THE EXPERIENCES OF INFORMAL CARE GIVERS IN CARING FOR PATIENTS WITH CANCER AT OCEAN ROAD CANCER INSTITUTE, DAR ES SALAAM, TANZANIA

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By

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CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance by the Muhimbili University of Health and Allied Sciences a dissertation entitled ***The experiences of Informal Care givers in caring for Patients with Cancer at Ocean Road Cancer Institute Dar es Salaam Tanzania*** in partial fulfillment of the requirements for the degree of Master of Critical Care and Trauma of Muhimbili University of Health and Allied Sciences.

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Dr Edith Tarimo

(Supervisor)

Date: ______________________________

DECLARATION

AND

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I, Raya Mohamed Abdalla declare that this dissertation is my own original work and that it has not been presented and will not be presented to any other University for a similar or any other degree award.

Signature…………………………… Date…………………………….

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DEDICATION

This work is dedicated to my brothers Talib, Salum and Abdalla who always supported and encouraged in my academic career. I thank GOD for such kind of brothers.

ABSTRACT

Background

Cancer is a major chronic problem which affects many people directly or indirectly. It causes much suffering among patients and families. Cancer patients require long-term treatment and a continuing need for care. Consequently, informal caregivers in various settings are now taking on the responsibility of caring for patients with cancer. Such informal caring may involve physical, psychological and economic stresses. In Tanzania, informal caregivers have become so essential that they provide large part of the care needed in hospitals and at home.

Aim

The aim of this dissertation is to understand the experiences of informal care givers in caring for cancer patients at Ocean Road Cancer Institute in Dar es Salaam, Tanzania.

Method

Study design was explorative qualitative study. The sampling technique was purposeful sampling. Data was collected through face to face interview and Focus group discussions. A sample of seven (7) and ten (10) informal care givers participated in face to face interview and two focus group discussions respectively. Content analysis approach was used to analyze the perspectives of the informal caregivers. The study took place between May and June 2013.

Findings

Caregivers of patients with cancer experienced many problems including psychological such as stress, and worries. They were disappointed with long waiting time for radiotherapy services at the hospital. They also experienced social problems such as inadequate social support during hospitalization such as food and lodging for caregiver from up country. The time spent in the hospital resulted into less time devoted for child care back home. Most participants stated that the task of taking care of the patients interfered with their daily activities which increased the economic problem they already had. In order to cope with the caring responsibilities, the participants desired to have professional, social, and financial support from the government and Non-Governmental Organizations.

Conclusions

Caregivers of patients with cancer experience many problems such as psychological, emotional, economical and social problems. These problems are influenced intrapersonally, interpersonally and communally. Professional assistance, public awareness social and financial support by the government and NGO's are important to enhance coping strategies.

Recommendations

The government should put more effort on buying another radiotherapy device to reduce the length of hospitalization waiting for therapy and hospital management should support caregivers by providing food and lodging those caregivers who are coming from far regions and they lack relatives to support them in the city.

Keywords:

Care giving, Informal caregivers, Experiences, cancer

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ABBREVIATIONS

ORCI - Ocean Road Cancer Institute.

MNH - Muhimbili National Hospital

MUHAS - Muhimbili University of Health and Allied Sciences

QOL - Quality Of Life

INT - Interview

FGD - Focus Group Discussion

CHAPTER ONE

INTRODUCTION

1.1 Background

Cancer is a major chronic problem which affects many people directly or indirectly. It causes much suffering among patients and families. A cancer patient, once being diagnosed as such, may undergo various crisis moments along the trajectory of his/her illness. The initial diagnosis of cancer may be one, and the diagnosis of relapse may be another. Cancer treatment, be it of curative or palliative intent, can be a demanding period for the patient and family both physically and emotionally. As the disease advances, disabilities and symptom progression are major sources of sufferings. Finally, when facing death, anticipatory grief can be overwhelming (Girgis, Johnson, Aoun & Currow, 2006). However, today more people are living longer, with chronic and debilitating illnesses, than ever before. Recent treatment, economic and policy changes have resulted in a shift from inpatient to outpatient care for many serious illnesses, including cancer, placing an increased caregiving responsibility on family and friends of ill patients (John, Kathryn, Patricia & Robin, 2003). Informal caregivers may be providing essential and unpaid support for patients that healthcare systems cannot provide. Throughout this journey, the family members, being with the patient, are also facing their own stresses and changing roles which may be directly or indirectly related to the patients' illness (Girgis et al, 2006). The incidence of patients with cancer increases rapidly, according to global cancer statistics, Jemal stated that about 12.7 million new cancer cases have occurred worldwide; 56% of these new cases have occurred in economically developing countries. (Jemal et al, 2011). ORCI statistics (2009), figures show that for the few decades the number of cancer patients treated at ORCI has been rising steadily example in 1975 were 48 new patients, 1989 were 916, 1995 were 1639 and in 2004 were 2866 new cases (ORCI,2009). With this increasing number of persons with cancer, and with the shift from inpatient to outpatient treatment, the importance of informal caregivers continues to increase (Osse et al, 2006).

On the other hand, care giving can be highly rewarding, but it can also be burdensome and pose a risk for depression, anxiety and sleep disruption (Joad, Mayamol & Chaturvedi, 2011). The majority of research examining the psychological, emotional, economical and physical impact of providing care to relative with cancer has been conducted in high income countries. However, in low income countries such as Tanzania there is a paucity of research examining the experience of providing care to relatives with cancer. Therefore, describing experiences of caring for cancer patients is important in the process of finding ways of helping or supporting caregivers to provide proper care for their relatives.

1.2 Problem Statement

The diagnosis of cancer presents a major event not only to the patient, but also to the family caregivers (Girgis et al, 2006). Informal caregivers are major form of support for the cancer patient because they provide most care outside of the hospital environment (Osse et al, 2006). Numerous studies have documented that a diagnosis of cancer is associated with high levels of stress to patients as well as informal caregivers. Specific sources of stress to caregiver include learning to cope with the unanticipated event of having close relative with cancer, varying physical and psychological demands of patients care and the likelihood of lifelong dependency. The problem of stress is also compounded with the lack of information and resources to care for the patients. However, studies addressing the experiences of informal caregivers in giving care to cancer patients have been carried out in various countries particularly in high income countries. While it is well known that caring for cancer patient is challenging, little is known concerning issue of informal care-giving to cancer patients in low income countries like Tanzania. Caring for patients with cancer may put the caregivers in our setting at risk of developing various types of health problems (mentally, physically and emotionally). If the caregivers’ concerns will not be addressed, these caregivers and their dependants may end up with unrecognized challenges.

1.3 Rationale

This study contributes knowledge on experiences of informal care to patients with cancer at Ocean Road Hospital in Tanzania. The study is therefore significant because it allows the caregivers to express their needs. The study also puts nurses in a better position to understand the caregiver's experience, and also facilitates nurses to find ways of supporting the informal caregiver in their role of caring for cancer patients at home. Overall, the study gives broader picture on how these experiences may contribute to deterioration of health among informal caregivers and incites more researchers toward designing other studies related to it.

1.4 Objectives

General objective

- To explore the experiences of informal caregivers for patients with cancer at Ocean Road Cancer Institute, Dar es Salaam, Tanzania.

Specific objectives

- To assess the perspectives of informal care while caring for patient with cancer
- To describe how caring for patients with cancer affects the caregivers' lives
- To investigate types of support provided to the caregivers.
- To investigate the coping resources employed to minimize the burden of caring on the informal caregivers.

1.5 Operational definitions

- In this study, caregivers are unpaid people who give care to patients with cancer.
- In this study, informal caregiver(s) are family members, friends, neighbors who are caring for a relative with cancer at Ocean Road Cancer Institute
- In this study, experiences refer to the feelings, perception, fears and attitudes experienced by informal caregivers in caring for cancer patient.

1.6 Conceptual model

The Ecological Perspective Model: this is a multilevel approach which was developed by Mc.Leroy and colleagues (1988). The model was created based on health behavior control and improving health of people. The ecological perspective emphasizes the interaction between, and interdependence of factors within and across all levels of a health problem. It highlights people’s interactions with their physical and socio-cultural environments.

Two key concepts of the ecological perspective help to identify intervention points for promoting health: first behavior both affects, and is affected by multiple levels of influence, second individual behavior both shapes, and is shaped by the social environment.

Mc Leroy and colleagues (1988) explain the three levels of influence for health related behaviors and conditions. These levels include:

- *Intrapersonal level* which represent individual characteristics that influence behavior, such as knowledge, attitude, belief and personality traits.

- *Interpersonal level* which represents the interpersonal processes and primary groups, including family, friends, and peers that provide social identity, support and role definition.

- *Community level*: this include three factors which are
    - ✓ **Institutions factors** this represents rules, regulations, policies, and informal structures which may constrain or promote recommended behaviors.
    - ✓ **Community factors** this represents social networks and norms, or standards which exist as formal or informal among individuals, groups and organizations.
    - ✓ **Public policy**: local, state and federal policies and laws that regulate or support healthy actions and practices for disease prevention, early detection, control, and management.

In practice, addressing the community level requires taking into consideration institutional and public policy factors, as well as social networks and norms.

The model for health focuses on both individuals and social environmental factors as targets for health promotion interventions. It addresses the importance of interventions directed at changing interpersonal, organizational, community and public policy factors which support and maintain unhealthy behaviors. The model assumes that the appropriate changes in the social environment will produce changes in individual, and that support of individuals in the population is essential for health promotion. Therefore, informal caregivers need social support from social environment to maintain their psychological and physical health. This dissertation drew ideas from this model to guide the study objectives, and construct the interview and focus group guides. Furthermore, this model is being loosely used to describe the findings, discussion and recommendations.

