

**PERCEPTIONS OF FAMILY CANCER CAREGIVERS IN TANZANIA: A  
QUALITATIVE STUDY**

by

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There has been a documented increase in incidence and prevalence of noncommunicable diseases, in particular cancer, in low- and middle-income countries. With a lack of healthcare facilities and trained health care providers to support this new patient population, relatives and close friends provide the majority of care. The majority of research examining the emotional and physical impact of providing care to a loved one with cancer has been conducted in developed nations; however, there is a paucity of research examining the experience of providing care to a loved one with cancer in low- and middle-income countries, specifically in Tanzania. The overall goal of this study was to gain an in-depth understanding of the experiences of cancer caregivers in Tanzania.

This study utilized a qualitative, cross-sectional design. Family caregivers of cancer patients were administered face-to-face interviews that lasted for approximately two hours. The participants were queried regarding sociodemographic information as well as overall well being, difficulties and positive aspects of providing care, access to information and resources, family and friends, and health care provider communication. These interviews were audiotaped and transcribed verbatim. Content analysis was used to identify the emergent themes. Ten themes emerged from the participant interviews. The themes that were relevant to the specific aims of this study were accessibility of information, social support, providing care, and end of life. Other themes that emerged from the interviews and are important to highlight are: access to

medication, time to diagnosis, no hope/no cure, access to hospital, symptom management, and formal healthcare. The results of the analysis suggest that caregivers have several unmet needs throughout the care situation and experience increased feelings of emotional and financial burden.

With the rising incidence of cancer in Africa and the lack of institutional facilities and specialists to support this new patient population, family and friends become the primary caregiver. If caregivers' emotional and physical health is not preserved, the quality of care they deliver may suffer and more demands placed on the health care system by both the patient and caregiver.

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## **PREFACE**

I would like to thank the participants for sharing their stories with me, my committee members for guiding me throughout this process and allowing me to create a product I am very excited about, Dr. Paula Sherwood and the Family Care Studies research team for their continued support, and the SHED foundation for providing logistical support during my time in Tanzania.



## 1.0 INTRODUCTION

Over three decades of research has well documented that in developed countries, providing care to a loved one with a chronic illness such as cancer can cause a great deal of emotional and physical distress for family members. Family caregivers in the United States, Asia, and Western Europe have shown high levels of depression, anxiety, poor immune function, and higher levels of mortality than non-caregivers (Morimoto, Schreiner, & Asano, 2003; Pinquart & Sorensen, 2003; Rossi et al, 2007; Vitaliano, Zhang, & Scanlan, 2003). Due to the estimated 66 million family caregivers in the United States alone, and the fact that this number is expected to continue to grow (NAC, 2009), negative effects from providing care have become a significant public health concern. If caregivers' emotional and physical health is not preserved, the quality of care they deliver may suffer and more demands placed on the health care system by both the patient and caregiver.

The amount of distress caregivers report as a result of providing care has been shown to differ by ethnicity and cultural setting (Parveen, Morrison, & Robinson, 2011; Pinquart & Sorensen, 2005). Unfortunately, evaluating cultural differences in caregiver distress has been limited to developed countries. To date, there is a dearth of research examining the effects of providing care for a person with cancer in developing countries, and sub-Saharan Africa in particular, where family members' roles are even more vital as a resource for healthcare. With the rising incidence of cancer in sub-Sahara Africa (Huerta & Grey, 2007) and the lack of

institutional facilities and specialists in the country, the majority of care rests heavily on relatives or close friends.

The overall goal of this study was to gain an in-depth understanding of the factors contributing to caregiver distress in a developing country. Specifically, the project aimed to explore the phenomenon of family care for persons with cancer in Tanzania. Data such as these are vital to the development and implementation of programs to improve caregiver and patient health throughout the care trajectory.

## **2.0 BACKGROUND**

There is an increase in incidence and prevalence of noncommunicable diseases, specifically cancer, in low- and middle-income countries, a lack of healthcare facilities, and few trained health care providers to support this new patient population (Beaglehole & Yach, 2003; Huerta & Grey, 2007). Therefore, relatives and close friends often provide the majority of care. To date, the majority of research examining the emotional and physical impact of providing care to a loved one with cancer has been conducted in developed nations. There is a paucity of research examining the experience of providing care to a loved one with cancer in low- and middle-income countries, in particular Tanzania.

### **2.1 INCREASE IN PREVALENCE OF CANCER IN LOW- AND MIDDLE-INCOME COUNTRIES**

Noncommunicable diseases include heart disease, stroke, cancer, chronic respiratory diseases, and diabetes. These diseases were once thought to be a problem known only to the developed world; however, in the recent past, low- and middle-income countries have begun to share the burden of noncommunicable diseases (Ferlay et al., 2008; Sloan & Gelband, 2007; WHO, 2005). Over the next decade, deaths from communicable diseases are expected to

decrease by 3% and deaths from noncommunicable diseases increase by 17% (Huerta & Grey, 2007; WHO, 2005). It was projected that noncommunicable diseases would cause 35 million of the 58 million total deaths worldwide in 2005 (WHO, 2005). This number is expected to increase significantly over the upcoming decades. By 2030, the number of noncommunicable deaths is projected to increase to 50 million, which is more than three times the deaths expected for communicable diseases as well as deaths expected for maternal and perinatal conditions (Huerta & Grey, 2007; Mathers & Loncar, 2006). These statistics show that noncommunicable diseases have become a leading cause of death in both developed and developing countries (Beaglehole & Yach, 2003). Not only are the numbers of projected deaths by noncommunicable diseases astounding, but also the impact resulting from these diseases is significant (Huerta & Grey, 2007). The increase in noncommunicable diseases not only impacts the patient and their quality of life, but also impacts the caregivers and community at large.

Cancer, in particular, is a noncommunicable disease whose incidence has increased significantly over the past decades. It is one of the leading causes of death worldwide accounting for 13% of total deaths in 2005 (Huerta & Grey, 2007). In 2008 cancer accounted for 13.8% of total deaths (WHO, 2004a) and in 2030 it is projected to account for 17.6% of total deaths (WHO, 2004b). This upward trend in deaths resulting from cancer is a public health concern and a problem that needs to be addressed. Interventions in developed countries have been successful in decreasing the numbers of death caused by cancer. However, in low- and middle-income countries, cancer is a problem that has been given little attention (WHO, 2005). Cancer incidence and prevalence have been rising over the past few decades and in 2030 it is expected that 70% of newly reported cancer cases will occur in developing countries. This is a vast difference from 1970 when 15% of newly reported cancer cases occurred in developing

countries (Beaulieu, Bloom, Bloom, Stein, & Breakaway, 2009; Boyle & Levin, 2008; Ferlay et al., 2008). Not only are developing countries experiencing an increase in incidence and prevalence of cancer cases, the mortality rate for cancer is significantly higher than in developed countries. According to the WHO, only 20% of noncommunicable disease deaths occur in high-income countries while 80% occur in low- and middle-income countries (WHO, 2005). One of the underlying reasons for this disparity in mortality rates is the lack of screening services available in developing countries. The majority of cancer cases diagnosed in low- and middle-income countries are in a later stage and successful treatment is less likely. One-third of the burden caused by cancer might be decreased if cases were detected and treated earlier (WHO, 2011).

