PSYCHOSOCIAL NEEDS AND CHALLENGES OF CAREGIVERS AT ELDORET HOSPICE IN ELDORET TOWN

BY

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DECLARATION

Declaration by the candidate

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DEDICATION

I dedicate this thesis to all caregivers who dedicate their entire lives caring for others. This makes them to become "secondary clients" in their course of duty since caring takes strength.

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ABSTRACT

Hospice care is a type and philosophy of care that focuses on the palliation of a terminally ill or seriously ill patient's pain and symptoms, and attending to their emotional and spiritual needs. In Kenya's hospice there have been many challenges faced by caregivers that cuts across social, economic, political and psychological. Many efforts have been done and even institutions created to address them but there is still more to be done. In Eldoret Hospice, cancer clients and their caregivers go there for care. The structure is in such a way that hospice forms social network with neighboring hospitals and do follow ups in home setting. This gives institutional caregivers' big workload. The emerging trends of home care and institutional care give leeway for most care to be done in home setting by family members (nuclear and/or extended) and friends to the cancer clients. These caregivers are less trained to take care of these clients and are likely to show sympathy and not empathy because of close relationship. Therefore, professionalism is at stake. Theoretically, many studies conducted on caregivers' psychosocial needs and challenges have been carried out outside Kenya, in western world, and a few done in Africa. The specific objectives of this study were: to find out psychological needs and challenges faced by caregivers at Eldoret Hospice in Eldoret town, to investigate social needs and challenges faced by caregivers and to find out the coping strategies for psychosocial needs and challenges faced by caregivers. The study was based on self-care deficit nursing theory by Dorothea Orem. The study was conducted in Eldoret town and was a mixed research (qualitative and quantitative) in nature. The sample size was 18 respondents; 6 caregivers from MTRH hospital, 6 caregivers at home setting and 6 caregivers from Eldoret Hospice. Psychological assessment, in-depth interviews, focused group discussion and life histories were used as the study methods. Research instruments were Self Rating Scale by Judy Bradley, Self-analysis questionnaire by Dr. Charles Spielberger, in-depth interview guide, focused group discussion guide and interview guide. Validity was ensured through piloting the instruments, methodological triangulation, peer consultation and consultation with supervisors. Reliability was ensured through test re test of instruments. Data collection procedures were embedded in the instruments used in the study. Saturation method marked the end of the process. Data was analyzed through recursive abstraction technique where descriptions, narrations, quotes and citations were used. The findings revealed Psychological challenges of caregivers were caregiver stress, compassion fatigue, depression, burnout and mood disorders. Psychological needs of caregivers were Information, debriefing, supervision, and training. Again, socially caregiving had affected caregivers' personal relationships and social life as they find themselves 'carrying their work home.' Caregivers need training on culture, modern visa vise indigenous medicine and traditional visa vise modern counseling. Caregivers used differentiation of self, basic counselling skills, self awareness, spirituality, seeking knowledge, clinical supervision, sharing and debriefing, reflection on lessons and insights as coping strategies. A conclusion is arrived at that all psychosocial challenges are universal; anyone is at risk. Psychosocial needs vary with personality, context, location, knowledge, gender, age, occupation, and status as well as coping strategies. Recommendation was that training programs adapted for caregivers should capture the aspect of culture from which the clients comes from and caregivers should embrace team work for better results.

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ACCRONYMS AND ABBREVIATIONS

ADRD   - Alzheimer's Disease and Related Dementia

MTRH   - Moi teaching and referral hospital

NACOSTI   -National Commission for Science and Innovation

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

According to Juliana (2014) caregivers are called so because they give care to other people but more often than not don't receive care in return. They have been trained to take care of others but not themselves. In many cases caring for the caregivers is a forgotten factor in that even the people they take care of rarely view them as merely people who need care as well. Ironically even the caregivers themselves forget taking care of themselves but sink in the cocoon of caring for others which is the critical issue.