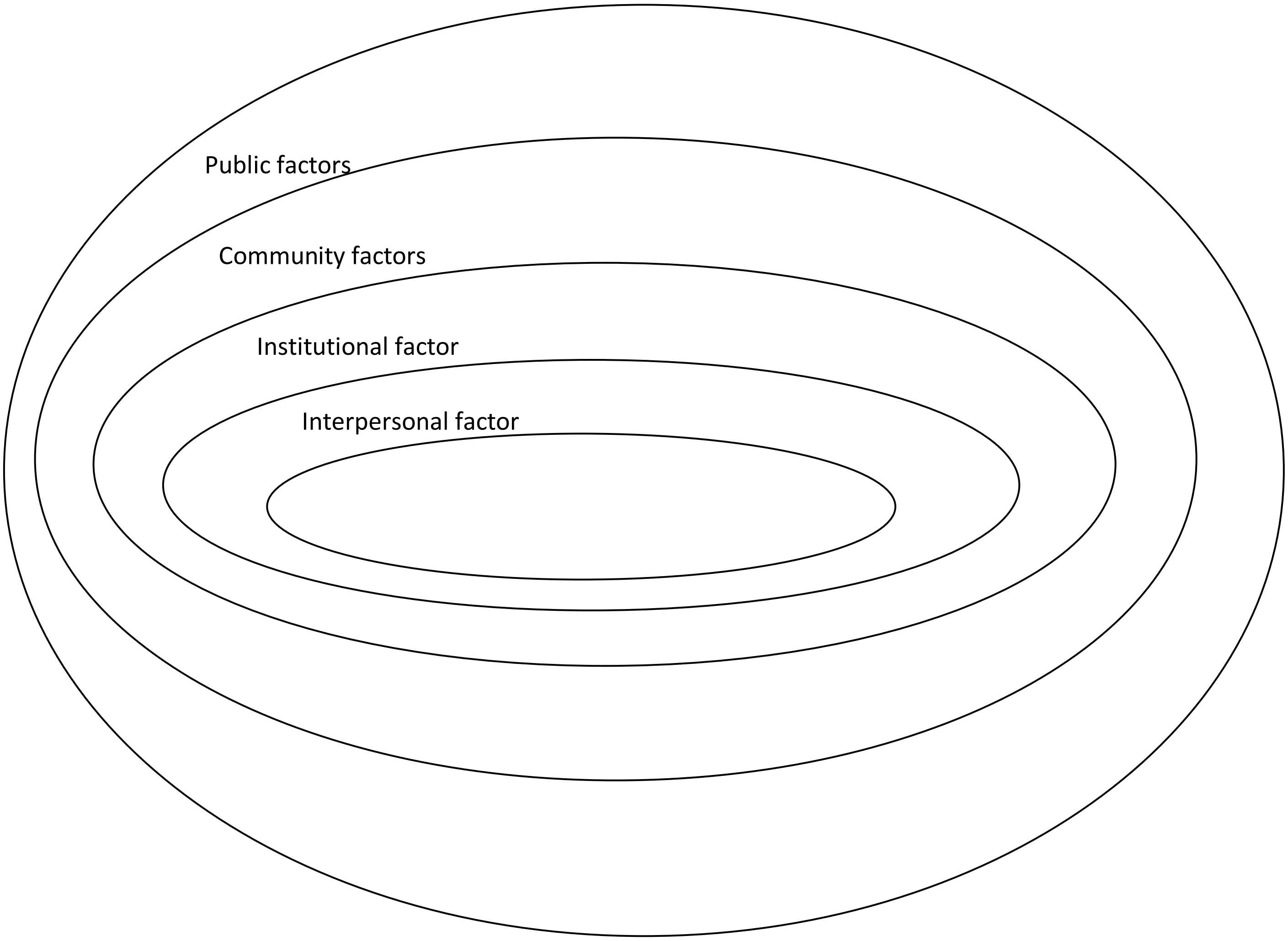

Figure 1: Diagrammatic representations of the Ecological Perspective Model: multilevel, interactive approach.

CHAPTER TWO

LITERATURE REVIEW

Care giving in general

Researchers have found that care giving leads to reduced working hours, wage penalties, significant outlays for medical treatment, as well as other direct costs such as hiring of home health workers. Caregivers also sacrifice leisure time and time managing a patient's treatment, among other indirect costs (Courtney, Scott & Audie, 2010). Difficulty communicating and negotiating family roles can hinder patients' and caregivers' ability to support one another, can decrease couples' intimacy, and have a detrimental effect on marital and family relationships (Porter, Keefe, Hurwitz & Faber, 2005). While caregivers' health status is initially like the normal population, caregivers often report more problems with fatigue, sleep disturbances, and impaired cognitive function than non caregivers. Over time, caregivers' burden and strain increases. Caregivers' physical well-being is at greater risk because they have little time to rest, engage in fewer self-care behaviors (e.g., exercise), or often fail to seek medical care for themselves when sick (Carter, 2002)

Compassion fatigue in family caregivers may be the combination of hopelessness, helplessness, apathy, and emotional disengagement that occurs after a prolonged exposure to suffering. Compassion fatigue depends upon concern and an empathic response from the caregiver for the care recipient, and this concern and emotional attachment is the motivation for the caregiver to relieve the suffering. If a caregiver experiences an empathic response, coupled with competing life demands and a lack of satisfaction from care giving they may be at risk for compassion fatigue. Nurses are also able to reduce perceived care recipient suffering through interventions such as medication and behavioral management. Additional interventions may utilize online resources such as chat groups as well as phone interventions that fit into the complex lives of caregivers (Day & Anderson, 2011).

Care giving to patients with cancer

Regardless of the known roles of informal caregiver in caring for a cancer patient, many studies have revealed challenges that caregivers face in caring for cancer patient. Bevan in her case study reported that unlike professional caregivers such as physicians and nurses, informal caregivers, typically family members or friends, provide care to individuals with a variety of conditions including advanced age, dementia, and cancer. This caregiver's experience is commonly perceived as a chronic stressor, and caregivers often experience negative psychological, behavioral, and physiological effects on their daily lives and health (Bevan & Sternber, 2012).

Care giving for cancer patients include personal care, assistance with mobility, transportation, communication and housework, emotional support, organizing appointments, social services, assistance with social activities, shopping, meal preparation, managing finances and management and coordination of medical care, including the complex management associated with patients in pain, administration of medications (Osse et al. 2006)

Psychological effect of care giving

Family caregivers of patients in the advanced stages of cancer reported to experience a high level of psychological distress, which increases significantly as the patient loses autonomy. There is a suggestion that health care policies and programs need to be revisited in order to take the reality of these patients and their families into account (Dumont et al, 2006) In the United Kingdom, a study was conducted for the purpose of understanding the multidimensional experience of patients and their caregiver as they progressed from receiving a diagnosis to the terminal phase of the disease. The results show the evidence of physical, social, psychological and existential distress even before a diagnosis was confirmed. Social decline followed a similar trajectory to that of physical decline, whereas psychological and existential distress was typically acute around diagnosis and again after initial treatment. Following acute psychological and existential distress before and immediately after diagnosis, patients and their relatives worked hard, despite physical and cognitive decline, to foster a sense of hope and well-being. Psychological and existential well-being were challenged again after initial treatment and as the tumors progressed (Cavers et al, 2012)

Sherwood in his study aimed in assessing physical and mental health effects of family care giving revealed that care giving often results in chronic stress, which compromises caregivers' physical and psychological health, and depression is one of the common negative effects of care giving (Sherwood & Given, 2006). The caregivers reported that they had no time for self-care, and care-giving experience drained them of energy and enthusiasm and affected interactions with other family and friends. They also had a disruption in personal routines and restriction on leisure time (Girgis et al,2011)

Physiological response to care giving

Over half of family caregivers have been reported with chronic health problems of their own, such as heart disease, hypertension, and arthritis. These health problems can be exacerbated by the stress of care giving (Girgis et al, 2006). Compared to non-caregivers, caregivers often experience psychological, behavioral, and physiological effects that can contribute to impaired immune system function and coronary heart disease, and early death (John et al, 2003)

Emotional response to care giving

Although many caregivers derive deep satisfaction and feel positively about caring, feelings of sadness anger, resentment and a sense of inadequacy are common reactions (Girgis et al, 2006). The caregivers' highest amount of burden is placed on their emotional needs, emphasizing the importance of providing appropriate medical and psychosocial support for caregivers to cope with emotional difficulties they face during the patients' treatment process. (Parvataneni et al, 2011).

Bevan and Stenber in their study mentioned challenges that caregiver faces in caring for cancer patient. These are: having multiple caregiving responsibilities, subsisted on limited finances, and managing their own multiple health conditions. Also lacking the physical presence of a support system, cleaning, driving, preparing meals, and coordinating medication, oxygen and other treatment-related activities contribute to the challenges. Severe emotional distress, significant fatigue, sleep impairment, and difficulty maintaining focus and energy are also reported (Bevan & Stenber, 2012).

The emotional and social burden of care giving contributes to significant mental health morbidity, with elevated rates of anxiety, depression, distress and poor quality of life among caregivers of patients with cancer (Girgis et al, 2006).

A study done in India indicated that caregiving to children with cancer among mothers and fathers of these children was the most time-consuming and difficult activity. Both mothers and fathers were responsible to give emotional support to the child with cancer, and supporting other children in the family. Mothers also found it difficult and time-consuming to manage behavioral problems and to structure and plan activities for the family. Fathers found it difficult to manage work and organize care for the child at the same time, and to give their partner emotional support (Svavarsdottir, 2005).

Socio - economic response to care giving

Spouses/partners are at increased risk for both physical and psychological disturbances, and this will vary depending on the quality of the marital relationship, the nature and type of illness, functional impairment, changes in family functioning, including finances and role changes, age, gender and coping style of the spouse/partner. Joad and his colleague in their study reported that only 16% of care givers reported to have time to attend social gatherings, most of participants had no time to attend social gatherings, most of care givers reported that they did not have time to socialize. The visit of family and relatives were of helped in psychological support, boosting the morale, and preventing depression. Some received support from religious organization. Most caregivers could not devote enough time to their children. They felt their care-giving role had affected their children's studies, general care and health. Some caregivers felt they could not spend enough time with their spouses, they felt that their care-giving role affected their other relationships and interactions (Joad et al, 2011).

Informal care of persons and friends both with a serious illness provides many benefits to patients, but can be costly to family in financial terms and in terms of the value of time spent in care giving and learning new care giving skills (Courtney et al, 2010)

In the study done in USA, financial problems were reported by all of the families, including issues around employment, difficulties in understanding insurance and other benefits, and insufficient income to meet all of the family's needs with the added burden of the cost of caring for a patient with a brain tumor. For some, the patient's job was either lost or threatened because of the disease (Schubat, Kinzie & Farace, 2008). Caregivers also felt that they had reduced opportunities of career advancement due to their care-giving role. Economic burden was higher for caregivers. Spouses faced higher economic burden than other relatives or friends (Courtney et al, 2010).

Coping strategies with care giving role

It has been stressed that in order to have better quality of life the needs of the families must also be assessed and addressed. One basic need is information which can be provided by health professional. Nurses can play an important role in teaching the families many skills including problem solving strategies with daily living and personal and family stressors. In a study done in sub Saharan countries (South Africa and Uganda) multicenter study, Selman detected that lack of knowledge and provision of information adversely affected patients and caregivers' ability to cope with their situation, directly affecting caregivers ability to care for patients as well as patients ability to care for themselves and plan for the future. For both groups, not having the information they needed was related to anxiety about the disease and the future (Selman et al, 2009). Parvataneni demonstrated that the caregivers need additional resources and information on coping with the emotional burden of the disease. The findings indicate that the information obtained during clinic visits is inadequate to satisfy these needs. Treating the caregivers' emotional needs can improve their quality of life and in turn improve the overall care of the patient. The caregivers' need to share the experience with someone else; thus, distributing information on support groups and educational sessions at clinic visits may be effective methods to satisfy this need (Parvataneni et al, 2011).