The increase of burden caused by noncommunicable diseases, specifically cancer, in developing nations is a public health concern that has been neglected (Beaglehole & Yach, 2003). Development of prevention strategies and infrastructure to support this increase of burden on the health system has been a low priority in sub-Saharan Africa, mainly because the focus has been on communicable diseases (Parkin et al., 2008). The increase in incidence of cancer and the lack of institutional facilities and specialists in developing countries has put the majority of patient care in the hands of close relatives and friends. If the health of family caregivers is not protected then they, too, will place a burden on the healthcare system and may not be able to supply high quality care to the patient, who solely depends on the caregiver for support. This problem can have a significant public health impact as it decreases quality of life for affected individuals, causes premature death, and emotionally, physically, and economically impacts families, communities, and societies at large (WHO, 2005).

One country in particular that has recognized cancer as a public health concern is Tanzania (Sloan & Gelband, 2007). Tanzania is a country in Central East Africa and is bordered by Kenya and Uganda to the North; Rwanda, Burundi, and Democratic Republic of the Congo to the West; Zambia, Malawi, and Mozambique to the South; and the Indian Ocean to the East. The total population is 39,459,000, (WHO, 2008) the gross national income per capita (PPP international \$) is 908 (WHO, 2008), and the gross domestic product (GDP) is \$21.623 billion (World Bank, 2009). The percentage of persons living in urban areas is 25% (WHO, 2008). Life expectancy at birth for males is 50 and for females is 51 (WHO, 2008). Healthy life expectancy at birth for males is 40 and for females is 41 (WHO, 2008). The probability of dying under the age of 5 is 118 per 1,000 live births (WHO, 2008). Probability of dying between the ages of 15 and 60 for males is 518 per 1,000 persons and for females is 493 per 1,000 persons (WHO, 2008). Total expenditure on health per capita (PPP international \$) is 45 and total expenditure on health as a percentage of GDP is 5.5% (WHO, 2008).

The government delivers the majority of health-care in Tanzania with the private sector contributing to less than 20 percent of health services offered. Most of the health centers have a rural emphasis because 75 percent of the population lives in rural areas (Sloan & Gelband, 2007). The government subsidizes health care in the public sector, with patients contributing through the national health insurance fund (Sloan & Gelband, 2007). This insurance plan covers government employees, such as teachers and health care workers and is fairly comprehensive as it covers both inpatient and outpatient services (E. Kawira, personal communication, April 3, 2011). However, the majority of Tanzanians are not able to meet their basic health needs as a result of low-income and unemployment (Sloan & Gelband, 2007).

Tanzania currently has a lack of human resource capacity. In 2001 it was estimated that there was an active supply of 49,000 personnel in the health sector, which translates to 148 health workers per 100,000 persons. In 1994 it was estimated that there were 67,600 active health workers. This is a 19,300 decrease of health personnel in the span of seven years. It is predicted that the total workforce will continue to decrease to 37,900 by 2015 (Dominick & Kurowski, 2004). In 2007, it was estimated that there were two physicians per 100,000 persons (UNDP, 2007) and in 2005 it was estimated that there were six oncologists total in Tanzania, all working at Ocean Road Cancer Institute (ORCI) (Sloan & Gelband, 2007). OCRI is the only cancer institute in the country and is located in Dar es Salaam on the eastern coast. It is estimated that there are about 30,000 new cancer cases each year in Tanzania. Less than 10% of newly diagnosed cancer patients are able to go for treatment at ORCI, and of this population 80% arrive when the cancer is too far advanced to treat effectively. The prevalence of HIV/AIDS, malaria, and other infectious diseases has overshadowed the increase in cancer cases and the emotional and physical impact this may have on close relatives and friends of the patient (Sloan & Gelband, 2007)

## **2.2 IMPACT OF PROVIDING CARE ON CAREGIVERS IN HIGH-INCOME COUNTRIES**

The majority of research examining the impact of providing care to a loved one with cancer has been conducted in developed countries, specifically in the United States, Western Europe, China, Japan, and Taiwan. Economic shifts in US healthcare have resulted in earlier discharge from the hospital after surgery or treatment leaving family members and close friends

responsible for providing the majority of care (Sharpe, Butow, Smith, McConnell, & Clarke, 2005). In Asia it is common for family members to accompany the patient to the hospital as well as provide other caregiving responsibilities, which has been shown to negatively influence the emotional quality of life (QOL) of spouse caregivers (Chen, Chu, & Chen, 2004). In Western Europe, specifically Italy, the National Health Service provides health aid to all patients with cancer; however, access to this assistance is difficult to obtain. This puts the burden of financially providing for these services, as well as other end of life services that are not covered by the National Health Service, on the caregiver (Rossi et al., 2006). As a result of limited access to and provision of healthcare in these regions, there are an increasing number of caregivers worldwide.

The transition from family member or friend to providing care to a loved one with cancer is sudden and unplanned. There is little time for preparation or for the caregiver to learn how to perform the various tasks that will be required throughout the care situation. This transition may have a large impact on the caregiver's life as they take on new roles and responsibilities. The literature over the past several decades has shown that providing care to a loved one with cancer or dementia may cause negative emotional and physical responses in the caregiver (Pinquart & Sorenson, 2003).

### **2.2.1 Caregiver Emotional Responses**

Research has well documented that providing care to a loved one with cancer can impact caregiver depressive symptoms, burden, and anxiety (Pinquart & Sorenson, 2003a). Overall, caregivers report higher levels of depression and stress than noncaregivers (Pinquart & Sorenson, 2003b). An analysis in the United States of 152 family caregivers of patients with cancer who



had died revealed that the majority of participants reported moderate to high levels of depressive symptoms (Given et al., 2005).

Factors that negatively impact feelings of depression and burden have also been examined. A meta-analysis examining caregivers of different populations of patients in the United States described the associations between patient impairments, involvement of caregivers, and uplifts of caregiving with caregiver burden and depression. It was found that caregiver burden and depression were most strongly related to patient behavior problems (Pinquart & Sorenson, 2003a). Similar findings were found in an analysis of caregivers of stroke patients recruited through seven different neurological hospitals in Japan. It was reported that increased caregiving hours was significantly correlated to increased caregiver burden, which was found to relate to increased depressive symptoms in caregivers (Morimoto et al., 2003). These analyses highlight the emotional impact that the various tasks and responsibilities of caring for a loved with cancer can have on the caregiver throughout the care trajectory; however, the majority of studies examined caregivers of the chronically ill or disabled, without looking specifically at cancer caregivers.

Certain aspects of caregiving have been shown to cause higher levels of stress in caregivers, which contribute to feelings of depression and burden. Research by Tsai and Jirovec (2005) examined caregivers of chronically ill relatives and found that hours of care provided, gender, and age are important factors contributing to perceived stress and indirectly to caregiver depression. Higher perceived stress was significantly correlated with an increase in depressive symptoms, which can lead to poor health function, lower self-esteem, and lower marital satisfaction. The retrospective design of this study prevented the authors from gaining a more

detailed understanding of what the caregivers were going through when caring for their chronically ill family member or friend.