Caregiving in this study was both institutional and home based. Institutional caregiving is done in institutions by institutional caregivers who are usually professionals. Home based caregiving is done in home setting by primary caregivers who are of close relationship with client(s). Description of clients in the study was cancer clients. Laurel Northouse, et.al. (2012) conducted a study where the focus was on the family caregivers. Findings were that caregiver stress can lead to psychological and sleep disturbances and changes in caregivers' physical health, immune function, and financial well-being. Research-tested interventions delivered to caregivers of patients with cancer or other chronic illnesses can reduce many of these negative effects and improve caregivers' coping skills, knowledge, and quality of life. Although these interventions also decrease patients' symptoms, reduce mortality (non-dementia patients), and improve patients' physical and mental health, they are seldom implemented in practice.

According to McGrath (1992), gender of the caregiver was studied as well as family relationship with the clients. It was found that husbands reported to have more behavioral and emotional problems in those for whom they care as compared to wives and daughters. On the same note, wives report greater strain than husbands but also report more behavioural and emotional problems in those for whom they care (Barusch&Spaid, 1989). Another study found that husbands providing care were more anxious than wives (Croog*et al*, 2001), possibly because it is a less familiar role. The researcher, therefore, wanted to find out how gender affected psychosocial needs and challenges of caregivers and are there other demographic factors that affect caregivers' psychosocial needs and challenges as well.

Australian Bureau of Statistics, (1999), reported that caregivers of cancer patients are an important target group for further research to better understand how their needs change over the course of the patient's illness and to streamline their access to available services that may assist in addressing identified needs.

In Kenya there have been many challenges creating many social, economic, political and psychological problems. These challenges are insecurity, ignorance, poverty, diseases, corruption, lack of proper infrastructure and sanitation. Many efforts have been done and even institutions created to address them. However, those involved in the care giving in those institutions seem to be a forgotten lot.

Juan, Paola, Adriana, KathrynFrancis, Miguel and Teresita (2014), found that interdependence needs were most commonly reported as unmet by caregivers, whereas self-concept and physical needs were most frequently reported as met. Approximately half of the care-givers reported increased burden and depression, although nearly 75% reported feeling relatively satisfied with their lives. Caregiver

physical, role function, and interdependence needs were positively correlated with depression. In addition, physical and interdependence needs were positively correlated with burden. Caregiver physical and role function needs were negatively correlated with self-perceived health status. Moreover, interdependence needs were negatively correlated with satisfaction with life, whereas physical and interdependence needs were negatively correlated with perceived social support. Future interventions should focus on addressing the needs of caregivers of individuals with Multiple Sclerosis and improving their psychosocial outcomes.

Arango, Plaza, Drew, Romero, Pizarro, Francis , & Kreutzer (2010), found that Information, economic, emotional, community support, and respite needs were most frequently reported among Colombian caregivers. Forty-three percent of the family caregivers reported some level of depression, 68% reported being overwhelmed by their caretaking responsibilities, and 43% reported dissatisfaction with their lives. Information, emotional, economic, physical, sleep, and psychological needs were positively correlated with depression and burden. Those with more household, physical, sleep, economic, and psychological needs had less satisfaction with life and social support. Caregivers with more community and respite needs had less social support, while those with more emotional needs had less satisfaction with life. Caregivers with more respite needs had more burden and those with more household needs had more depression.

Jan (2004) reviewed that research and current thinking would suggest that those caregivers who are able to draw on a range of coping strategies adapt more easily to the demands of caring. Nolan, Keady, and Grant (1995) surveyed the range of coping strategies used by a sample of caregivers whereby they divided the possible strategies

into 'managing events', 'managing meanings' and 'managing stress'.In many cases, family members not only provide practical help and personal care but also give emotional support in the often inevitable change in the nature of the underlying emotional relationship (Jan 2004). Coping strategies is one of the objectives of the study under question.

The study by Steven Zarit, Femia, Elia (2008) found that effective treatments for caregivers have four overlapping characteristics: a psychological rather than purely educational approach, multidimensionality, flexibility, and sufficiency in the amount or dosage of treatment. In a psycho educational treatment, the therapist uses psychotherapeutic techniques to encourage behavior change and, in particular, to overcome barriers to change whereby caregivers practice new skills, receive feedback, and develop plans to implement these skills in situations they might encounter.