In a study done in Sudan to assess quality of life of stable Sudanese women with cancer and their family care giver, shown that Cancer patients in stable condition and with psychosocial support can hope to enjoy good Quality of Life (QOL) with treatment. The findings constitute an evidence base for the country's cancer care program to boost national health education about prognosis in cancer. Families living with women cancer patients are vulnerable and need support if the patient is recently diagnosed, less educated, single, not formally employed, and the caregiver is female, parent, younger, less educated unemployed and feels sick. The patient and caregiver should be regarded as a unit for treatment in cancer care. The findings suggested that clinicians need to invest in the education and support of family caregivers in order to enhance their caregiving role (Awadalla et al, 2007). It was concluded that provision of help and support, within and outside the extended family, including health education and other services, was perceived as helpful (Shortman et al, 2012). In a study done in South Africa, patients and family members expressed different levels of and fluctuating manifestations of information need. Forie (2008) concluded that more attention should be paid to unexpressed and dormant information needs. Consequently, since the informal caregivers provide most of psychological support to the patient, they should be recognized for their psychological and technical support needs in giving palliative care (Joad et al, 2011).

The patients' caregivers reported that they were not able to find out all they had wanted to know about the patient's medical condition and how it would affect him or her. Caregivers identified a need for updates on the course and prognosis of the disease and treatment. Not knowing much about the illness and fear of not knowing what to do or to expect was perceived as very stressful and led to an increase in caregiver anxiety, increasing frustration and uncertainty. Understanding details relating to the illness were reported to help caregivers cope (Girgis et al, 2006).

Joad suggested that Clinicians need to recognize that patients and their caregivers react to cancer as a unit and programs of care directed only toward patients are seldom sufficient to meet patients’ needs because so much of the patient's care depends on family caregivers. Thus to provide optimal comprehensive cancer care, the care plan must focus on these patient-caregiver units (Joad et al, 2011). Therefore, caregiving to patients with cancer may impose diverse critical challenges to the informal caregivers in Tanzania.

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CHAPTER THREE

METHODOLOGY

3.1 Study Design

This study was designed to achieve insight on the perspectives of informal caregivers for patients with cancer. Therefore, a qualitative explorative and descriptive approach was used. This method is concerned with studying human experiences from the view point of the of the research participants.

3.2 Description of the study area

This study was conducted in Ocean Road Cancer Institute (ORCI). This institute is located in Ilala District, Dar es salaam Region. The institute provides inpatient and outpatients services for patients with cancer. The patients from other regions of Tanzania or those who cannot afford to go and come back after treatment are also treated at ORCI. The institute comprises of 4 wards: one ward for very serious patients (both male and female), one for male patients and two wards for female patients. Because of limited space in the Ocean Road surroundings, the institute is using another building in Muhimbili National Hospital (MNH) for children with cancer. This study did not involve participants from (MNH).

3.3 Target population

The study population comprises of informal caregiver who were caring for patients with cancer at ORCI. These informal caregivers were the one who stay with the admitted patients in the hospital and those who brought their patients to get chemotherapy or radiotherapy at ORCI.

3.4 Inclusion criteria

The following caregivers were included in the study:

Any caregivers with age of between 18 – 60years old

Any caregiver who had caring role for the patient with cancer for more than three months

3.5 Exclusion criteria

The following caregivers were excluded :

Any caregiver with a medical/nursing background

3.6 Sampling technique (sampling method)

A purposive sampling procedure was used in selecting participants for this study. Purposive sampling involved the conscious selection, of participants or elements that are typical or representative, in other words participants that had specific characteristics of the phenomenon (or topic) being studied (Burns and Grove 1997). Example in this study the participants were male/female caregivers with age of between 18 and 60years old, who were caring for the patients with cancer for more than three months. This period was considered to be adequate period for the potential participants to have reasonable experience. Also the participants were not supposed to have medical/nursing background.

3.7 Sample size

The estimated sample size was 7 informal caregivers for interview and 10 participants for two Focus Group Discussions. However the actual sample size for interviews was determined by the principles of saturation, the data collection continued until no new information was gained from interviewee. Bloor and colleague explained data saturation as a continuation of sampling and data collection until no new conceptual insights are generated (Bloor et al, 2006).

3.8 Data collection

Seven (7) face to face interviews and two focus group discussions (FGDs) were conducted. Six females and one male participated in interviews. Five males and five females with various relationships with patients (eg the patient's sister, patient's daughter, patient's brother etc.) participated in FGDs sessions. Conduction of interviews was stopped after realizing that no more information would be gained by interviewing more caregivers. In focus group discussions the male and female participants were separated for the purpose of eliciting ideas, thoughts and perceptions about the topic. The participants share their views freely when they are separated than when they were mixed (male and female) FGDs were planned to generate participants' shared perspective on care giving.

Study participants were approached individually for face to face interviews. During this contact the researcher explained the study objectives and also asked for their willingness to participate in the research. Participants were informed of their rights to participate or refuse to participate in the study. The participants who agreed to participate voluntarily in the research were requested to sign a consent form to ensure their participation in the study. The interview and Focus Group Discussion was conducted in the venue that was determined suitable for privacy. Data collection was guided by semi structured interview guide which contained eleven questions and FGD guide which contained six questions. Examples of questions for face to face interview were (i) Please tell me about your experiences of caring patients with cancer.(ii) What was your reaction towards your patients condition? (see appendix I). The interview guide was translated into Kiswahili (see appendix II) because all potential participants speak Kiswahili.

Example of questions in FGD guide was: Explain your experiences of caring for patients with cancer? (see appendix III). The FGD guide was translated into Kiswahili (see appendix IV)

The researcher conducted all interviews after gaining the potential participants' permission to use the audio- recorder to capture the interviews which were transcribed verbatim. Also field notes were written immediately after each interview to ensure that non verbal responses were captured. During FGDs, the moderator (researcher) led the discussion and kept the conversation flowing while the researcher assistant recorded the discussion and took notes.

Interviews were conducted to gather data on psychological, social and economic challenges that caregivers faced. All interviews were digitally recorded and field notes were taken.

The quality of the interview was ensured by employing a high quality audio-recorder and use of participants who met the stipulated inclusion criteria. Before actual data collection, the interview guide was pre-tested at Ocean Road Cancer Institute with three participants to make sure that the questions were clear and yield responses that were in line with the study objectives. The interviews were immediately transcribed to determine if they could elicit the required response if similar technique was to be used with other participants. The data obtained in pretesting were not used in the final analysis; the pretesting was performed with some of the study subjects in the same site to ensure that the tool used was clear and yielded the required responses from the same population.

3.9 Data analysis

The first aspect of data analysis took place immediately after each interview and FGD. Data collected was transcribed verbatim. Analysis was guided by content analysis approach. According to Grunheim content analysis is a qualitative content analytical approaches focusing on analyzing both manifest content as well as the interpretation of the latent content of texts. Content analysis is strongly focused on data coding (Grunheim, 2004). In the present study, coding was done independently by the researcher and the main supervisor to ensure trustworthiness in data analysis (See tables 1 and 2: Example of coding process). After coding, the researcher constructed the categories. The construction of categories was guided by the components of ecological perspective model and one major theme emerged. During analysis, preliminary recommendations were made and were straight away used to inform the nurses working in cancer institute about the experiences of the caregivers and their role in supporting care givers at ORCI.

Table 1: Example of meaning unit, condensed meaning and codes

Meaning unit	Condensed meaning unit	Code
caring for the patient with cancer is very big task. Like this my patient sometimes becomes annoyed without reason, sometimes refuses everything eating washing her body even being touched by any one, you can feel that he is doing on her consciousness, but sometimes you can say that it is because of her illness	Caring is big task like my patient has changed her behavior she became hard you can think that she is doing purposely	Feelings of caring hardship
I don’t have any information on the patient’s disease. I don’t know really what is the cause of cancer, is it be cured, is it transferable? If I knew any It would not have bothered me much it could have helped	I don’t know any about cancer it would not have bothered me	Lack of adequate information Fear of disease

Table 2: Example of categories and codes

Codes	Category
Feelings of caring hardship Feelings of exhausted Lack of adequate information Fear of disease Having Sympathetic soul Patience possession	Intrapersonal influence
Interference with socialization. Inadequate time and money for children care. Inadequate social support	Interpersonal influence
Inconvenient duration for hospitalization. restricting policies influence	Institutional factor
Economic hardship due to usual standards.	Community factor
Economic burden due to restricting policies.	Public factor

3.10 Ethical considerations

Ethical clearance for this study was obtained from the Muhimbili University of Health and Allied Sciences (MUHAS) Institutional Review Board (see appendix VIII) and permission to conduct the study was obtained from the Executive Director of Ocean Road Cancer Institute. The in-charges of wards and outpatient services were informed about the objectives, procedures, potential risks and benefits of the study in order to give permission prior to conducting the study. Written informed consent was obtained from each potential participant (see appendix VII) to ensure their participation. The researcher observed the principles of confidentiality to the participants. To avoid unnecessary social or psychological harm, the researcher strived to avoid disclosing of any private or personal information of the participants to anybody. The researcher also observed all ethical considerations in data collection, analysis, interpretation, processing and presentation in order to get correct and accurate results.

CHAPTER FOUR

RESULTS

4.1 Description of population

A total of seventeen respondents participated in this study. Seven participated in the interview and ten participated in focus group discussion. The participants' age ranged between 26 and 58 years; majority were in their 30s. Two participants who participated in the interviews were married, one widow, three were single. Most of the participants had primary education and one was a university graduate. Most of the participants who participated in the focus group discussions were farmers, others were doing petty business and one was working as a teacher in secondary school. Detailed socio-demographic characteristics are shown in table 3

Table 3: Socio-Demographic characteristics of the participants

Id No.	Age	Marital status	Occupation	Gender	Level of education	Relation-ship
INT 01	36	Married	Farmer	Female	Primary	Sister
INT 02	32	Married	Teacher	Female	university	Sister in law
INT 03	48	Widow	Business	Female	Primary	Mother
INT 04	30	Single	Farmer	Female	Primary	Sister
INT 05	56	Single	Farmer	Female	Primary	Sister
INT 06	35	Married	Business	Male	Primary	Wife
INT 07	29	Married	Business	Female	Primary	Mother
FGD 01	33	Married	House wife	Female	Primary	Daughter
FGD 02	25	Single	Business	Female	Primary	Sister
FGD 03	41	Married	Housewife	Female	Primary	Son
FGD 04	58	Married	Farmer	Female	Primary	Grandmother
FGD 05	38	Married	Farmer	Female	Primary	Mother
FGD 06	29	Single	Business	Male	Primary	Brother
FGD 07	36	Married	Farmer	Male	Primary	Son
FGD 08	36	Married	Farmer	Male	Primary	Brother
FGD 09	43	Married	Farmer	Male	Primary	Brother
FGD 10	40	Married	Business	Male	Primary	Son

4.2 Overall findings

The findings highlight experiences of informal caregivers in caring for patients with cancer through one major theme: ‘Caring burden as influenced by interaction between physical and socio-cultural environment’. The theme is supported by categories which were guided by components of ecological perspectives: intrapersonal influence, interpersonal influence, community influence, institutional factors, and public factors. (See table 4).