In summary, caregiver burden and depression are significantly impacted by caregiving involvement, hours of care provided, patient behavior problems, and caregiver/patient symptoms. As family members and friends make the transition to primary caregiver, they may experience increased burden, stress, and depressive symptoms, which have been shown to negatively impact overall physical health in caregivers (Pinqart & Sorenson, 2003b). The Pittsburgh Mind Body Center Model depicts the relationship seen between providing care to a loved one with cancer and the negative impact this may have on the caregiver (Sherwood et al., 2008). For the purpose of this thesis, the emotional aspect of the model was used as the theoretical foundation for the study and also guided the study design and development of questionnaires.

### **2.2.2 Caregiver Overall Physical Health**

Several studies have highlighted the impact that providing care to a family member or friend with cancer can have on the caregiver's overall physical health. One hypothesis states that the emotional response caregivers experience throughout the care situation triggers negative biological responses. At diagnosis, caregiver stress levels are elevated and the "fight or flight" response is initiated. While this response is beneficial in the short-term, it has been shown to be detrimental over an extended period of time. Caregivers experience a chronic stress response (e.g., release of glucocorticoids and catecholamines) as a result of prolonged treatment and disease progression of the patient. This prolonged response can negatively impact the caregiver's immune system and overall health (Elenkov & Chrousos, 2002). A meta-analysis examining the difference in physical health between caregivers of frail older adults and

noncaregivers showed that caregivers reported lower levels of physical health than their noncaregiver counterparts (Pinquart & Sorenson, 2003b). In an analysis conducted by Vitaliano et al. (2003) it was reported that caregivers had higher levels of stress hormones and lower levels of antibody responses than noncaregivers.

Not only does the literature report that caregivers are at greater risk for poor physical health, it also suggests that caregiving is an independent risk factor for mortality. In an analysis of 392 caregivers and 427 noncaregivers, it was found that caregivers who reported feeling burdened from providing care were 63% more likely to die within 4 years than caregivers who did not report emotional strain and than noncaregivers (Schulz & Beach, 1999). This suggests that caregivers who experience more burden and strain are at a greater risk of dying prematurely than caregivers who do not experience as much burden and persons who provide no care to their spouse. While the implications of this study are important, the population being examined was elderly individuals with a disability. Fewer studies have looked at the impact of providing care to a loved one with cancer on caregiver physical health.

While it is not known whether caregiving causes illness, these data suggest that caregiving may increase susceptibility to disease by causing immune system dysfunction. More research needs to be done to better understand the relationship between providing care and overall health. This has important clinical implications for medical personnel who have the ability to screen caregivers that may be at risk for developing poor health as well as implications for healthcare systems that may be burdened by the increasing caregiver population.

## **2.3 IMPACT OF PROVIDING CARE ON CAREGIVERS IN LOW- AND MIDDLE-INCOME COUNTRIES**

The literature reflects some research that has examined the distress felt by family caregivers in developing countries; however, this area is largely unexplored, especially in sub-Saharan Africa and Tanzania in particular. While there is a paucity of research examining the experience of caregivers in low- and middle-income countries, there is also a lack of research examining the needs of patients and their caregivers. The majority of research in this area focuses on how caring for someone dying from cancer emotionally impacts the caregiver through quantitative means (Awadalla et al., 2007; Ohaeri, Campbell, Ilesanmi, & Omigbodun, 1999; Ohaeri & Shokunbi, 2002). Common outcome measures used for these analyses are burden, QOL, and general health outcomes. To date, there are few exploratory studies using qualitative means to gain a broader understanding of the experiences of caregivers in sub-Saharan Africa as well as their needs throughout the care trajectory.

### **2.3.1 Emotional Impact**

It has been reported that caregivers in low- and middle-income countries experience negative psychological outcomes. A cross-sectional study conducted in Nigeria of caregivers of persons with sickle cell disease in crisis and sickle cell disease in stable condition compared with a similar study of cancer patients examined the financial, social, and emotional impact of providing care. Data showed that the cancer population and the sickle cell disease (SCD) in crisis population both experienced similar perceived financial, social, and psychological distress (Ohaeri & Shokunbi, 2002). The author suggests that controlling the frequency of crises related

to SCD while concurrently providing relevant information and socioeconomic support to the caregivers would significantly decrease psychosocial burden. While the SCD in crises caregiver population and the cancer caregiver population were found to experience similar levels of perceived stress and burden, these findings cannot be generalized to the cancer caregiver population. Ohaeri et al. (1999) examined the psychosocial burden of providing care for a relative with breast cancer in Nigeria. It was reported that high levels of burden in caregivers did not jeopardize the social relationships of caregivers at home and in the neighborhood. This suggests tolerance of change in routine and lack of social stigma with regard to the care situation. Furthermore, overall perceived burden of the caregiver was most strongly related to limitations caused by the disease for both the patient and caregiver at home and at work. Yusuf et al. (2010) conducted a descriptive study in an outpatient clinic in Nigeria examining the emotional and physical impact of providing care to a loved one with cancer. The results of this study show that caregivers experience high levels of burden and psychological morbidity. This seems to be indicative of the unmet needs of the patient and caregiver, which primarily were lack of financial support, not having enough time for self, and the stress of caring for a loved one with cancer. These analyses highlight that providing care to a loved one with cancer may result in increased burden and distress, as well as lower quality of life. The majority of these studies were conducted in urban settings where patients had easy access to a referral hospital and treatment. This cannot be generalized to patients and caregivers in a more rural setting where access to healthcare is difficult and resources are limited.

### **2.3.2 Needs of Caregivers**

There is a paucity of research examining the information needs and availability of services for caregivers in sub-Saharan Africa. Selman et al. (2009) conducted a semi-structured qualitative study in South Africa and Uganda to examine information and communication of patients with an incurable progressive disease and their caregivers. Researchers found that poor knowledge and provision of information negatively impacted the patients' and caregivers' ability to cope with the diagnosis and the caregivers' ability to care for the patient. The majority of the participants in this analysis were caregivers to patients diagnosed with HIV, which may be a different care situation than caregivers of cancer patients. Murray et al. (2003) conducted a comparison study in Scotland (longitudinal study with qualitative interviews) and Kenya (cross-sectional study with qualitative interviews) looking at the needs of patients with an incurable disease and their caregivers. It was reported that the needs of patients and caregivers in Kenya (pain management and financial concerns) were much different from those in Scotland (the emotional pain of facing death). This study highlighted the importance of understanding needs and how they are met in different cultural contexts; however, the vast difference in geographic, social, and cultural issues around death and dying may limit these findings from being generalized to other communities.

These studies shed light on the importance of understanding and improving the emotional well-being of family caregivers in sub-Saharan Africa so they can provide high quality care to the patient as well as providing the caregivers with the necessary information and services to guide them throughout the care trajectory. While Selman et al. (2009), Murray et al. (2003), and other investigators in this field provided foundational work examining the needs of cancer patients and their families, future research is needed to have a better understanding of the

experiences that caregivers go through in developing countries and what specific information and resources are necessary to assist them with caring for someone with cancer. Specifically, further research is necessary to examine the experiences of cancer caregivers in Tanzania where there have been no studies found to date. This additional information will aid in the development of programs to help caregivers better cope with the diagnosis of cancer as well as supplement the knowledge of resources, services, and information that caregivers' desire.

