupanga nthowa zakulutishira pathazi wovwiri wa awo wakusungilira walwali

Malipiro kwa awo wakutolapo lwande

Palije malipiro ghalighose ku awo wakutolapo lwande pa kafukufuku uyu

Chisisi

Vyose ivo muzzgolenge visungikenge mwachisisi. Munyikwenge nanambala ndipo Dzna linu ligwirishikenge ntchito chara mukafukufuku uyu. Vyose vyakukhuza imweviwenge padera ndipo uyo wamanyenge vaimwe ni munthu uyo wakupanga kafukufuku uyu pera mbwenu. Vyakukhuzana na imwe visungikenge mwachisisi. Palije uyo watolenge vyakukhuzana na imwe kupatulako walawiriri wa ku Malawi College of Medicine Research Ethics Committee (COMREC).

Kugawa ivyo vasangika

Ivyo nisangenge mu kafukufuku uyu vizamugawika kwenderaa muma seminars, kulembeka muma journals namuma service trainings. Vizamugawikaso ku COMREC and vizamulembakaso nawakulemba wanyake kwambula kufumisha vyachisisi.

Uyo wakwenera kukhwashika pala pali vinyake

Pala pali vakufumba vilivose munganifumba sono, panji nyengo yinyake panjiso paumaliro pa kafukufuku uyu. Pala mukuuhumba kufumba pala kafukufuku wamala mugaiyimbira foi pa maambala agha **088 657 37 38** panji **0999 442 812.** Munganifumba chilichose pachilichose palamukukhumba. Pala muli nama fumbo ghanyake pakukhuzana na ufulu winu wakutolapo lwande panji yayi mungayowoya na wa ku COMREC pa nambala iyi **0888 11 89 93.** Muli na mafumbo?

Gawo lachiwiri: Kuzomerezga kutolapo lwande

Nawerenga panji waniwerengera vyose vwakukhuzana na kafukufuku iyi. Nanguwa na mpata wakufumba mafumbo ndipo nazgoleka mwakwenerera ndipo niliwakukhutira. Khuzomerezga kutolapo lwande pa kafukufuku uyu mwakujipereka.

Dzina____

Saini____

Dzuwa: Dadzi______Mwezi_______Chaka____________

Para wakutolapo lwande wakumanya yayi kuwerenga

Khukhozgera kuwerenga kwa kutolapo lwande pa kafukufuku uyu kwa wakutolapo lwande ndipo wakutolapo lwande wanguwa namupata wakufumba mafumbo. Khukhozgera kuti wakutolapo lwande uyu wakhumba nadi kutolapo lwande

Dzina la wakukhozgera_______________________________

Saini____

Chala/Munwe cha/wa wakutolapo lwande_______________

Dzuwa: Dadzi______Mwezi_______Chaka____________

Kwa uyo wakufumba mafumbo

Nawerenga mwakukwanira vyakukhumbikwa kwa wakutolapo lwande ndipo mwaumanyi wane naoneshesha kuti wakutolapo lwande wapulikisha kuti chisisi chiwengepo, kutolapo lwande khwakujipereka, na vyakupokera pa kafukufuku uyu.

Khusimikizga kuti wakutolapo lwande wanguwa namupata wakufumba mafumbo ghakukhuzana na kafukufuku uyu ndipo mafumbo ghose agho ghafumbika ghazgoleka mwakwenerera ndipo mwakufikapo kwakuyana na umanyi wane. Khusimikizga kuti wakutolapo lwande uyu wanda chichizgike pakuzomerezga kutolapo lwande ndipo kutolapo lwande uku kwatoleka mwaulere namwakujipereka.

Ndipo pepala la vyose vyakukhuzana na kafukufuku uyu vyaperekeka kwa wakutolapo lwande uyu.

Dzina la wakufumba mafumbo____

Saini ya wakufumba mafumbo/wakutolapo lwande______________________________

Dadzi: Dzuwa_________Mwezi______Chaka____________

Appendix 7: Interview Guide for the Caregiver - English Version

PART A: DEMOGRAPHIC DETAILS

Gender	Male…………………...1 Female..........................2
Age	18- 45 years……………1 46-60 years……………2 Above 61years………...3
Relationship with the patient	Spouse………………….1 Parent…………………..2 Other relations…………3 Sibling…………………4
Duration for caring the patient	6 12months………………1 13-60 months……… …...2 Above 61months………..3
Marital Status	Single…………………1 Married……………….2 Separated……………..3 Divorced......................4 Widowed…………….5 Never Married……….6
Educational level	Never………………….1 Primary level………….2

	Secondary level……....3 Tertiary level………… 4 Other…………………..5
Employment	Formal employment…...1 Self-employed…………2 Unemployed…………...3 Small scale business…...4 Large scale business…...5 Others…………………6

INTERVIEW GUIDE FOR CAREGIVER

- What does your role as a caregiver involve?
- How does caregiving affect you psychologically?
- Are there moments you feel stressed, depressed and anxious in course of caregiving?
- May you provide examples of such moments?
- How does caregiving affect your relationship with others? Probe: Stigma, isolation
- How does caregiving affect you economically? Probe: costs for transport, inability to participate in income generating activities, costs of food, medication.
- How does such impact affect the quality of care received by the patients?
- What recommendations would you suggest to address the psychological, social and economic impact? Probe: what relatives should do, what health workers should do, what non-governmental organisations should do?