Table 4: categories and theme

Categories	**Theme**
Intrapersonal influence Interpersonal influence Community factor Institutional factor Public factor	Caring burden as influenced by interaction between physical and socio-cultural environment.

4.3 Categories

4.3.1 Intrapersonal influence

The study findings showed that care giving role of patients with cancer was influenced by: feelings, beliefs, knowledge and personality traits. The following section describes these aspects in detail:

Attitude of caregivers towards care giving

Participants expressed negative feelings about the caring role of the patients with cancer. They said caring had imposed hardship in their life style. For example, most of the participants explained how the daily needs of the patients increased the hardship in their lives. A 33 years old woman whose patient had cancer of the tongue expressed:

"The hardship is because of increasing patients' needs on my daily responsibilities, my patient has a lot of needs, I have to give her bath, I have to help her going to toilet, sometimes I have to feed her. Therefore the daily activities increase on top of what I usually have; you may find that I cannot finish my daily activities" (INT 04)

Another female, 56 years caregiver explained how the change of patient's behavior after illness contributed to the hardship:

"…… caring for a patient with cancer is a very big task. Like my patient, sometimes she/he becomes annoyed without any apparent reason; sometimes he/she refuses everything: eating, taking bath, even to be touched by any one is a problem. You can feel that he is doing things on her consciousness, but sometimes you realize it is because of her illness" (INT 05)

Participants reported that caring of patients with cancer was unpredictable. A male caregiver of 29 years old added that:

"My feelings concerning caring of patient with cancer is that, for me I feel that it is a hard task, without patience and soul, you may give up before the end [of that task]. Caring for a patient with cancer is unpredictable, you can see him going well today, but tomorrow morning you may find he/she has changed; cannot even walk to toilet. For me, worry and anxiety has

taken a large part of my thoughts; you may plan activities for tomorrow because the patient is doing well, but as a result in the morning you may end up supporting the patient to the toilet. Those are the challenges of caring for patients with cancer" (FGD 06)

Feelings of change in caregivers lives

Most caregivers reported that their lives had been affected by having patients with cancer. They said that having patients with cancer had affected them at home, work place and in social gatherings. They said that the caring duty had changed their life style, the ability to work was reduced and the economic generating activities had been reduced. One female informal caregiver of 48 years old who was selling clothes reported how care giving changed her working environment:

"My work became totally different after having a patient with cancer. Before having a patient I was going out, truly I was going out my friend [researcher], I was going out to choose clothes which would satisfy my customers, ...but now I go there (to choose clothes) late. Therefore I cannot get clothes which can please my customers, so my business has slowed down. Now I have to stay with the patient, prepare food for her, I have to make sure she has eaten, but little time which I get I go there to buy clothes, I go there and take what I find, you are supposed to go there very early to get quality coloured clothes;, most girls like coloured clothes, when I get them I sell a lot, but when I go there late I find others have taken all" (INT 03)

Some caregivers reported that their lives at home totally changed such that they cannot carry out their daily activities as it was before because of having patient with cancer. One female of 56 years was reported

"My life has changed because of taking care of my sister. Now I cannot fulfill my home responsibilities as it was before. Sometimes I have to take my sister to health center because of severe pain she experiences, I have to help her toileting, I have to feed her, I have to take care for her children as well as my own children. I have to wash her body, I have to make sure she is comfortable"(INT 01)

Also this care giver reported how care giving affected her in ability of caring of her own children. She explained:

"In fact the problems which affected me is caring for children. Caring for two children is not like caring for one child. I was responsible to care for two children before my sister's illness, but after her illness they became five, all of them have different school and home needs, they need good care, I don't have time.....so even caring for my own children is a problem" (INT 01)

The caregivers reported to miss some important social events due to caring role:

"Another problem as I have said before is that I cannot even go to various social gatherings.....sometimes I go if the condition of the patient allows" (INT 01).

Another caregiver explained that she missed work for some days because of caring role. A female of 32 years old reported:

"Sometimes I miss work (school) I stay with my patient at home or sometimes I send the patient to the hospital. In wedding ceremonies I cannot go, however, I attend some of the funeral ceremonies; it depends on patient's condition....." (INT 02)

Some of the caregivers reported to cease the business because of care giving role. A 26 years old lady who was selling green vegetables reported:

"My life before and after having the patient has changed. I sell green vegetables at the market, but after having the patient with cancer, I stopped my business because I cannot carry it over, sometimes if she is doing well I take my vegetables to market to sell… Also because household responsibilities have increased, I use most of my time for the patient than for children" (INT 07)

Most of the informal caregivers view that caring for patients with cancer has affected them psychologically in the sense that worry and anxiety took most of their time. Such worries were due to the unbalanced patient’s condition. A male informal caregiver of 46 years old explained:

“Caring task is a tough job, most of the time I think of the patient, anxiety and worry increase because of his condition; his condition is not stable, can change rapidly, sometimes he has severe pain, sometimes diarrhea , sometimes has swelling of the body, I cannot continue with my income generating activities, as a father I am supposed to take care of my family, my family remain in bad condition” (FGD 10)

A female of 33 years reported that she became frustrated because of patient’s condition:

“….my brain is not well because of her [patient]*. I have a lot of worry, I don’t know her end, and this is how she is suffering while we are waiting for radiotherapy, severely it is frustrating me, sometimes I think of asking for discharge until the date of radiation, but I am afraid of lacking transport fare to come back on that appointment date, Kigoma is very far, is takes two days, I don’t know what to do” (INT 04)*

Most of the caregivers approach the care giving role with fear because of assuming that the patient will not be cured, but they get treatment to prolong their lives for a while. A female of 26 years old reported:

“Psychologically I am not well, I have a lot of frustrations and worry, I was caring for my father until death and the problem was the same (cancer), so what I feel and now my mother is on the same track, I have to think of that issue, aah! I ask God for help” (INT 07)

Daily life of caregivers and their activities in this study were very much affected by presence of patient with cancer. A lot of time was spent looking after the patient, and as a result they were not able to do other important activities such as business and farming. Income generation in the family was affected and this further increased family’s poverty. A male caregiver of 29 years reported:

“My patient has been sick for a long time now, more than a year, large amount of money has been spent for his treatment, This has made my economic status to decline, because I cannot

continue with my income generating activities, I stay thinking where can I get money which will enable caring for the patient and my family? (silent) if I am at home I get little chance to work, but here in the hospital problems increase, because this is the city, you have to buy everything at a high cost" (FGD 06)

Most of caregivers view that care giving put them in poverty; they had to sell some of their assets to compensate with their economic burden. One 36 years old male caregiver reported:

"Economic problems which I faced because of caring and the transport expenses from one area to another to search for treatment, I found myself with nothing, I had to sell some of my assets to get money" (INT 06)

Knowledge of care giving to patients with cancer

Knowledge is important in caring task. Knowledge guides activities to be done to the patients. Caregivers had feelings of unpreparedness when taking on the care giving role. They felt that they were misinformed, or didn't have full information on the disease causation, transmission, and progression. For example, the majority of caregivers reported that they had never been given any information on the patient's disease. The caregivers talked about not being told how to care for the patients with cancer. Several caregivers reported being concerned that the disease was contagious and were hesitating in providing certain services like washing clothes without gloves because of fear of contracting the disease.

One female caregiver of 33 years old whose patient had cancer of tongue reported:

"Most of us don't know anything about the disease, even I ask myself is this disease transmissible? What makes me worry is to be told that it is communicable, because I wash her clothes without gloves, most of the time my patient has a lot of secretions which comes out of her mouth with the foul smell because of her disease (cancer of the tongue), nurses do not give us gloves" (INT 04)

Educating the caregiver has been shown to decrease stress levels. A female of 33 years old explained:

" We give each other unreliable information , some say it is communicable, some say is not communicable, some say it can be cured, some say it cannot be cured, If I knew all I would not be bothered, it would help me" (INT 04)

However one caregiver reported to get information but not from responsible health workers within institution, but she used to ask her friend about the disease. She reported

"I got information about the disease, I went to my friend who is working in one hospital and told me a lot about the disease. That information helped to alleviate some of the stresses concerning the patient, but still I wonder if she will survive or not; her condition is deteriorating as the days go on" (INT 02)

Having un-reliable information on the outcome of the disease in this study is reported to be among the causes of fear in most of the caregivers of patients with cancer:

"Fear took a large part of my thoughts,...because of being informed by some peoples that the disease will not be cured, hence I am thinking, how long will I stay with my mother in this condition? Sometimes I could not sleep the whole night, I think deeply" (INT 03).

When caregivers were asked what they would have liked to know more about while caring for their patients, most of the caregivers reported that they wished they had known more about the disease, its progression, and how to care for someone with this type of disease.

Beliefs about care giving to patients with cancer

Spiritual belief was found to be helpful for most caregivers of patients with cancer. Two major ways through which they received spiritual help were through Religion and attending a traditional healer's services. They said that Religious help was obtained by praying to God for their patients with family members, and reading religious books. A female caregiver of 56 years old reported

"I did not call the priest to pray for her but every day we pray for her. I did not go to traditional healer, I was satisfied with the treatment which I get here and what God gives us through prayers" (INT 05)

Another female caregiver added:

"I have never visited a traditional healer, I am satisfied with these treatments we get here and God will help us" (INT ...)

"When I become overwhelmed with various thoughts, I tried to read religious books, sometimes I thank and pray to God , I feel that is helpful, unnecessary thoughts and worries dissolved and went out of my mind, what I felt was getting relief" (FGD 03).