### 3.0 METHODS

This study utilized a qualitative, cross-sectional design that was carried out under the supervision of Shirati Health, Education, and Development (SHED) Foundation in Shirati, Tanzania. SHED is a non-governmental organization (NGO) that focuses on the fight against Burkitt's lymphoma, malaria, and schistosomiasis as well as connecting chronically ill and disabled persons with medical and social services through the Sota Health Clinic. This study was approved by the Institutional Review Board (IRB) at the University of Pittsburgh as well as by the host organization, SHED.

The author conducted this research as part of required practicum hours for the University of Pittsburgh, Graduate School of Public Health. The research presented in this thesis was funded by the Center for Global Health and supported by an ongoing study at the School of Nursing, *Mind-body Interactions in Neuro-oncology Family Caregivers* (RO1CA118711), which examines the emotional and physical impact of providing care to a loved one with a primary malignant brain tumors. While in Tanzania, the author worked with Dr. Esther Kawira, the founder of SHED and the only physician at the Sota Health Clinic, as well as Glorius Nyakyema, who is fluent in the various languages spoken in the region where the research was conducted: English, Swahili, and Luo. The author also collaborated with Paula Sherwood, the principal investigator of the ongoing study listed above, as well as Jason Weimer, the project director of the ongoing study listed above.



### **3.1 RECRUITMENT**

Family caregivers were eligible for the study if they were 1) over 21 years of age, 2) a primary nonprofessional, unpaid caregiver as identified by the patient, 3) not currently considered to be a primary caregiver for anyone else other than children under the age of 21, and 4) providing some form of support (e.g. physical care, emotional support, or financial assistance) to someone who was diagnosed with cancer at least 3 months prior to the interview, which will ensure the caregiver had some experience providing care. Medical personnel at SHED reviewed patients and their caregivers who had come through the clinic and identified subjects who met the above criteria. Participants gave permission to be approached by research team members. The author approached eligible subjects, with the aid of an interpreter if necessary, to ensure that participants were fully informed of what was expected from them and to answer any questions they may have. Verbal consent was obtained from willing participants. For this study, 15 subjects were screened and approached with a 100% recruitment rate. Participants were given a mosquito net as reimbursement for their time and effort.

### **3.2 DATA COLLECTION**

A face-to-face interview was administered the same day consent was obtained. The interview lasted approximately one and a half hours and consisted of a sociodemographic questionnaire as well as several open ended questions based on interviews used in the United States (NIH RO1CA117811; Sherwood PI) and other cultures (Selman et al., 2009). Questions were chosen that addressed the physical, emotional, and financial impact of caring for a family

member or friend with cancer. The questions were written in English, translated into the local dialect, and back translated to English prior to conducting the study in Tanzania. The questions were read to the family caregivers in English and the interpreter hired for the study read a script containing the translated questions. The interpreter verbally translated the caregiver responses back to the interviewer. All of the interviews were audiotaped and transcribed verbatim. Caregivers were assigned participant numbers and all identifiable information was deleted from the transcriptions. All audio recordings were erased after the interviews were transcribed.

### **3.3 CAREGIVER MEASURES**

All measures were administered to the caregiver by the author with the aid of an interpreter, if necessary. Two interviews were conducted in English without the use of the interpreter. Family members were queried regarding sociodemographic information as well as overall well being, difficulties and positive aspects of providing care, access to information and resources, dealing with family and friends, and health care provider communication. Appendix A contains the sociodemographic questionnaire and open-ended questions that were administered during the interview.

### **3.4 ANALYSIS**

Content analysis, or analyzing text to determine what patterns of text or concepts predominate, was performed to identify recurring themes among interviews (Bernard, 1995;

Ulin, Robinson, & Tolley, 2005). To enhance confirmability, the author along with Paula Sherwood and Jason Weimer, read through and coded the interviews independently to identify themes. The reviewers then met as a group to come to a consensus on the emergent themes of the interviews. Saturation was reached during the 14<sup>th</sup> or 15<sup>th</sup> interview when no new themes emerged. Dr. Esther Kawira, who is familiar with the area where the participants were recruited, read through the transcriptions and reviewed the themes. All 4 reviewers came to a consensus and finalized the emergent themes. Any disagreements that arose regarding identification of themes or theme definitions were discussed until consensus was reached.

## **4.0 RESULTS**

### **4.1 SAMPLE CHARACTERISTICS**

The majority of participants were female (66.7%, N=10), from the Luo tribe (100%, N=15) and the spouse of the patient (60%, N=9). The highest level of education for the majority of the participants was primary school (53.3%, N=8) and the average income was \$1053.14 per year, ranging from \$0 - \$6000. None of the participants had health care insurance. The mean age of the participants was 54.33 years, ranging from 35-77 (see Appendix B).

### **4.2 QUALITATIVE FINDINGS**

Ten themes emerged from the participant interviews. The themes that were relevant to the specific aims of this study were accessibility of information, social support, providing care, and end of life. Other themes that emerged from the interviews and are important to highlight are: access to medication, time to diagnosis, no hope/no cure, access to hospital, symptom management, and formal healthcare. These themes are discussed in the following sections.

#### 4.2.1 Accessibility of Information

Accessibility of information was defined as the transfer of information from medical personnel to the patient/caregiver dyad concerning the disease as well as how to care for someone with cancer. The majority of caregivers reported that they were never given any information on the patient's disease.

“Any information that I needed, if I would know really what [cancer diagnosis] is and the cause and complications, if I knew then earlier, I think, I could have been well prepared and it would not have bothered me so much.... Yeah, and sometimes you want to ask the doctor, maybe the doctor has no time to explain to you all these, because to see a doctor is even difficult, so if there could be maybe information available, then I think it could have helped.” (007)

Some caregivers talked about not being told how to prepare for disease progression. Several caregivers reported being concerned that the disease was contagious, and were hesitant to provide treatment to the patient in case they would “catch” the disease.

“I even asked myself “is it transferrable?” Yeah so that was the thing that even worried me to say that was it transferrable from one person to another.” (003)

Other participants described problems that arose in their family because of a lack of information on the origin of the disease. It was unknown if the disease was hereditary and often times family members blamed the family of the patient for bringing in the “bad genes.”

“So even in the family my [inaudible], my sister-in-laws, my mother-in-law people, but they been saying something like this is not a disease from our, our, our family. This is something from your family. In our family

we don't have this and all this. So it was something that, I went back home and tried to ask my father and mother if they happened to know any of their parents or their family who died of something like this but I couldn't find that answer. And also in my husband's family, they can't recall something like this in their family. So this is also another thing, another question, where did this come from." (007)

The last concern in regards to accessibility of information was the lack of information given to the caregivers on how to provide care. The majority of caregivers reported difficulty caring for the patient.

"I didn't get information about how to care for the child but I did this in my own way, I did it in my own way.... Maybe if the kid wanted to eat I, if maybe she want some certain kind of food, I bring it to her, try.... I was not given any condition of how to care for her." (002)

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

#### **4.2.2 Social Support**

Social support is defined as the amount of support family and friends provided considering their own financial, social, and time constraints. A number of caregivers reported that family members helped monetarily and with provision of food as much as they could. While it may not have been enough to cover the cost of medication, the caregivers were appreciative.