Multidimensional addresses multiple stressors and other risk factors that affect caregivers' health and well-being. The type of help caregivers are most likely to receive is case management, which matches people's needs with available programs. Flexibility means the counselor should find help from a set of approaches, such as addressing behavior problems and increasing family support, but had considerable latitude in allocating time to different problems whereby the results have consistently been positive, with reduced depression and burden and increased time to institutionalization of the care recipient (Steven et.al. 2008).

Interventions that provide more treatment found generally to have better outcomes. However, after completing the core treatment program (about six sessions), participants were referred to ongoing support groups. Counselors could also engage in additional follow-up sessions by telephone or in person, according to the caregiver's

needs. Given the long-term course of dementia care, it is not surprising that an intervention that provided ongoing support was found to have good immediate and long-term outcomes (Steven et.al 2008). These are coping strategies to psychosocial needs and challenges which is a key objective of this study.

1.2 Statement of the Problem

Hospice is an institution that helps patients suffering from cancer for which curative treatment is no longer appropriate and to give information, counseling and support to their families and close associates before and after death of the patient. Hospice care is a type and philosophy of care that focuses on the palliation of a terminally ill or seriously ill patient's pain and symptoms, and attending to their emotional and spiritual needs. In Eldoret Hospice, cancer clients and primary caregivers go there for care. The structure is in such a way that hospice forms social network with neighboring hospitals and do follow ups in home setting. This gives institutional caregivers' big workload. The emerging trends of home care and institutional care give leeway for most care to be done in home setting by family members (nuclear and/or extended) and friends to the cancer clients. Primary caregivers are less trained to take care of these clients and are likely to show sympathy and not empathy because of close relationship. This study focused on both institutional and primary caregivers.

From a practical point of view, there have been incidences where the caregivers have gone through more vicarious traumatization, compassion fatigue, caregiver syndrome and burn out experiences that need more attention than even their clients. These have caused health issues and social problems like phobias, hypertensions, depression, broken families, addictions, psychopaths, etc. this happens because more care is focused on cancer clients than caregivers. Figley,1995, co-author of compassion

fatigue: coping with secondary traumatic stress disorder in those who treat the traumatized, states that, "there is a cost to caring. Professionals who listen to clients' stories of fear, pain, and suffering may feel similar fear, pain, and suffering because they care. Sometimes professionals feel we are losing our sense of self to the clients we serve. Therapists who work with rape victims, for example, often develop a general disgust for rapists that extend to all males/ females. Those who have worked with victims of other types of crime often 'feel paranoid' about their own safety and seek greater security. Ironically, the most effective therapists are most vulnerable to this mirroring or contagion effect. Those who have enormous capacity for feeling and expressing empathy tend to be more at risk of compassion stress" (Figley, 1995).

Theoretically, many studies conducted on caregivers' psychosocial needs and challenges have been carried out outside Kenya, western world, and a few done in Africa. For example, Juan, et.al (2014) study was conducted in Mexico. Again many studies are carried out on family and primary caregivers and a few on caregivers across institutions. For example, Laurel, et.al (2012) conducted a study where the focus was on the family caregivers. Therefore, this raised the need for this study on both institutional and primary caregivers to be carried out.

1.3 Objectives of the Study

The main objective of this study was to find out psycho-social needs and challenges experienced by the caregivers in institutions

The specific objectives were:

i. To find out psychological needs and challenges faced by caregivers at Eldoret hospice in Eldoret town.

ii.   To establish social needs and challenges faced by caregivers at Eldoret hospice in Eldoret town.

iii. To find out the coping strategies for psychosocial needs and challenges faced by caregivers at Eldoret hospice in Eldoret town.

1.4 Research Questions

The study was guided by the following research questions:

i.   What are the psychological needs and challenges faced by caregivers at Eldoret hospice in Eldoret town?

ii.   What are social needs and challenges faced by caregivers at Eldoret hospice in Eldoret town?

iii. What are coping strategies for psychosocial needs and challenges faced by caregivers at Eldoret hospice in Eldoret town?

1.5 Purpose of the Study

The purpose of the study was to create awareness on psychosocial needs and challenges faced by caregivers thereby explaining how they cope in their course of duty of caregiving.