Another female of 38 yrs old said:

"Also I help myself by praying and asking God for help (here in the hospital), if we are at home we search for medicine and spiritual help from the priest. I can't do more" (FGD 05)

However, because of inability to access medical care and financial problems, some caregivers in this study said they wished to go to traditional healers who were found in their villages to get alternative treatment for their patients. They wanted to consult traditional healers when they face problems of accessing medical services because of poverty. As it was expressed by 36 years old man, a father of a child who had cancer. He said that:

"Even me, I had my cow, I sold it to get bus fare to hospital, if I had nothing I would go to a traditional healer to seek for help; what could I do then?"(FGD 07)

Personality traits towards care giving

Most caregivers in this study reported that being patient in care giving is of important value, it induces good relationship between caregiver and the patients. One female caregiver of 45 years reported:

"Aahh! I become patient only to my patient; without being patient to her [patient] you can quarrel with her [patient] with no apparent reasons. The only best thing is to ask God to give you strength" (INT 05)

Also the study findings showed that kindness and humanity are the behaviors which influenced caring in positive manner for the whole duration of caring. They maintain love and good relationship between the patient and the caregiver, and these have been successful in caring role. A 36 years male who was caring for his wife with cancer of cervix said:

"What makes me ready to continue with caring for this patient is just humanity. According to how we interact with each other I cannot leave her alone suffering from the disease. I have to take care of her until death separates us."(INT 06).

4.2 Interpersonal influence

Interpersonal level which represents the interpersonal processes and primary groups, including family, friends, and peers shows the importance of these groups in minimizing the caring burden among the caregivers. The findings of this study revealed that most of the caregivers who were from other regions [outside Dar es Salaam] lacked social support when their patients were admitted because they were not prepared. They only came to hospital with their patients. Some of the caregivers said that family members and friends were unable to provide support, whether financially or food; sometimes they recognized that their family and friends did not have much to help them. One caregiver of a patient with cancer of tongue explained that:

"But here in the hospital I don't have any one to support me. They cannot send me money, but I know they have nothing; life in the village is very difficult. Here in the city, I have few relatives, but I can't depend on them. They come to visit patient once a week. I stay at Ocean Road Hospital from morning to evening. Since my patient cannot eat because of the cancer of tongue, I prepare large amount of porridge for my patient which can be enough for her for the whole day". (INT 04)

Because of having inadequate social support the caregivers fall in various social problems. Most of the caregivers in this study reported to have social problems. The most commonly reported social problems included less time for children care. They realized that the time spent in patients care affected children studies, and less time to participate in social gathering. These social problems were compounded by lack of social support or inadequate social support the care givers could get from the surrounding community.

Also the study revealed that because of increase in treatment cost, some of the caregivers could not send their children to school because of not having adequate support from the family members. This was reported by the daughter of mother with cancer of cervix:

"…my son planned to join college of business previous year, I collected money for college fee, but that money which I collected, hee! was used for his grandmother's treatment. Therefore, I could not support children's education because of caring for the patient." (INT 03)

Some could not participate in social events because of not having any one from family to support them when they wanted to participate in those events. So their participation depended on the patient's condition:

"If the condition of the patient allows, I go to church on Sundays …if the condition does not allow I stay with her at home…" (INT 01)

A 32 years old female caregiver whose sister in law had hypopharyngeal carcinoma reported:

"I don't participate in the wedding ceremony, but in funeral ceremony I participate according to the patient's condition, if not in severe pain I go there, if in severe pain I don't go." (INT 02)

However some of the caregivers appreciated the support they got from their family members, neighbours and friends which motivate them continuing caring for their patients.

A 33years old female caregiver whose patient had metastasized hypopharyngeal cancer reported:

"What motivates me to continue caring for my patient is cooperation from my friends and the patient's friends, and social support which I get from family; I appreciate" (INT 02)

A number of caregivers reported that family members helped them financially and with provision of food. Although it was not enough to cover the cost of medication and life expenses for caregiver during hospitalization, still they appreciated what they got from them. They said it helped them to meet certain needs of the patient. A 36 years old woman reported:

"My brother is in this city; he helps us to meet some of the life expenses. When we were at home Mbeya he sent us some money. Although it was not enough… and the patients have a lot of expenses… sister, ahhh! Especially the medicine takes a lot of money, food needs money, caring children needs money, therefore money which we are given is not adequate at all …" (INT 01)

A 45 years old woman who was caring for her mother with cancer of cervix explained the details of the financial support she got from her brother, and alternative support when in need. She said:

"My brother who is musician is the one who was supporting me., He has his own car, he was helping to take the mother to hospital if she needed transport but now the car has broken down. We use bajaj. Therefore for small requirements, he helps us, it is helpful, if there is a problem I call him …. he tried to find for me a house girl, but she stayed with me little and went away" (INT 03)

Some caregivers reported to get support from their friends. They said that friends helped them to take care of their responsibilities such as taking care of children and going to 'shamba' because they could no longer fulfill such responsibilities in the presence of the patients. A female of 40 years reported on how she benefited from physical support she got from neighbors and relatives:

"I don't have special person to help me at home but neighbours and relatives come to visit the patient and they help me with some home responsibilities. My neighbours help me in some of my duty. Example, those who cultivate close to my farm do help because I can't go there every day. They clean my farm, they care for my crops; I fulfill other responsibilities myself" (INT 05)

Another woman of 34 years old who was caring for her mother also stated:
"My husband is supporting me, he stay with my children and care for them" (INT 07)

4.3 Institutional level

The institutional policies and structures were reported to affect a lot caregiver's lives and hence had negative consequences. The caregivers stated that they faced a lot of problems and they expected to get support from the hospital [institution]. However, the institutional structures and policies were noted to increase care giving burden instead of lessening the burden as narrated in the following section:

Influence of institution structures on care giving.

Admission of the patients in the hospital for prolonged time was expressed as a constraint to care giving. They said at Ocean Road there is only one device for radiotherapy, so patients get appointments to get radiotherapy in the date according to the availability of the chance. So the patient can be given appointment after more than two months after doctor's order. It is known that cancer treatment itself takes long duration. In addition, most patients were annoyed as well as their caregivers after realizing that they had to wait for more than two months. They said that both the patient and the caregiver suffer from the fact that this waiting interfered with their daily activities as they had to spend more time in the new area [hospital] waiting for such treatment. A 30 years old female said most caregivers had presented their blames by saying

"……I remained with little money, my patient is waiting for radiotherapy. The patient was admitted in April and the radiotherapy appointment date will be in July 15/7/2013, three months waiting and we don't know how long the treatment will take. I suffer with my patient." (INT 04)

Influence of Institutional Policies on care giving

The caregivers reported a lot of trouble when the patients were admitted in the referral hospital (ORCI) due to the restricting policies. They said that caregivers were not allowed to stay with their patients during night. However, some of the caregivers had no relatives in the City so that they could visit and spend the night while the patient was admitted. In addition, the institution (hospital) does not provide food for caregivers; this created economic burden among the caregivers. One male caregiver complained that if the hospital could provide food and lodging for family members would have helped him a lot. This 43 male caregiver reported:

"Because I had no other relatives, I had to sleep outside the hospital gate, so it would be better if we were separated, people who don't have relatives or anybody to help over there [City] they could have provided a place for us to stay; they give the food to the patient only… I am not given any food. Sometimes I just drink a bottle of water for a day" (FGD 09)

Also another caregiver of 30 years old complained:

"Economic problems yes, because I am here in a new place, when I was at home I had less problems, home is home! If you miss something you could ask from others, but here who knows you? the health personnel should help us (caregivers) in provision of food. We don't have money we stay here from morning to evening without putting any thing in the stomach" (INT 04)

4.4 Community influence

Standards

Another caring burden the participants explained in this study is their experiences of economic hardships due to the community standards. According to the cultural standards it is the men's duty to provide everything for the family, but for single woman they had to provide everything for their families. Married male caregivers experienced more burden than female married caregivers. Most of the informants were unemployed and they needed money to meet their daily expenses. Their finances depended on participation in the income generating activities like farming and selling crops, caring hens and cows. However, because of having patients with cancer who were continually sick, this affected their income generating activities and hence economic problems. They explained that lack of money affected their ability to give proper care to the patient. Male participants narrated their inability to fulfill the provider's role as expected in their community. One 43years male participant sadly explained:

"My family is not in good condition, my child has left studies, and one has been chased away from school because of lack of money. They depend on me; my family was affected a lot, I cannot solve problems which affect me. I don't know how to explain. I have been here since

April last year. I wish if the Government could put the services closer to us which would simplify transport to the hospitals and hence the economic burden would be less" (FGD 09)

Another widow female of 45 years reported:

"Economically it is a problem because I can't continue with my business as usual. I find myself dropping financially, I cannot meet some of the patient's needs; at the same time life expenses increase because of caring for the patient including buying drugs. You will find what you have is going away and nothing is coming in financially" (INT 03)

Another man insisted on the socioeconomic problem that he faced during caring

"It reaches a time when you think about family at home, sometimes I don't call them, sometimes they tell you someone is sick and they don't have money to send the patient to hospital. I am from Musoma, it reaches time you think, do I go home or he will be cured, sometimes you think about family" (FGD09)

A 36 years male who was caring for his brother said:

"Financially is a problem. The problem is not only drugs, specifically food is a big problem, if you ask support from home they say even here we have nothing. For our poor families, we get problem, we don't have money. A big problem is money because this is a city everything needs money and this condition takes very long time in caring especially when you are here in the hospital. At home also there are others who need your support as a father" (FGD08)

4.5 Public policy

National policy

Participants expressed the view that the national policy concerning the care giving burden did not take their concerns into account. They said that they do not know if the government is aware of the burden they were facing. They all explained that they were already in stressful life of having patients who were diagnosed with cancer. In addition they have stressful life of having financial burden which have been influenced by having long duration of patient hospitalization and policies used in institutions do not show that the government took is taking this issue seriously.

A 58 years woman presented her cry of having cost sharing for chemotherapy:

"I think the government does not take this caring burden as a serious issue. The government would help us especially with medicine and money, for example there is injection; my patient is required to buy twelve of them and each injection cost sixty thousands Tanzanian shillings, it is difficult to get we can't afford, we get one today and days pass and then you get another one, things go like that" (FGD04)

The services for patients with cancer were only to be accessed at referral hospital in the city, which they have to travel for the whole day or some for about two days. With such problems participants reported to be disturbed, and increased risk of having continuous financial and social problems. They wished if the services could be put closer to them, it would help them.

A 36 years male said:

"The government should put these services at nearby hospitals like regional hospital or village health centers. If we are treated near home the economic and social problems would be less compared to when you are very far from home" (FGD07)

A 38 years woman stated

"For those who came from distant regions the services should be issued in the nearby hospital. The government should send specialist and drugs for these types of disease there, because we get a lot of problems, when the patient get sudden problem we have to travel to come here in the city to get services, sometimes we don't have money; we stay home; we look at the patient; nothing can be done" (FGD05)

CHAPTER FIVE

DISCUSSION

The purpose of this study was to understand experiences of family caregivers in caring for patients with cancer in a Tanzanian context and to learn how various types of support and coping resources can influence the caring burden as experienced by the informal caregivers.