"OK financially, my sons and children had done a lot of financial support, though it's not total enough because the treatment was

expensive in the cities and also the families big. So even the money was actually coming as income was being distributed, the family was not quite enough. Yea that is, so a lot of money could go to treatment and leave other expenses unattended.” (003)

The caregivers were understanding of family members and friends who were unable to provide support, whether it was in the form of money, food, or emotionally. They stated that they understood their family and friends did not have much to offer. Almost all of the caregivers reported that they could not “force” others to help.

“I understand the type of life they are living and they are such a like a poor family so I can’t force anybody or maybe family member to contribute or to help in one way or another if they don’t feel like. So I just, I just thanks those who help me and maybe those will feel like doing so another day they can keep doing so. I can’t force anybody. I don’t have money, if somebody give money, like if somebody give something like clothes.” (008)

A few caregivers reported that they would have liked family and friends to be more supportive emotionally and physically, not necessarily just financially.

“I could have, the, the other family and friends maybe if somebody is sick they should be together to look how they can help the person who is sick not to abandon them.” (013)

Other caregivers mentioned they would have liked someone to look after the patient so they could leave the house to earn extra money.

“I didn’t get help from anybody so I would just sometimes I could leave the husband at home I go for fish from the lake to go to sell to get money. So it was extremely difficult for me.” (006)

While a couple of the caregivers mentioned wishing they had more emotional support, the majority of them referred to social support as helping them financially or with food.

Another sub-theme that emerged was the inability of family or friends to help because they were taking on the roles and responsibilities that the patient could no longer fulfill. This led to less time and resources available to provide direct help to the caregiver.

“When I was in X there were others that were here at home cooking, after they went from Shamba, the farm, they were the one cooking, taking care of the home.” (002)

While social support was not always available to the caregivers, they were still appreciative of the help and support that their friends and family were able to offer.

#### **4.2.3 Providing Care**

Providing care is defined as assisting the patient with activities of daily life (ADLs) and instrumental activities of daily life (IADLs) considering their own roles and responsibilities. Caregivers reported having to help the patient with bathing, eating, and cleaning up after emesis and stool.

“I was to make the food for my husband and feed him with a spoon, I was to help him take shower and at the last stage, he was urinating on the bed, so I had to change the bed sheets. Sometimes I was not to sleep at all during the nighttime; I had to stay with my husband because he used to cry because of the pain he was feeling.” (015)



A number of caregivers also discussed helping the patient with IADLs. One caregiver in particular reported that she would have to carry the patient on her back because they were in too much pain to walk.

“Sometimes the child was in a, in a pain, I was to take her to carry her on my back. And sometimes I was to put her on some exercise walking around, wherever I, wherever I walk maybe sometime the child do some stretch so I was to take, to carry her.” (008)

The majority of caregivers reported that the change or loss of appetite in the patient caused them distress. Patient’s refused food they normally ate, and often preferred food that was more expensive and harder for the caregiver to provide.

“What made me, the difficulty I faced was about finance, because most of the time the food that she needed was a little bit hard to find, nutritious food she needed but it was difficult. Sometimes she didn't want this type of food, I had to look for another food, I didn't have money to buy this food, that part made it difficult. “ (007)

Several caregivers reported having to take on additional jobs to earn enough money to pay for food that the patient would eat.

“I had a boat which was to sail on the sea, in the lake there, we used the boat to catch fishes and some dagaas we used to sell to get money, and some for food, so that helped me a lot in case of food and other stuff at home, like soap, like kerosene.” (014)

One caregiver partook in illegal activities in order to earn more money so they could provide for the patient.

“Sometimes I was to go to make some alcohol, the traditional alcohol, to sell for me to get money. No one was helping... sometimes when I was

to make the alcohol I thought I was not allowed.... Yea that would help to get the money but I was not allowed to make the.... The government does not allow that, to make the local alcohol” (009)

It was reported by several caregivers that it was hard for them to care for the rest of their family while they were caring for the patient.

“So it really affected me because I was worried about the health of my child and what was taken care of. I was worried about the children I left, the family, my, my, my marriage also. So I had a lot of things to worry about, yeah.” (007)

With the additional responsibilities of providing care to the patient, the caregiver did not have enough time to maintain their regular responsibilities as well as those of the patient. The patient required a lot of the caregiver’s attention, which made it difficult for caregivers to provide for the rest of the family, especially if the patient was the main source of income.

“I was not worried that my husband could die at any time, but my husband was kind of annoying (laughs) because he never wanted me to leave beside him, everytime I would leave he would just call me come back here. (Laughter) Because he was in pain. I was not even to take a walk from here to there, because my husband would send somebody to call me to come back.” (015)

#### **4.2.4 End of Life**

End of life is defined as the physical, emotional, and financial hardships that caregivers faced as the disease progressed and the patient neared death. As the disease progressed and the

patient was unable to maintain their responsibilities, caregivers reported financial difficulty as the patient was often the main source of income for the household.

“We were depending on the husband, he was a fish monger selling some fishes, so the time start getting sick there weren’t any means of getting money so I was to take care of the family and to get money for the treatment for my husband for the drugs.”

Several caregivers reported missing the relationship they had with the patient, especially if the patient was their spouse. As the disease progressed, their relationship changed. A number of caregivers said that they were no longer intimate with their spouse and were not able to spend as much time together.

“The relationship changed because were were no longer together. Firstly before, during the time when just the urine was smelling and we were together, but later on when she started getting the stomach pains, we stopped I never stayed with her.” (014)

The majority of caregivers reported being worried about the patient dying and what would happen after their death.

“Yea we are worried for our future; we are worried of our future, if our husband dies. So that was the biggest worry, we miss their love and we miss the future and we worry about the future. So those are the two biggest issues actually.” (003)

When the patient was diagnosed with cancer most of the caregivers thought the final verdict was death. This caused distress.

After the patient passed away several caregivers cited difficulty in getting the body back to their home. Whether it was a means of transporting it or being able to afford the transportation this proved to be a difficult process for the caregivers.

“Then he went away, the time he died, I had a relative over there. He tried very hard to bring back the body. So he found another plane, with the army plane. So he told me, he asked them to bring back the body to X. Then the church here, he was sent there by car to bring us here.”

(001)

A few caregivers reported financial difficulty in regards to the funeral. One caregiver explained that when a family member dies and family and friends come to pay their respects they need to provide food and lodging for them. This may be difficult financially for the family.

“Do you know in our culture when someone died, people come real-, real-, a lot of people come and you have to do something to them. Eh to [inaudible] something to them, food and everything. But, you know, those are the things because of money. That is why the problem which we had.” (004)

Several caregivers reported having emotional difficulties after the death of the patient.

“Yea, I have to admit there were emotional problems. It really took me many years to, to really accept this situation and take it easy. When my daughter died, I really felt bad and I really, another thing, I got a lot of fear that even the children I had would die like her. So when they became even sick after the death of my daughter, any time a child could sick then I was thinking of death. So this brought a lot of fear in me. And I also, some, some sort of depression I had because I, the, my daughter, X, was so bright in school. She was always number one. She

was very smart and she was like uh, in our family, my husband, she was the one whom we, we, we were thinking maybe one day she will be somebody and can help the family.” (007)

It took caregivers a while to adjust to the death of their loved one and to be able to cope emotionally.