1.6 Significance of the Study

From a practical point of view, the study was useful to the caregivers in that they became aware that if their psycho-social needs and challenges are not taken care of, then they may not be effective in their line of duty. The study helped in creating awareness to the caregivers that they should shun away the misconceptions that hinder them towards being cared for as well as caring for themselves.

The study will help the entire public to embrace psycho-social care for oneself since we are all caregivers in one way or another. Theoretically, the study will bridge knowledge gap in that little has been done on psycho-social needs and challenges for the caregivers especially in Kenya. So it sets base for further research.

1.7 Scope of the Study

The study was conducted in Eldoret town between September 2015 and September 2016. It was done in Eldoret Hospice, MTRH and home settings that are at a radius of 50-70 kilometers from Eldoret town. The study focused on psychosocial needs and challenges of caregivers in institutions and home setting. It was done in Eldoret town which was picked at random and because it has many institutions like Eldoret Hospice, MTRH, with caregivers offering services too many clients with diverse issues on health and social life across the country. This forms a fertile ground to address the study problem on psychosocial needs and challenges of the caregivers in institutions and home setting.

1.8 Assumptions and Limitations of the Study

The assumption of the study was that the findings can be generalized to any other hospice in Kenya. However, the findings are limited to caregivers taking care of cancer client (s) and not any other terminal disease, say HIV/AIDS, because of psychological burden of cancer.

1.9 Operational Definition of Terms

Care – is the provision of information, counseling and support (emotional, psychological and spiritual) to cancer clients and caregivers

Caregiver – this refers to a person who took care of cancer client which were institutional, home setting, MTRH and primary caregivers.

Institutional caregiver – refers to professionals working in Eldoret Hospice which were counselor, a nurses and social workers.

Primary caregiver- refers to a person who had direct contact with and could take care of cancer client(s) in MTRH and home setting.

MTRH caregivers- refers to family members who took care of clients in MTRH hospital

Home setting caregivers- refers to family members and/or primary caregivers who took care of cancer client(s) in home setting.

Client – refers to a person suffering from cancer.

Psychological need - something that an individual requires for mind and mental processes to function normally

Psychological challenge – is anything that interferes with the mind and mental processes of an individual which are individually defined.

Social need - something that expose a person to interact with other people

Social challenge   **-**is anything that interferes with interactions between and/or

among individuals.

1.10 Theoretical Framework

The study was based self-care deficit nursing theory. Dorothea Orem's self-care deficit nursing theory (1959 and 2001) explained the concept of independency by clients since every client wish to care for oneself (Orem DE and Taylor 2011). She explained concepts; Self-care requisites, self-care deficit self-care deficit, support modalities and Universal Self-Care Requisites Universal Self-Care Requisites (SCRs). Self-care requisites are groups of needs or requirements which are classified as universal self-care requisites: those needs that all people have, developmental self-care requisites; maturational: progress toward higher levels of maturation and situational: prevention of deleterious effects related to development, health deviation requisites: those needs that arise as a result of a patient's condition (Orem DE and Taylor 2011).

When an individual is unable to meet their own self-care requisites, a "self-care deficit" occurs. It is the job of the caregiver to determine these deficits, and define a support modality. Caregivers are encouraged to rate their client's dependencies or each of the self-care deficits on the following scale: total compensation, partial compensation and educative/supportive. The Universal Self-Care Requisites (SCRs) that are needed for health are: air, water, food, elimination, activity and rest, solitude and social interaction, hazard prevention and one promotion of normality. A caregiver is encouraged to assign a support modality to each of the self-care requisites (Orem DE and Taylor 2011).

In this study self-care deficit nursing theory was useful by the fact that caregivers are equipped with what it takes to enhance independency of their clients as clients wish to care for themselves. This will eventually help in reducing psychosocial challenges as well as developing a coping strategy in their line of duty.