In this study the experiences of informal care givers in caring for patients with cancer have been synthesized in the light of ecological perspective model: multilevel approach. The findings revealed various experiences that the caregivers experience in providing care. These experiences are psychological, social and economical problems. These experiences are commonly perceived as a caring burden. Similar experiences were revealed in a previous study (Bevan & Sternber, 2012). There are factors that influence the caregivers to have such experiences; these factors are explained under the ecological perspective model: intrapersonal level, interpersonal level and community level which encompasses institution factor, community factor and public factor.

5.1 The perspectives of informal care while caring for patient with cancer

The results show that intrapersonal influence took part in the experiencing, viewing and defining the care giving role in the sense that all caregivers view the care giving role as a tough task. Although they differ in the extent of hardship, some viewed that the hardship was due to increased daily life responsibilities, increasing cost of treatment that increases risk of economic and psychological burden. Some saw that hardship was due to changing of patients' behaviour. All these were considered to create economic, social, and psychological problems to the caregiver. To reduce the hardship of the care giving individual caregivers have to change personal behaviour. This includes sympathy, kindness and patience. These behaviours are needed to reduce the negative thought which will discourage caregivers in this moral role. Nurses can play an important part in teaching many of these skills including problem solving strategies with daily living and personal and family stressor to the families (Shortman et al, 2008). Nurses should initiate counselling session for caregivers which among the information which is going to be discussed is being kind, patient, and having sympathy to the patient (Day & Anderson, 2011).

Fear was reported to emerge from various factors such as the general condition of the patient, diagnosed disease, and expected outcome of the patient. Poor progress of the patient created fear among caregivers which gave them the feelings of giving up and escaping to take medical treatments for their patients. Knowing that the patient has cancer put these caregivers in frustration. The same experiences of fear, anxiety was found in the study done elsewhere (Sherwood et al, 2006). These feelings generated fear in the caregivers' lives; they created thoughts of giving up and wish to return home.

5.2 How caring for patients with cancer affects the caregivers' lives

Change in caregivers life means that the care givers cannot live in the style he/she used to live before having the patient e.g. in his working area, perform home responsibilities, continuing with business, participating in social activities like various types of ceremonies etc.

The change of the caregivers' lives was revealed in this study, their lives had been affected by having patients with cancer. Having patients with cancer had affected them at home, working area and in social gatherings, the caring duty had changed their life style, the ability of working was reduced and the economic generating activities had been reduced, The caregivers' life at home totally changed such that they cannot carry out their daily activities as it was before having patient with cancer because of increasing of the patients' needs and increasing the caring responsibilities. Similar results were reported by Joad that, care giving had a disruption in personal routines and restriction on leisure time (Joad et al, 2011)

Also this study revealed that the care giving affected the ability of caregivers on caring own children. Similar results were revealed in previous studies, where most caregivers could not devote enough time to their children. They felt their care-giving role had affected their childrens' studies (Joad et al, 2011). Also, the caregivers reported to miss some important social events due to caring role, like attending church on Sundays, ceremonies, due to inadequate social support (interpersonal influence). The fact that caregivers ceased the business because of care giving role is reported by Courtney, that the caregivers felt that they had reduced opportunities of career advancement due to their care-giving role.(Courtney et al, 2010), and that some caregivers missed work for some days because of caring role.

Most of the informal caregivers view that caring for patients with cancer has affected them psychologically, in the sense that worry and anxiety took most of their time. Such worry is due to the unbalanced patient's condition. Also the caregivers approached the care giving role with fear because of assuming that the patient will not be cured, but they get treatment to prolong their lives for a while. Daily life of caregivers and their activities in this study were very much affected by presence of patient with cancer. A lot of time was spent looking after the patient and as a result they were not able to do other important activities such as business, and farming. Income generation in the family was affected and this further increased family's poverty. Most of caregivers view that care giving put them in poverty in the sense that they had to sell some of their assets to compensate the economic burden. Similar financial problems among caregivers were reported by Schubat (Schubat et al, 2008).

5.3 The effect of interpersonal relationship in the care giving,

The study revealed that the caregivers got some social support, and they highlighted that such support was important because it had positive impact on the emotional and physical health of caregivers. Similar benefits of receiving social support have been well documented in developed countries by Shortman (Shortman et al, 2008). However, some caregivers in the current study desired social support but could not receive it. Some of the caregivers reported to get some support when they were at home, but when they were hospitalized in that referral hospital, most of them reported to miss such support. This is because they were new in the city, and most of them had few relatives or not having at all; they did not have friends in the city since all of their friends were found in the village. So they faced severe social-economic problems. In addition long duration of hospitalization because of the trend of cancer treatment that is administered in phases, most of them could not go home between treatment phases because of transport costs. If they go home, they could not afford returning to hospital for another phase; they do not work in the city as most of them were farmers. So they used what they had and no income unless they get help from other people. As documented by Shortman, involving social networks in the care process could alleviate some of the burden and allow the caregivers to share the responsibilities of providing care with others. (Shortman et al, 2008)

The study results revealed the feelings of decrease in the social activities that the caregiver usually engages in because they are required to take on extra tasks to help their patients; those social activities were such as less time for children care, inability to support children training, and failure to participate in social gathering. Similarly in a study done in India revealed that the care-givers felt their care-giving role had affected their children's studies, general care and health (Joad et al,2011)

The results of this study has shown that institution give little support to caregivers; the institution only give some free services to the patients, but the caregivers/families have to pay most of treatment cost which put them in the economic burden. Similar findings are reported by Courtney and Schubat (Courtney et al, 2010; Schubat et al, 2008).

The caregivers noted that policies used in this institution do not support them in the sense that the policies negatively influence the care giving roles. From this study we understand that caregivers face a lot of economical problems during the task of caring which then produce psychological burden. Furthermore, caregivers faced more economical problem when they are admitted in the hospital than they are at home. At hospital because they are in new area without income generating activity, cancer treatment takes long duration. In addition, long waiting time for radiotherapy treatment, increased number of patients and being in institution waiting to access only one radiotherapy device, inability to go back home (most of the admitted patients are from far regions) because of transport **costs** to return in the date of appointment were reported as severe consequences. At the same time this difficult was compounded by the institutional policy that did not allow them to stay within hospital during night and did not give them food. This burden can be reduced by reviewing the hospital policy; the institution have to assess who are eligible to get support from institution and support them or invite any private sectors, individual person or NGO who can support these caregivers. Similar situation has been reported by other scholars (Awadalla et al 2007, Pavataneni et al 2011)

The results of this study show that the government policy may partly influence the care giving task as it does not consider the caregivers life. For example the caregivers in this study were blaming the government for not putting cancer services in every region in this country to accelerate accessibility to all patients. The results showed that some of the caregivers had to sell their possession to get transport costs to referral hospital (ORCI) and remained at ORCI for at least one year. Lack of regional facilities forced every patient to travel to ORCI to seek medical treatment. Whereas existing poverty is a problem, transportation of patient to referral hospital is also a big problem. Accumulation of these problems increase caring burden. Consequently the caregivers reported to have less burden at home than when they are in hospital. Therefore, the health policies and programs need to be revisited in order to take the reality of these patients and their families into account (Dumont et al, 2006). This burden can be reduced by searching the way of having another radiotherapy device to reduce length of staying in hospital, and other sectors should be invited to help these caregivers. The policy of restricting caregivers to stay and get services in hospitals should be revisited to accommodate and the caregivers' concerns.

5.4 The coping resources employed to minimize the burden of caring on the informal caregivers

Coping resources are the ways in which the caregivers can use to minimize the burden like participation in prayers, and counseling sessions in order to cope with situation. The caregivers may have to change themselves and use available resources; For example, the study revealed that caregivers used spiritual support to minimize the burden of caring, they used prayers to cope with the situation, they used to call priest to pray for the patients or sometimes they pray themselves. This process alleviate some of psychological burden because most of the caregivers were worried while caring for their patients; they were not able to cope with the situation because of knowledge deficit concerning the disease**.**

The study findings revealed a large gap of knowledge concerning details of the disease which was reported to create more burden as most of the caregivers failed to predict if the patients were suffering from the diagnosed disease or they were suffering from other problems. For example, by not understanding whether the disease is contagious or not exerted fear to the caregivers and some were hesitating to provide certain kind of care to the patients and hence found themselves in doubt. Lack of adequate information has been reported in a developing country (Selman et al, 2009). Parvataneni found that the caregivers need additional resources and information on coping with the emotional burden of the disease. (Parvataneni et al, 2011). In this study the caregivers showed more interest specifically in information about the disease; how it progresses, and how a person can contract the disease. In contrast, another study documented that caregivers are interested more in general information (Girgis et al, 2006),

The findings indicate that the information obtained during clinic visits is inadequate to satisfy these needs. Treating the caregivers' emotional needs can improve their quality of life and in turn improve the overall care of the patient. The caregivers' need to share the experience with someone else; thus, distributing information, support groups and educational sessions at clinic visits may be effective methods to satisfy this need (Parvataneni et al, 2011).

5.5 Limitations

The findings from the present study cannot be judged beyond the studied sample, given that some patients were unable to seek medical attention and their caregivers may experience a heavier burden than those who are able to obtain medical care. However, the knowledge generated in this study may be relevant in similar context.

CHAPTER SIX

Conclusions and Recommendations

6.1 Conclusions

An increased awareness and understanding of experiences and problems faced by informal caregivers may give direction to the implementations of appropriate interventions to support them.

Caregivers of patients with cancer experience problems such as psychological and emotional (fears, worries), social problems such as inadequate social support, and less time devoted for child care which is influenced intrapersonal, interpersonal and communal factors. Professional assistance, public awareness social and financial support by the government and NGO's are important in coping strategies

This study shows that nurses need to provide relevant information to care givers. Provision of psychosocial support to caregivers caring for patients with cancer is necessary in order to meet their needs. This can be accomplished by offering counseling services to caregivers in order to address their concerns.

As a result of the lack of knowledge on the disease among caregivers, nurses should provide the caregiver with information immediately when the patient is diagnosed with cancer. This can include general information on the disease, signs to look for as the disease progresses, and symptoms management that the patient may experience such as pain. This may alleviate some of the worries that the caregivers may experience.

Another concern that the data highlights concerns the difficult the caregiver faces in relation to policies used in the health care institutions (institutional influence). For example, providing food for the caregivers can be done by inviting NGO's and private sectors who can help those care givers who are coming from far regions to do so. Social support was desired by the caregivers, but was not adequately received. The institution should initiate the program for supporting these caregivers when they face any problem. Palliative care committee should be established to work for the patients as well as their caregivers to reduce the caring burden.

According to caregivers' views poor living condition among majority of Tanzanian hindered good provision of care, because patient with cancer needs long term care. Furthermore, thinking of those informal caregivers is needed because caring patients with cancer is costly and time consuming.