#### **4.2.5 Access to Medication**

Access to medication is defined as the availability of medication in health centers and the ability of the patient/caregiver to financially or physically obtain the medication. Caregivers overwhelmingly described the difficulties they had in getting treatment and medication for the patient, whether it was a result of cost, transportation, or availability.

Considering the average income of this population, the cost of treatment and painkillers was very expensive for the caregivers. They often had to sell their possessions in order to afford the medication.

“During the normal day my husband has some, some goats, goat, goat, animals, he kept them at home. So by the time he became sick, I sold the goats to get the money and pay for the drugs.” (012)

The medications that were prescribed were often more than a month’s salary. Selling the family’s possessions would help pay for a portion of the treatment but not all of it. Caregivers would take on additional responsibilities in order to make enough money to pay for the treatment.

“Because my husband was the source of income in the family so by the time he started getting sick we couldn’t make it, we couldn’t have money

we have no how to get the drugs, buy the drugs and take care of the kids.... I used to sell some, some fish from the lake and I could sell them to get some drugs.” (006)

Caregivers also expressed concern about the availability of medication. It was not always guaranteed that the local health center or referral hospitals would have the medication that was prescribed.

“Therefore they have to put her on another medicine. When we were there, that medicine, they, they, the last person finished the medicine and we had no medicine left at that time.... And they came here back again for two months, I, I, I tried to talk to doctor, the doctor, Dr. Z. Dr. Z said that now I have that medicine therefore I have to send you medicine. Therefore he send me that medicine.... And that time there is a, there combination of this medicine. And then he say that the other medicine which you can get for X and the other we can buy and then that medicine was not here but the Dr. Z in charge of [inaudible] he rang for another guy who the doctor was in a seminar in X. Then he said the medicine was in X. So he tried to communicate how we can get that medicine.”  
(004)

There was one participant who had to travel 24 hours by bus to get medication for his wife. Others reported having to travel shorter distances for medication as well. It was not only the cost of medication that was a barrier to receiving treatment but also the cost of transportation to get the medication, which was reported by the caregivers to be problematic.

#### 4.2.6 Time to Diagnosis

Time to diagnosis is defined as the amount of time from onset of symptoms to seeking treatment and receiving an accurate diagnosis. The majority of the participants often sought traditional medicine first before going to a health center. When caregivers were asked what they would do differently if they were to relive the care situation, the majority of them said they would go directly to the hospital as soon as the patient experienced any symptoms.

“Before we went for traditional medicine. And when it failed is when I went to the hospital. But this time I would go directly to the hospital.”

(012)

A number of caregivers also reported that once the patient was taken to the health center, they were misdiagnosed before receiving an accurate diagnosis. Some were diagnosed first with malaria, typhoid, and other more common diseases.

“And in fact she had some general body pain, like the body swell, and when we took her to the hospital, over there, the X Hospital they thought it’s maybe malaria then they put her on malaria medications, but when she went back home, it’s like she had like some frequent urination, now and then, and sometimes she was getting the blood when she go to urinate and later on we took her to X’s place in X and the Dr. X wrote a, some letter to take her to X in X.” (013)

#### 4.2.7 No Hope/No Cure

No hope/no cure is defined as the relationship between the caregiver being told the patient won't survive and the emotional well being of the caregiver. A number of caregivers reported that the medical personnel told them that there was no treatment that would cure the disease.

“The doctor told me that they just give him some drugs for my husband to [inaudible] then told him not to go for an operation just wait, because you can't cure the disease.” (006)

The patients were not given an option for survival. A number of caregivers reported that they were told to take the patient home to die.

“So the doctor just asked me how many children I had then they told me, she just advised me just take the child home because in two weeks time she will not survive.” (007)

Several caregivers were distressed by the idea that they could not help their loved one and that there was no cure for this disease. One caregiver was not willing to accept this as the end.

“But uh, it was hard for me. Because when I saw my daughter after the blood transfusion she was just OK. So I was asking myself how could I take her home and wait for her to die and I asked the doctor if there is any place in this world where you can get treatment. And he told me, she told me if I had millions of dollars I could go to Europe, America or India. But I had no money and the doctor told me it is expensive that even herself could not manage.” (007)



Being told that there was no cure for the patient was hard for the caregiver to accept, and several caregivers reported symptoms of depression and distress.

#### **4.2.8 Access to Hospital**

Access to hospital is defined as means of transportation to/from health centers as well as the availability of doctors and specialists. A number of caregivers reported that the same doctor did not see them every time they went to the health center.

“So that time we go to Dr. Y there. And Dr. Y was maybe, the, he was, the friend of Dr. X from X. Dr. X was a friend of Dr. Y. Eh, from X. So Dr. Y who was in charge of X Hospital at that time, and then we discuss and then Dr. X-, Dr. Y give Dr. X [inaudible] to do examination and whatever the case to diagnose what was going on, what is the problem.” (004)

Furthermore, because of a lack of specialists at the local health centers, patients had to travel far distances to receive medical treatment. Transportation to these referral hospitals was often expensive for the patient/caregiver. There were a couple of participants that reported having to travel separately from the patient in order to save money.

“I went to, yea, to X, then put him in the airplane. Myself I went with the bus. So we meted there.” (001)

Another participant reported having to sell possessions in order to afford transportation to the health center.

“I had a cow. I selled the cow and get the cash for transport” (010)

For some, transportation to the local health center was also a problem. The closest health clinic for several of the patients/caregivers was 22 kilometers, and without a vehicle this was very difficult for them to reach.

“Maybe if something like this were to happen again maybe we could have something like a bicycle or something that could help us to get to X at the time, would be better.” (002)

#### **4.2.9 Symptom Management**

Symptom management is defined as the effectiveness of treating symptoms of the disease and the impact this has on the caregiver. Several caregivers reported that their loved ones experienced a lot of pain during the progression of the disease

“After becoming ill, he was having a lot of pain and couldn’t even stand. He was just sleeping. The last day that he died, he couldn’t even walk.”  
(015)

Some patients were given painkillers; however, they still experienced pain. Others were not given anything to manage their pain nor were they given medication to relieve nausea or vomiting. A number of caregivers reported that watching their loved ones experience these symptoms caused distress.

“OK in fact the, the, the sickness was a process it started slowly, started slowly and later it grew to a lot of pains. Our husband was feeling a lot of pains, feel from here, feel from here and as it was coming up was a lot of pains. He couldn’t sleep mostly.... He had to be supported for everything and there was so much hard because they couldn’t feel, how, the man’s pains. So due to the man’s pains we also feeling pains, you

see. We also feeling the hardship of seeing our love-, beloved one also having the pain and weakening.” (003)

The majority of patients were not given an option of survival; however, they were also not given an option of palliative care. Not only were the caregivers unable to manage the symptoms of the disease as it progressed, but they reported distress as they watched their loved ones in discomfort.

#### **4.2.10 Formal Healthcare**

Formal healthcare is defined as the performance of the medical personnel and the availability of resources and services for the patient/caregiver. The majority of caregivers stated that the medical personnel did “the best they could.” However, there were a few caregivers that specified areas in need of improvement.