1.11 Conceptual Framework

This study adopted Pearlin's stress–process model of stress in caregivers (Pearlin et al, 1990) as a conceptual framework to explain variable. This model explains where psychosocial needs and challenges faced by caregivers where they emerge from (background and context, primary stressors) intervening variables (mediators, secondary role strains) and the effects this has on caregivers (secondary intra-psychic strains and outcomes).
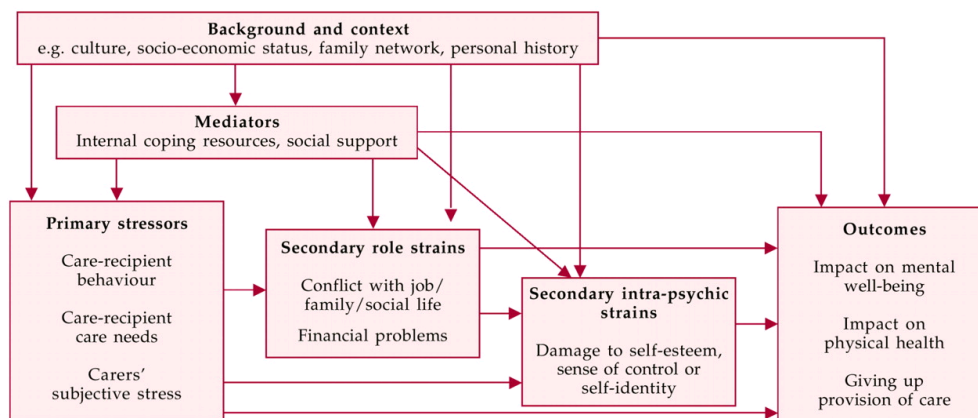
Figure 1.1: Pearlin's Stress- Process Model of Stress

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter examines what has been said concerning psychosocial needs and challenges faced by caregivers as well as their coping strategies on the same which are as per the objectives of the study. Included are the theoretical and conceptual frameworks of the study.

2.1 The Concept of Cancer

Cancer it is the abnormal multiplication of body cells. It is also known medically as a malignant neoplasm which is a broad group of diseases involving unregulated cell growth. In cancer, cells divide and grow uncontrollably, forming malignant tumors, and invading nearby parts of the body. The cancer may also spread to more distant parts of the body through the lymphatic system or bloodstream. Not all tumors are cancerous; benign tumors do not invade neighboring tissues and do not spread throughout the body. There are over 200 different known cancers that affect humans (Jemal, et.al 2011).

Facts about cancer are that cancer is not curable but if detected at an early stage .i.e. stage one, and the person seeks treatment, the individual can live a life near cure…cancer survivor/cancer conqueror. It is not contagious though people with multiple sex partner stands at risk of contracting cervical cancer caused by HPV which is transferable through sexual intercourse from one partner with the virus to another. It Metastasis – i.e. spreads from one body organ to another and can reoccur.

Cancer in itself is not painful; pain emerges from its effects. i.e multiplication to the body organ causes pain . It is caused by a tumor but not all tumors are cancerous. There are two types of tumors; malignant (cancer) and benign tumors. Malignant tumor, cancer, is operable, can reoccur and spreads to the body organs. Benign tumors are operable and neither reoccurs nor spreads to the body organs. However, it stands as a risk factor to cancer causation (Jemal, et.al 2011). Cancer goes through four stages whereby:

- ❖ Stage 1: it's the early stage characterized by presence of a localized tumor, no pain, no spreading from one organ to another and its operable to enable the victim live life next to cure.
- ❖ Stage 11: the tumor roots to the neighboring body organs.
- ❖ Stage 111: the tumor spreads to the lymph nodes and presence of pain.
- ❖ Stage 1V: symptoms of the previous, above, stages and severe bleeding.

When client is in stage 1 and 2, the client can attend to his/her physical needs like bathing, feeding. etc unlike when in stage 3 and 4 the client is totally dependent on caregiver to attend to his/her needs almost in everything. At these stages caregiving is very demanding on the side of caregiver whereby the caregiver has to be with the client almost every time. Counseling helps in this scenario.

Counseling can be defined in different way. It is personal, client oriented and done on limited number of clients. It is also less structured, looks at issues at a personalized matter and provides talk therapy only. Again it deals with normal people with normal issues, operates with conscious level of the mind and voluntary. Counseling is a process that involves three stages; exploration, understanding and action where skills

are applied in each stage. Skill is a practical ability. There are different kinds of counseling skills which some are as follows (Cormier and Hackney 1999).