6.2 Recommendations

Appropriate interventions should be put in place with a view to reduce the psychological distress among caregivers. This will enable them to cope with caring demands

Health personnel should equip the informal caregivers with proper knowledge which will help them in providing care to their patients.

Government should put more effort on buying another radiotherapy device and increasing number of radiotherapists which will help in reducing waiting time for radiotherapy services. It has been stressful to both patients and their caregivers to stay in hospital for more than two months waiting for date of appointment to get radiotherapy.

The government should employ more nurses to reduce the shortage of staffing in this institution.

Hospital management should support caregivers by providing food for those caregivers who are coming from other regions and lack relatives who can support them in Dar es Salaam. As we know a patient needs family support even he/she is in hospital because of shortage of staffing, and because nurses cannot do everything for the patient. These family caregivers help with washing patients' clothes and other activities which the patient cannot do for herself.

The Ocean Road Institution should invite NGO's and private sectors to help those care givers who are coming from distant regions.

More studies are needed in large population since this information is not conclusive to all caregivers in Tanzania. Further studies are required on this area to explore more experiences that influence caring for patients with cancer.

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APPENDICES

Appendix I Interview guide

Part 1: SOCIAL DEMOGRAPHIC DATA

Serial number….

Date of Interview:

1. Age
2. Sex
3. Level of education
4. Marital status:
    - Single
    - Married
    - Living with partner
    - Widowed
    - Separated
    - Divorced
5. What is your relation to patient
6. Occupation

If not employed, how do you earn your daily income? Elaborate:

Interview guide

1. Please tell me about your experiences of caring patients with cancer.
2. What was your reaction towards your patient's condition?
3. Can you describe what a normal day was like before and after patient had cancer?

Probe:

- At work? At home? In social situations (church, party etc)

4. Did your relationship with patient change after he/she had cancer?
5. What problems have you had as a result of his/her illness?

Probe:

- Emotional, psychological, economic, physical social /Family problems eg. Care of children

6. Please tell me, what motivates you to continue caring and what is a barrier for your caring role?

Probes.

- Tell me about your family and friends how are they supporting you in caring role?
- Are there any other people whom you look after e.g. children, relatives etc.
- Is there anyone care for you and give you support? If yes, who? Friends, spouse, family

7. Have you received information about the illness? Where did you get this information? Was it helpful?
8. What do you wish you have to know more about while caring for patient? Do you know where you can get this information?
9. What kinds of things do you think nurses and other health care providers could do to better help you when you are caring for someone with cancer?

- At the government level what kind of support do you expect?

10. Can you explain to me any public regulation that supports informal care giving to chronically ill patients in Tanzania?
11. Do you have anything that you wanted to discuss about this topic that we have not covered?

APPENDIX II- MUONGOZO WA MAJADILIANO

Nambari

1. Umri
2. Jinsia
3. Kiwango cha elimu
4. Hali ya ndoa
5. Nieleze hisia zako za kuuguza mgonjwa mwenye saratani

- Umeolewa
- Hujaaolowa
- Unaishi na bwana
- Mjane
- Mmetengana
- Umeachwa

6. Kazi
7. Uhusiano na mgonjwa

Muongozo wa majadiliano.

1. Nieleze hisia zako kuhusu kuuguza mgonjwa mwenye saratani?
2. Ilikuathiri vipi hali ya mgonjwa.
3. Eleza zilikuwaje siku za kawaida kabla na baada ya kuwa na mgonjwa mwenye saratani?

Dadisi:

- Nyumbani.kazini, mikusanyiko ya kijamii

4. Jee uhusiano wako na mgonjwa umebadilika ya kuwa na mgonjwa wa saratani
5. Umepata matatizo gani kutokan na sababu ya kuugua kwake?

Dadisi:

- Kiakili, kimwili, kiuchumi, kijamii/matatizo ya kifamilia mfano kulea watoto.

6. Eleza kitu gani kinakuhamasisha kuendelea kumuuguza mgonjwa na kitu gani ni kikwazo katika kazi ya kuuguza?

Dadisi

- Eleza watu wa familia yako na marafiki wanakusaidia vipi katika kazi ya kuuguza.
- Jee una watu wengine wanaokutegemea?
- Kuna mwengine yoyote anayekusaidia?

7. Umewahi kupata maelekezo kuhusu ugonjwa huu?

Dadisi

- Yalisaidia?

8. Nini unahitaji kujua zaidi kuhusu kuuguza?
9. Vitu gani unfikiri wauguzi na wahudumu wengine wa afya wanaweza kufanya ili kukusaidia katika kuuguza?

Dadisi

- Unatarajia msaada wa aina gani kutoka katika daraja ya serikali?

10. Unaweza kuelezea sheria yoyote ambayo inasaidia wauguzaji wasiorasmi katika kuuguza wagonjwa wenye magonjwa sugu Tanzania?
11. Una chochote unataka tukijadili kuhusu mada hii ambacho hatukukijadili?

Appendix III – FGD guide

1. What is your experience of caring patients with cancer?
2. What are the daily problems caregivers face in caring for the patient with cancer?

   Probe: psychological, physical, economic, or social problems.

What do caregiver do to deal with these difficulties

Probe:

How do they deal with psychological difficulties?

How do they deal with social difficulties?

How do they deal with economic difficulties?

1. What kind of support do you think caregiver need that can help in taking care for patient with cancer?
2. What kinds of things do you think nurses and other health care providers could do to better help you when you are caring for someone with cancer?
3. Can you explain to me any public regulation that supports informal care giving to chronically ill patients in Tanzania?

Appendix IV – Muongozo wa majadiliano katika kikundi.

1. Nieleze hisia zako kuhusu kuuguza mgonjwa mwenye saratani?
2. Ni yepi matatizo ya kila siku wanayokabiliana nayo watu wenye kuuguza wagonjwa wenye saratani?

   Dadisi: kiakili, kimwili, kiuchumi au kijamii.

3. Je wauguzaji wanafanya nini ili kukabiliana na magumu hayo?

   Dadisi:

   Wanavyokabiliana na magumu kisaikologia

   Wanavyokabiliana na magumu kijamii

   Wanavyokabiliana na magumu kiuchumi.

4. Ni msaada wa aina gani ambao unafikiri wauguzaji wanahitaji unaoweza kuwasaidia katika kuuguza wagonjwa wenye saratani?
5. Vitu gani unfikiri wauguzi na wahudumu wengine wa afya wanaweza kufanya ili kusaidia katika kuuguza?
6. Unaweza kuelezea sheria yoyote ambayo inasaidia wauguzaji wasiorasmi katika kuuguza wagonjwa wenye magonjwa sugu Tanzania?

APPENDIX V : Table 1: Additional Example of meaning units, condensed meaning units and codes

Meaning unit	Condensed meaning unit	Code
caring for the patient with cancer is very big task. Like this my patient sometimes becomes annoyed without reason, sometimes refuses everything eating washing her body even being touched by any one, you can feel that he is doing on her consciousness, but sometimes you can say that it is because of her illness	Caring is big task like my patient has changed her behavior she became hard you can think that she is doing purposely	Feeling o caring hardship
I don't have any information on the patient's disease. I don't know really what is the cause of cancer, is it be cured, is it transferable? If I knew any It would not have bothered me much it could have helped	I don't know any about cancer it would not have bothered me	Lack of adequate information Fear of disease
What makes me ready continuing with caring this patient, is just humanity, according how we interacted each other I cannot leave her suffering from the disease alone, I have to care for her until we become separated each other by death.	I continue with caring because of kindness and how we interacted before. I will continue until death	Having Sympathetic soul

Aahh! I become patient only to my patient, without being patient to her (patient) you can quarrel with her(patient) with no reason. Best thing is only to ask God to give you strength	I become patient to her, otherwise you can quarrel with her. we have to ask strength from God	Patience possession
My brother give me financial support, although it is not enough because drug is too expensive	My brother give inadequate financial support drug is too expensive	. Inadequate financial and social support
In fact problems which I faced in caring children, one child is unlike two children. I had two children before sister's illness, but after her illness they became five and all have different school and home requirements, my income the same no increment, therefore even caring my own children became problematic, like I have said brother is supporting but is not enough for us	I care for many children after my sister illness, all have different requirements, with same income, therefore even caring my own children is a problem	inadequate time for children care.
If the condition of the patient allows I go to church on Sundays if the condition does not allow I stay with her at home.		

I remained with little money, my patient is waiting for radiotherapy. the patient was admitted in April and the radiotherapy appointment date will be in July 15/7/2013,three months waiting and we don't know for how long the treatment will be. I suffer with my patient	I remained with little money, my patient is waiting for radiotherapy appointment it took three months since ordered, I don't know how long will take the treatment.	Inconvenient duration for hospitalization.
Because I had no other relative, I had to sleep out the gate, so it would be better if we were separated, people who don't have relatives or anybody to help over there they could have provide somewhere to stay, they give the food to the patient only I am not given any food. Sometimes I just drink water for a day	I had no relatives, I had to sleep out of the gate it would be better if we were separated, who don't have relatives could have be provided somewhere to stay and given food	restricting policies.
I think the government did not take this caring burden as a serious issue would help us especially with medicine and money, for example there is injection my patient is required to buy twelve of them and it is sold 60 thousands Tanzanian shillings each, it is difficult to get we can't afford, we get one today and days pass and then you get one, things is like that	The government did not take it seriously, would help us, especially medicine and money we buy drugs for high cost	Economic burden due to restricting policies

My family is not in good condition, my child has left studies, and one has been chased away from school because of lack of money they depend on me my family was affected a lot I cannot solve problems which affect me. I don't know how to explain	My family is not in good condition, my children have left school because of money, they depend on me. I cannot solve problems affecting me. I can't explain	economic hardship due to cultural standards.

Appendix VI: Informed consent - English version

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
DIRECTORATE OF RESEARCH AND PUBLICATIONS, MUHAS
CONSENT FORM
ID NO ☐☐☐☐☐ ☐☐☐☐☐

Consent to participate in a study: entitled "EXPERIENCES OF INFORMAL CAREGIVERS IN GIVING CARE FOR CANCER PATIENTS AT OCEAN ROAD CANCER INSTITUTE"

Greetings! My name is Raya Abdala, a 2nd year student Master of Science critical care and trauma at Muhimbili University of Health and Allied Sciences (MUHAS), working on this research project with the objective of exploring the experiences of informal caregiver in caring for patients with cancer.

Purpose of the study: To explore the experiences of informal caregiver in caring for patients with cancer

Participation in this study:
If you consent to participate in the study you will be required to answer If you consent to involve yourself in this study, you will be required to answer questions which will be posed during face to face interview/focus group discussion. Do not hesitate because in this interview there is no RIGHT or WRONG answers.