“I needed support I think that one I didn’t get. What the doctors or nurses can do, what I would advise, when they see a cancer patient with a relative, at least today, try to find their time in the day, at least every day, to take even like thirty minutes or twenty minutes or even fifteen minutes, to sit with the relative there and talk and give hope. I think that would help because sometimes you even have questions to ask but who will you ask, people are busy. “ (007)

Several caregivers spoke about the lack of food provided to patients in the hospital. Caregivers reported that they had to bring food to the patient while still providing food for their family at home. One caregiver said that he would have to travel 22km everyday to bring food and firewood to his daughter who was in the hospital.

“OK we had no money to buy food and we were not able to be provide food over there so we had to take food from here to there. And we had to carry the firewood and certain things there for us to cook to X.” (002)

One caregiver reported that when his son was in the referral hospital across the country he was unable to provide food or lodging for himself because he didn't have the money. This was difficult for the caregiver because he wanted to be there with his son. The caregiver reported that if the hospital would provide food and lodging for family members that would have helped.

“Because I had no other relative in X I just ask, sometimes I was to sleep under the bed to take care of my child because I was not given any place to stay, sit. So it would be better if we are separate people who don't have relatives or anybody to help over there they could have provided somewhere to stay.... Yeah because they only give the food to the child. I was not given any food. Sometimes was to just drink water for a day.” (010)

A number of caregivers reported that they would like to have supplies provided by the health center to help them care for the patient at home. Specifically, caregivers mentioned needing gloves and wipes to clean up after the patient.

“Maybe they, they, the nurses could help to get some gloves to put on when I was caring for my husband during the toilet, taking him to the toilet and certain things could be better.” (006)

## 5.0 DISCUSSION

The results of the analysis suggest that caregivers have several unmet needs throughout the care situation and experience increased feelings of emotional and financial burden. Inadequate information regarding treatment, medication, and progression of disease, as well as the inability to manage the patient's symptoms and the lack of financial resources and social support were significant areas of concern for the majority of the caregivers interviewed.

Lack of adequate information has been reported in several studies conducted in developing countries (Murray et al., 2003; Selman et al., 2009). Similar results were found in this study as well. However, while the majority of previous research has documented caregivers' interest in more information in general, the results of this analysis show that caregivers specifically would like more information on the disease, how it progresses, and how to care for someone with that type of disease. The caregivers expressed a large gap in knowledge concerning details of the disease, which was reported to create more burden. For example, not understanding whether or not the disease is contagious caused some caregivers to be more hesitant in providing care to the patient.

It was no surprise that caregivers reported benefits of receiving social support, which has been well documented in developed countries (Pinquart & Sorenson, 2007). These studies have highlighted the importance of social support and the positive impact it has on the emotional and physical health of the caregiver. However, in this study, social support seemed to be something

that was desired but not received. Caregivers would have liked to receive support from family and friends, but they understood if they were not able to help and were appreciative for any type of support they did receive. Involving social networks in the care process could alleviate some of the burden and allow the caregiver to share the responsibilities of providing care with others (Pinquart & Sorenson, 2007).

A number of caregivers reported emotional burden resulting from seeing their loved one in pain and the inability to alleviate this pain. The literature documents the lack of access to pain medications (Clark et al., 2007; Murray et al., 2003); however, it does not examine the impact this has on the caregiver in developing countries. Watching a close friend or relative experience pain and knowing there is nothing that can be done to help them can be very stressful and can have a negative impact on the emotional health of caregivers. This may affect the caregiver's ability to care for the patient. These results suggest that palliative care may decrease the emotional burden of caregivers during the progression of the disease.

This is one of the first studies to examine the experiences of family caregivers of cancer patients in sub-Saharan Africa. While certain themes associated with caregiving distress in developing countries were found throughout the literature, results from this study provided unique insights into the care situation. Specifically, caregivers reported that if they had to relive this experience they would take the patient directly to a health clinic rather than going first to a traditional healer. Seeking medical attention from a traditional healer delayed the time to diagnosis from onset of symptoms, which may decrease the effectiveness of the treatment. Traditional healers are a part of the culture and should not necessarily be replaced; however, it is important to realize the benefits of seeking medical attention at a health clinic. Another important finding was the difficulty in providing food for the patient, whether it was because the

patient's appetite was lost and different types of food were desired that were more expensive or because the hospitals did not provide food for the patient and it was the family's responsibility. Most of the caregivers lived on the food they farmed; therefore, providing different food for the patient was financially difficult and was reported as burdensome for the caregiver. Caregivers were unaware that patient's appetite may change. It may be beneficial for the caregiver if they are instructed on nutrition and food selection in advance so they have time to prepare.

Results from this study suggest that caregivers in Tanzania experience challenges in meeting the needs of themselves and their families during the care situation. With limited resources, it is difficult to afford transportation to/from health centers and to provide food for their family and the patient. Often times the patient is given no chance of survival, which the caregivers may have to accept given that medication and treatment may not financially be an option. The caregivers interviewed do not have access to the necessary resources to provide adequate care to their loved ones and this was shown to have a negative emotional impact.

## **5.1 LIMITATIONS**

The goal of this study was to gain insight into the experiences of caregivers and highlight areas for future research. Convenience sampling was used to recruit participants. Participants were chosen based on persons known to the SHED personnel. This may have resulted in bias given that some patients are unable to seek medical attention and their caregivers may experience a heavier burden than those who are able to obtain medical care. While the participants enrolled in this study are representative of the caregiver population, the sample size for this analysis is small (n=15). The nature of the study was exploratory and was not meant to generalize to

everyone in the population; therefore, the sample size was considered sufficient. Use of an interpreter was another limitation of this study. Interpreters verbally translated the participant's responses into English, which were audiotaped and transcribed. Participants' responses may have been misunderstood or oversimplified. While this was a concern for the methodological rigor of qualitative research, the interviewer clarified participant responses with the help of the interpreter. In addition, any comments made by the interpreter that might indicate difficulty understanding the question were noted and further clarification with the participant was pursued. Lastly, the majority of caregivers interviewed were bereaved and may have been recalling experiences from the past. This may have resulted in recall bias.

## **5.2 CLINICAL IMPLICATIONS**

As a result of the lack of knowledge on the disease, practitioners may provide the caregiver with information when the patient is diagnosed. This can include general information on the disease, what signs to look for as the disease progresses, and treatment options. Practitioners can also provide information on how to care for someone with this type of disease, including how to manage their pain and other symptoms the patient may experience. For example, the data suggest that caregivers experienced burden and stress when the appetite of the patient changed. Practitioners may inform caregivers that patients' appetites may change and discuss some lower cost food options with them so they are prepared. This may alleviate some of the stress caregivers experience when the patient will no longer eat their regular diet.

Another concern that the data highlights concerns the difficulty the caregiver encounters providing food for the patient in the hospital as well as providing food for themselves and their



family during this time. A larger scale intervention could center on creating a program in the hospitals that provide food for the patients as well as the family members. This would eliminate the need for the caregiver to travel back and forth from their home to the hospital in order to bring the patient food.

Social support was desired by the caregivers but was not necessarily received. At the time of diagnosis, practitioners may discuss the importance of social support and community support throughout the care situation and provide tips on how to get other family members and friends involved. If other family members and friends are present at the time of diagnosis the practitioner may stress the importance of supporting the primary caregiver throughout the care trajectory as well as provide certain ways that they can help, which would alleviate some of the stress and burden of the caregiver. Furthermore, the practitioner may suggest that the caregiver come to the clinic to speak with them if they have any additional questions. A support group could also be developed consisting of caregivers who have gone through this process in the past, caregivers who are still currently going through this process, and caregivers who are new to the care situation. This would allow for the caregiver to discuss any concerns or questions they may have.