First we have challenging skills which challenge the client to provide accurate information, bring the person in a more direct contact with themselves and provide opportunity for self-image. These are immediacy, questioning. etc Secondly are supportive skills which encourage deeper and further exploration, communicate that client is not alone and frees the clients from their defensive nature. These are questioning, active listening, self-disclosure, UPR (unconditional positive regard), genuineness, empathy, etc. Thirdly are attending skills which communicate that client is not alone, encourage the client to talk more and reduce the ambiguity and anxiety about counseling. These are social skills, attending physically and psychologically, observing skills, listening and structuring. Fourthly are reflection skills which are done in two levels: content & feeling level. Content level involves paraphrasing and summarizing. Feeling level involves interpreting and empathy. Fifthly are probing skills which entail use of interjections, questioning skills, concreteness, confrontation, immediacy, self-disclosure and silence (Cormier and Hackney 1999).

2.2 Psychological Needs and Challenges Faced by Caregiver

According to Cambridge English Dictionary challenge is defined as something that needs great mental or physical effort in order to be done successfully and therefore tests a person's ability. Need is defined as to have to have something, or to want something very much.

2.2.1 Psychological Needs

According to a study done by Grbich, Maddocks and Parker (2001), it revealed that lack of adequate information is one of the most important concerns of caregivers of

patients with advanced cancer. Sixty per cent of close relatives of deceased cancer patients have 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.

A study done by Kirk, Kirk and Kristjanson (2004) found that 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 found to help caregivers cope according to Rose (1999). Once specialist palliative care services (SPCSs) are involved, communication is reportedly more likely to be honest and direct.

Family Caregiver Alliance (2013) found that caregivers experience lower stress and better health when they learn skills through caregiving training and participating in support groups. Participating in these groups allows caregivers to care for their family members longer in their homes.

Alzheimer's Association (2013) came up with REACH program (The Resources for Enhancing Alzheimer's Caregiver Health). This Project which was created in 1995 was designed to enhance family caregiving for those who were taking care of relatives that have Alzheimer's disease and other related dementia (ADRD). ADRD program includes support groups, behavioral skills training programs and family-based systems interventions. This program was designed specifically for people who are caring for a loved one with Alzheimer's Disease or Dementia at home, and makes it possible for those with dementia to live in their own homes longer. This is ensured by addressing these problems of caregiver health that force the caregiver to move their loved ones to

facilities .Again, the program equips individual caregivers find solutions to problems such as: caregiver stress, challenging behaviors, home safety, depression, self- care and social support. The issues addressed by these programs are also some of the issues experienced by caregivers caring for cancer clients in institutions and home setting.

2.2.2 Psychological Challenges

A psychological challenge normally interferes with the mind and mental processes of an individual and it is individually defined. Caregivers confronting serious illness have been found to experience as much distress, if not more distress than, the patient with cancer. This distress arises from the caregiver role itself as well as witnessing the patient's suffering (Weitzner, et al. 1999). Cumulative sleep disruption and fatigue are common among caregivers who are on duty 24 hours a day or only during nighttime hours. Behaviors such as not getting enough rest or exercise and neglecting their own health can mimic depression in caregivers but can also contribute to the impairment of their health and quality of life (Travis, et al. 2004).

Sheehy's study in 2010 found that caregiving is a rewarding process but can be stressing. Being there for your loved ones when they need you is a core value for many. But being a caregiver can exact a high toll, and caregiver stress is common. Caregiver stress is the emotional and physical strain of caregiving. Individuals who experience the most caregiver stress are the most vulnerable to changes in their own health (Sheehy, 2010). Caregiver syndrome or caregiver stress is a condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a chronically ill dependent (Christine, 2009). It is caused by the overwhelming duty of caring for a disabled or chronically ill person who results to an increased stress hormone level for

an extended period of time (Tunajek, 2010). Signs and symptoms include depression, anxiety, and anger. Chronic stress can create medical problems including high blood pressure, diabetes, and a compromised immune system. The impact may reduce the caregivers' life expectancy by an average of seven years (Andree, 2013). The early warning signs of chronic stress cut across physical, emotional, behavioral and relationships.