Confidentiality:
All information collected during this study will be kept strictly confidential and will not be revealed to anybody outside the research team.

Risks:
We do not expect that any harm will happen to you because of joining this study. Sometimes you may feel tired/exhausted, due to the nature of the caring duty, but you will be able to stop the interview temporarily or decline at any time if you feel too uncomfortable.

Rights to withdraw and alternatives
Taking part in this study is completely your choice. If you choose not to participate in the study or if you decide to stop participating in the study you will continue to receive all services that you would normally get from institution. You can stop participating in this study at any time even if you have already given your consent.

Benefits:

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals to better understand perspectives of different people with different characteristics (age, gender etc). The findings will help nurses working at Ocean Road Cancer Institute in addressing challenges facing informal care giver and hence finding solutions for those challenges if possible.

In case of injury

We do not anticipate that any harm will occur to you as a result of participation in this study. However if any physical injury resulting from participation in this study should occur, we will provide you with medical treatment according to the current standards of care in Tanzania. There will be no additional compensations to you.

Who to contact:

If you ever have questions about this study, you should contact the study coordinator or principal investigator Ms Raya Abdala, Tel.-0715965742, Muhimbili University of Health and Allied Sciences, P.O. Box 65001 Dar es Salaam. If you ever have questions about your rights as a participant, you may call Prof. Mainen J. Moshi, Chairman of the Senate Research and Publications Committee. P.O. Box 65001, Dar es Salaam. Tel 2150302-6 2152489

Signature:

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

I ____________________________________ have read the contents in this form. My questions have been answered. I agree to participate in this study.

Signature of participant ____________________________________

Signature of witness (if mother/ caretaker cannot read) _________________

Signature of researcher ____________________________________

Date of signature ____

Appendix VII: Fomu ya ridhaa – Kiswahili version

CHUO KIKUU CHA SAYANSI ZA AFYA NA TIBA MUHIMBILI
IDARA YA UTAFITI NA MACHAPISHO
CONSENT FORM
ID NO

Ridhaa ya kushiriki katika utafiti wenye jina "HISIA WANAZOPATA WAUGUZI WASIO RASMI WANAPOUGUZA WAGONJWA WENYE SARATANI KATIKA KITENGO CHA SARATANI CHA OCEAN ROAD.

Greetings! Jina langu ni Raya Abdala, mwanafunzi wa mwaka wa pili wa shahada ya uzamili ya sayansi ya uuguzaji wagonjwa walo hali mbaya na walioumia katika chuo Kikuu cha Muhimbili nafanya utafiti huu kwa lengo la kugundua hisia walizonazo wauguzaji wasiorasmi wakati wakiuguza wagonjwa wenye saratani.

Dhumuni la utafiti: kugundua hisia walizonano wauguzaji wasiorasmi wakati wakiuguza wagonjwa wenye saratani

Ushiriki katika utafiti:

Ukiridhia kushiriki katika utafiti huu utahitajika kujibu maswali ambayo utaulizwa kwenye majadiliano ya ana kwa ana/**kwenye kikundi**. Usisite kujibu kwa sababu kwenye majadiliano haya hakutakuwa na jibu ambalo litakalokuwa si sahihi.

Usiri:
maelezo yote yatakayokusanywa wakati wa utafiti huu yatafanywa kuwa siri na hayatotangazwa kwa mtu mwengine yoyote nje ya timu ya utafiti.

Hatari :
Hatutarajii kutokea madhara yoyote kwa sababu ya kujiunga na utafiti huu. Wakati mwengine unaweza kujisikia kuchoka kwa sababu ya kuuguza, lakini unaweza kusimama kutoendelea na majadiliano kwa muda or kujitoa wakati wowote ikiwa unajihisi huko sawa.

Haki ya kujitoa na mambo mbadala
Kushiriki katika utafiti huu ni uchaguzi wako mwenyewe. Ukiamua kutoshiriki kwenye utafiti au ukiamua kusimama kushiriki kwako utaendelea kupata huduma zote ambazo kawaida ulikuwa ukipata kutoka kwenye kitengo hiki. Unaweza kusimamisha ushiriki wako katika utafiti wakati wowote japokuwa ushasaini fomu ya ridhaa.

Faida:
Hapatakuwa na faida ya moja kwa moja kwako kwa kushiriki kwenye utafiti huu. Ingawa maelezo utakayotowa yatasaidia wahudumu wa afya uelewa bora zaidi wa maoni ya watu mbali mbali wenye sifa tofauti. Na kitakachogunduliwa kitasaidia nurses wanaofanya kazi kitengo cha wagonjwa wenye saratani katika kuongelea changamoto zinazowakuta wauguzaji wasiorasmi katika kuuguza wagonjwa wenye saratani na kutafuta utatuzi wa changamoto hizo ikiwezekana.

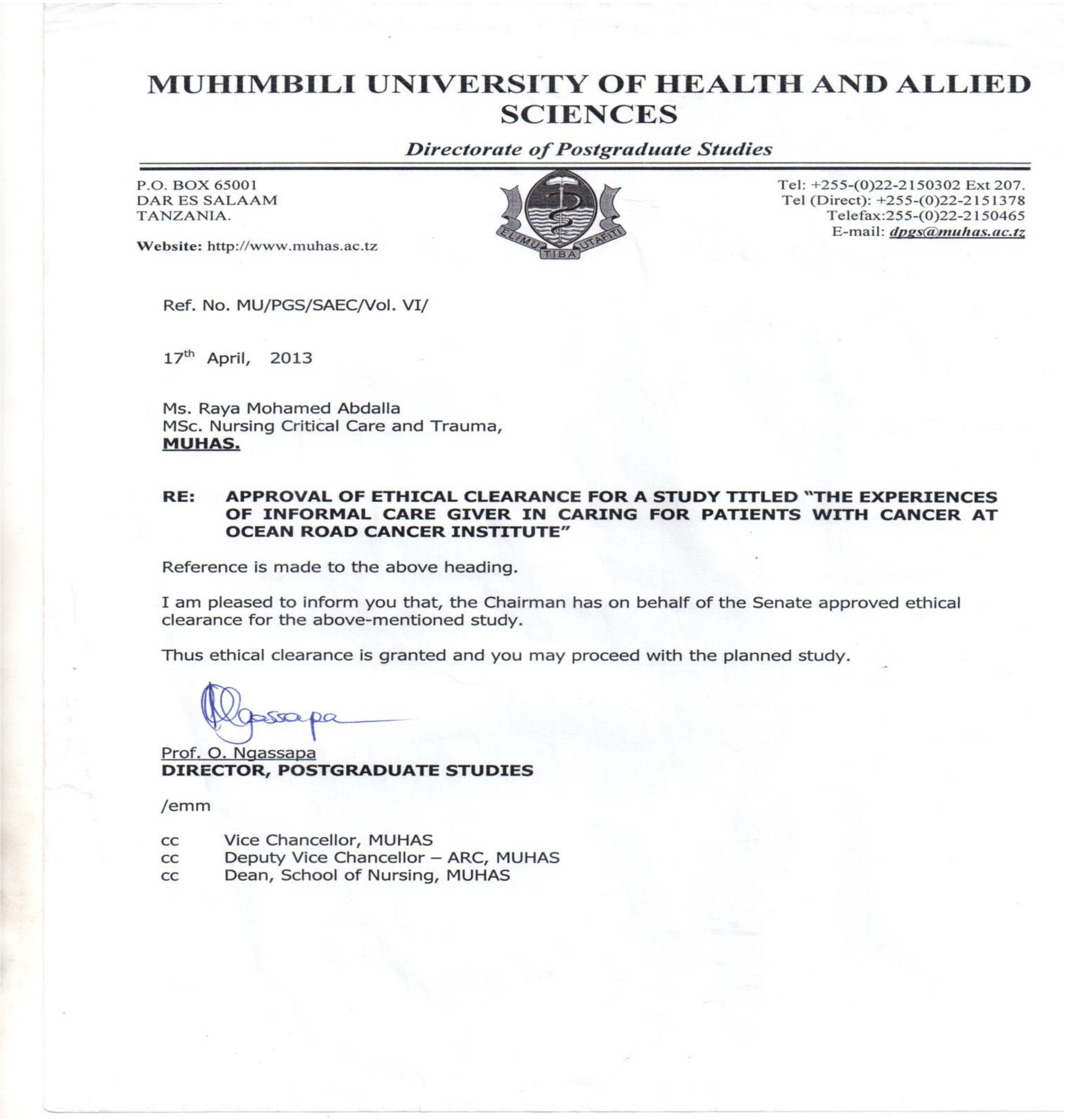
Pakitokea madhara
Hatutaraji kutokea madhara yoyote kwa ajili ya kushiriki kwako. Hata hivyo yakitokea madhara yoyote ya kimwili kutokana na kushiriki kwako katika utafiti tutakupatia matibabu kwa mujibu wa muongozo wa matibabu wa Tanzania.

Mawasiliano
Iwapo utakuwa na suali kuhusu utafiti huu wasiliana na mtafiti bibi Raya Abdala, Simu-0715965742, chuo kikuu cha sayansi afya na za tiba, POBOX 65001 Dar es Salaam. Iwapo utakuwa na suali kuhusu haki zako kama mshiriki, wasiliana na Prof. Mainen J. Moshi, mwenyekiti wa kamati ya maadili ya utafiti ya Chuo Kikuu Cha Sayansi Za Tiba Muhimbili.. P.O. Box 65001, Dar es Salaam. Tel 2150302-6 2152489

Sahihi

Mshiriki anakubali…………………….. Mshiriki hakubali …………………
Mimi _______________________________________ nimesoma maelekezo yote ya fomu hii. Masuali yangu yamejibiwa. Nnakubali kushiriki katika utafiti huu.
Sahihi ya mshiriki ______________________________________
Sahihi ya shahidi (iwapo muuguzaji hawezi kusoma) __________________
Sahihi ya mtafiti ____________________________________
Tarehe ya sahihi ____

Appendix VIII - Ethical approval letter



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Ref. No. MU/PGS/SAEC/Vol. VI/

17th April, 2013

Ms. Raya Mohamed Abdalla
MSc. Nursing Critical Care and Trauma,
MUHAS.

RE: APPROVAL OF ETHICAL CLEARANCE FOR A STUDY TITLED "THE EXPERIENCES OF INFORMAL CARE GIVER IN CARING FOR PATIENTS WITH CANCER AT OCEAN ROAD CANCER INSTITUTE"

Reference is made to the above heading.

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

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

Prof. O. Ngassapa
DIRECTOR, POSTGRADUATE STUDIES

/emm

cc Vice Chancellor, MUHAS
cc Deputy Vice Chancellor – ARC, MUHAS
cc Dean, School of Nursing, MUHAS