Appendix 8: Questionnaire - Tumbuka Version

PART A: DEMOGRAPHIC DETAILS FOR THE CAREGIVER

Mwanalume payake mwanakazi	Mwanalume………………1 Mwanakazi..........................2
Muli na vilimika vilinga?	Kulekezga 17 ………...1 18- 39 ……………….. 2 40-60 ………………..…3 Kuyambira 60 kuluta kunthazi………..4
Pali ubali uli na muluwali uyu?	Tili pa banja…………………1 Mbapapi wane……………….2 Ni mwana wane………….....3 Ubale unyake (Lembani)……4
Mwakhala kusamalira muluwali uyu kwa nyengo itali uli?	Mwezi 6 -12 ………………1 Mwezi 13-60……… …......2 Kujumpha mwezi 61………3
Ka muli pa nthegwa?	Nichali nekha……………………1 Nili pa nthengwa………………..2 Tili kupatukana………………….3 Nthengwa ili kumala......................4 Mwanalume walikutayika/ Mwanakazi wlikutayika……………..5 Nindatolepo/Nindatengwepo ………..6

Ka sukulu mulikufipa mphani	Nindaluteko…………………l Ku pulayimale………………2 Ku sekondale……................3 Ku kolegi/yunivesiite……… 4
Mukugwira ntchito uli?	Kungwira mu boma/mucompane…...1 Kupanga vinthu vane…………2 Nili pa ntchito yayi…………...3 Nkhupanga bizines yidoko waka…...4 Nkhupanga bizinesi yikulu…...5 Zgola linyake(lembani)………………….6

INTERVIEW GUIDE FOR CARE GIVER

1. Mukatiphalirako kuti ka pa udindo winu wkuluwazga waluwaili mukupanganga vichi na vichi?
2. Nanga udindo uyu wakusamalira muluwali ukumukhuzani uli mu maganizo?
3. Nanga pala mukusamalira muluwali, pali nyengo zinyake zakuti mukuwa wakukhumudwa nakukwinyiririka?
4. Tiphalirako nyengo izi mwakukhala mukukhumudwa na kunyinyirika mu nyengo yakuluwazga muluwali?
5. Nanga mu nyengo yakuluwazga muluwali, ukhaliro win una wanthu wangukhuzika uli?
6. Nanga kusamalira muluwali kwakhuza uli chitukuko cha pa nyumba pinu? Nkhani ya kwayendero, kutondeka kutola nawo luwande pa ma buzinesi?
7. Nanga namu umu mwakhuzikila mamaganizo na chiukoko, kwakhuza uli chisamaliro ichi mwakhala mukupeleka kwa muluwali?

8. Nanga mukapeleka maganizo uli kuti kukhuzika kwinu muyanoyano kweniso chitukuko kuchepe? Mukowona kuti wabale wangacjhitapo uli? Nanga wakuchipatala wakachitapo vichi? Nanga wa boma wangachitapo vichi? Nanga mabungwe yangatolapo luwande uli?

Appendix 9: Interview Guide for Health Workers

PART A: DEMOGRAPHIC DETAILS

Gender	Male…………………...1 Female..........................2
Age	Up to 17 years………..1 18- 39 years……………2 40- 59 years……………3 Above 61years………....4
Duration caring for the Mentally challenged client's patient	6- 12months……………1 13-60 months……… ....2 . Above 61months………3
Marital Status	Single…………………1 Married………………2 Separated……………..3 Divorced......................4 Widowed……………..5 Never Married………..6
CADRE	Nurse…………………1 Clinician……………...2

PART B: INTERVIEW GUIDE TO HEALTH WORKERS

- What do you perceive to be the role of the caregivers for the mentally challenged older persons?
- What is your perception of the psychological, social and economic impact on caregiving on such care givers?
    - Probe: stress, depression, anxiety, stigma, social isolation, general care costs, opportunity costs
- How does such impact affect the quality of care received by the patient?
- What recommendations would you suggest to address the psychological, social and economic impact?
    - Probe: what relatives should do, what health workers should do, what ministry of health should do, what non-governmental organisations should do?

Appendix 10: Certificate for Ethical Approval

UNIVERSITY OF MALAWI

CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.03/20/3035 - Assessing the psychological, social and economic impact of caregiving on caregivers of mentally challenged older patients accessing services at St John of God hospital, Mzuzu by Fryness Chikopa

On 02-Sep-20

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC some of which are indicated on the next page for your study

Prof. E. Umar -Chairperson (COMREC)

02-Sep-20

Date

Approved by
College of Medicine
02-Sep-2020
(COMREC)
Research and Ethics Committee