### **5.3 FUTURE RESEARCH**

While this study gives insight into the experiences of caregivers at a defined time, longitudinal studies are important to understanding how the care situation changes over the duration of the care situation. At the time of diagnosis, caregivers may have a very different outlook on the care trajectory than at 4 months later and 12 months after diagnosis. This

information is vital to knowing how caregiver needs can change and the best times to intervene. Another area for future research is to include quantitative as well as qualitative methods. Quantitative methods would give a different perspective on the caregiver situation. Using depression, anxiety, and QOL scales, for example, would allow for a better understanding of the physical and emotional impact of providing care. The results of this analysis can be useful as a screening tool to determine which caregivers are most at risk of experiencing negative effects and which caregivers should be targeted for the intervention. The last recommendation for future research would be to conduct focus groups with cancer caregivers as well as medical personnel and community health workers. This will allow for a more holistic understanding of the care situation and what can be done to improve the experiences of caregivers. Focus groups conducted by local facilitators will give key stakeholders the opportunity to express their opinions and develop strategies that will help decrease the burden and stress of caregivers. This will also allow for the proposed strategies to be more sustainable within the community and empower the stakeholders to become involved in developing interventions for this population. Continual research in this area is crucial to gaining insight into the experiences of cancer caregivers in Tanzania and helping them to provide the best care possible to the patients.

#### **5.4 CONCLUSION**

The increase in incidence and prevalence of cancer cases in sub-Saharan Africa and the insufficient healthcare infrastructure to support this population results in family members and friends becoming the primary caregiver. Research in developed countries has well documented the negative physical and emotional impact of providing care to a loved one with cancer;

however, there is a paucity of research examining cancer caregivers in developing countries and no research found to date looking at the experiences of cancer caregivers in Tanzania. This study sought to better understand the experiences and needs of cancer caregivers in Tanzania and to continue to fill the gap in research concerning cancer caregivers in sub-Saharan Africa. Several of the emergent themes identified in this analysis were consistent with the literature while others provided a unique perspective into the experiences of caregivers. This study highlighted the negative emotional impact that providing care may have on the caregiver as well as the importance of providing services and information for family members and friends throughout the care trajectory. The results reported support the need for the development of interventions that will be aimed at improving caregiver and patient health in Tanzania throughout the care situation.

## APPENDIX A

### CAREGIVER MEASURES

#### A.1 SOCIODEMOGRAPHIC QUESTIONNAIRE

1. What is your gender?
2. When were you born?
3. What is your age?
4. Relation to patient?
5. When was the patient born?
6. What is the patient's diagnosis?
7. Which one of the following best describes your marital status
  - a. Single
  - b. Currently married
  - c. Living with partner/significant other
  - d. Widowed
  - e. Separated
  - f. Divorced
  - g. Other (specify\_\_\_\_\_)
8. How many years have you been at your current marital status?
9. What is your cultural identity/affiliation
10. What is your mother tongue?

11. What is your national language?
12. What is your official language?
13. Where do you live?
14. In what type of area did you live most of your childhood?
  - a. Urban, large city
  - b. Urban, small city
  - c. Suburb of large city
  - d. Suburb of small city
  - e. Rural, farm
  - f. Rural, non-farm
  - g. Other (specify \_\_\_\_\_)
15. How many years of education have you completed?
16. What is the highest level of education you completed?
17. Are you employed?
18. Do you have health care insurance?
  - a. If yes, does insurance cover the cost of medication?
  - b. If yes, does insurance cover the cost of health care?
19. Are you currently employed?
  - a. What is your primary occupation?
  - b. How many employees does your employer have?
  - c. Has this been your primary occupation for most of your working life?
  - d. Did you change occupations since [patient's name] diagnosis?
  - e. What change did you make?
  - f. Did that affect your insurance coverage?
  - g. Has [patient's name] cancer or treatment caused you to take paid time off work?
  - h. Has [patient's name] cancer or treatment caused you to take unpaid time off work?
20. Do you have any children?
21. How many people presently live in your household including yourself?
22. Do you have a religious background or preference?

23. How important is religion or spirituality in your life?
24. To what extent do you follow the customs and practices of your religion?
25. Where do you receive income from?
26. If you are currently employed, what is your monthly income?
27. If you are not currently employed, but were in the past, what was your monthly income the last year you worked?
28. What is the monthly income for your household from all sources?
29. Does your current household income meet your basic needs?
30. How difficult is it to pay for your basic needs?

## **A.2 OPEN-ENDED INTERVIEW**

1. Can you describe what a normal day was like before [patient name] had cancer?  
Prompts: at work? at home? in social situations (church, party, etc)?
2. What is/was a normal day like after [patient name]'s had cancer?  
Prompts: at work? at home? in social situations (church, party, etc)?
3. Did your relationship with [patient's name] change after he/she had cancer?
4. What do/did you help with since [patient's name] got cancer that you did not do before?
5. What is/was the most difficult thing you had to help [patient's name] with?
6. Tell me what things make it difficult to be a caregiver.
7. Tell me what things make it easier to be a caregiver.
8. What do you wish you had known more about while caring for [patient's name]? Do you know where you can get this information?

9. If you went through this experience again,
  - a. What would you do differently?
  - b. What would you ask or want your friends and family members to do differently?
  - c. What would you want your doctors or nurses or healthcare professionals to do differently?
10. What did you learn while caring for [patient's name] that you think could help others in the same situation?
11. What kinds of things do you think doctors, nurses, social workers, and other health care providers could do to better help you when you are caring for someone with cancer?
12. Can you tell me about when the [patient] first got ill?  
Prompts: symptoms, doctor's visits, etc
13. Can you tell me about what treatment they received and where they received this treatment?
14. What problems have you had as a result of their illness?  
Prompts:
  1. Emotional/worry/psychological/spiritual
  2. Economic/social
  3. Family problems—for example, care of children
15. Are there any other people whom you look after?  
Prompts: children, relatives, friends
16. Does/did anyone care for you and give you support? If yes, who?  
Prompts: spouse, friends, family, services
17. What is/was your biggest worry while caring for [patient's name]?
18. Have you received information about the illness? Where did you get this information? Was it helpful? What would you like more information about, if anything?
19. Have you ever been a caregiver to a friend or family member in the past?

## APPENDIX B

### SAMPLE DEMOGRAPHICS

Variable		N	%
Sex	Female	10	66.7
	Male	5	33.3
Ethnicity	Luo	14	93.3
	Mkaguru	1	6.7
Level of Education	Some primary	1	6.7
	Primary	8	53.3
	Secondary	2	13.3
	Vocational	4	26.7
Insurance	Yes	0	0
	No	15	100
Marital Status	Currently Married	6	40
	Widowed	9	60
Relationship to Patient	Spouse/Sig. Other	9	60
	Parent/Grandparent	6	40
Age	Range: 35-77	Mean	53.33
Income/yr	Range: \$0-\$6000	Mean	1053.14



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