Physical signs of chronic stress are headaches, appetite or weight changes, feeling tired all the time, changes in sleep habits, muscle aches, getting sick often, stooped posture, sweaty palms, neck pain and weight gain or loss (Andree, 2013). Emotional signs are anger, sadness or crying spells, irritability or short temper, worry or anxiety, discouragement, trouble relaxing, emptiness or loss of direction, looking for magic solutions, inability to concentrate and frequent mood swings (Andree, 2013). Behavioral signs are increased use of drugs or alcohol, trouble concentrating, avoiding decisions, low productivity, forgetfulness, boredom, over-reacting, acting on impulse, changing jobs often. Relationships are seen to be affected as manifested by problems with marriage or children, intolerance of others, fewer contact with friends, nagging, lowered sex drive, loneliness and resentment (Andree, 2013).

Vicarious traumatization (VT) is a transformation in the self of a trauma worker or helper that results from empathic engagement with traumatized clients and their reports of traumatic experiences (Saakvitne, et al., 2000). Vicarious trauma, conceptually based in constructivist self-development theory, arises from an interaction between individuals and their situations. In other words anything that interferes with caregiver's ability to fulfill his/her responsibility to assist traumatized clients can contribute to vicarious trauma (Saakvitne, et al., 2000) The major signs

and symptoms are as follows but are not limited to only them: social withdrawal; mood swings; aggression; greater sensitivity to violence; somatic symptoms; sleep difficulties; intrusive imagery; cynicism; sexual difficulties; difficulty managing boundaries with clients; and core beliefs and resulting difficulty in relationships reflecting problems with security, trust, esteem, intimacy, and control (Bober, Regehr,& Zhou, 2006).

Impairment, in health, refers to any loss or abnormality of physiological, psychological, or anatomical structure or function, whether permanent or temporary. Identifying impairments that contribute to disability, a functional problem for a patient is a key factor for a health professional to determine appropriate treatment (WHO, 1994).

Compassion fatigue, also known as secondary traumatic stress (STS), is a condition characterized by a gradual lessening of compassion over time (Meadors, et al. 2008). The major symptoms are hopelessness, a decrease in experiences of pleasure, constant stress and anxiety, sleeplessness or nightmares, and a pervasive negative attitude. Some risk factors are Persons who are overly conscientious, perfectionists, and self-giving, low levels of social support or high levels of stress in personal life, previous histories of trauma that led to negative coping skills, such as bottling up or avoiding emotions (Meadors, et al. 2008). To the Caregivers STS results from the taxing nature of showing compassion for someone whose suffering is continuous and unresolvable which makes them hopeless and helpless to ease the client from the suffering situation (ibid, 2013).

Between 16 and 85% of health care workers in various fields develop compassion fatigue. In one study, approximately 85% of emergency room nurses met the criteria

for compassion fatigue (Hooper, et al. 2010). In another study, more than 25% of ambulance paramedics were identified as having severe ranges of post-traumatic symptoms (Beck, 2011). In addition, 34% of hospice nurses in another study met the criteria for secondary traumatic stress/compassion fatigue (Beck, 2011).

The researcher wanted to find out whether caregiver stress, compassion fatigue, vicarious traumatization and impairment are also experienced by caregivers in Eldoret town. Do they manifest their warning signs in the same manner? Are caregivers aware of these challenges?

2.3 Social Needs and Challenges Faced by Caregiver

Research has identified a significant impact of care giving on areas including holidays, time away, travel and having limited time for social life, personal relationships, and hobbies for themselves (Schofield, 1997). These limitations result in social isolation and loneliness, changes in family and other relationships and a sense of grief and loss (Briggs, 2000). Caregivers report trying to participate in social activities, but give up due to concern for the patient whilst they are absent

According to Australian Bureau of Statistics (1999) caregivers were seen to face work related challenges in that they were employed and had clients to take care at home. So caregiving appears to reduce a person's chance of being employed in that many caregivers are unable to work, need to take leave without pay, work fewer hours, are in lower paid jobs or work from home to manage the caregiver demands (Grunfeld, et al, 2004).

According to the study done by the Caregiver Education and Support Services, et al, (1993) found that love for caregivers towards their family member and the satisfaction they derive from helping may coexist with feelings of resentment about the loss of

their privacy and frustration at believing that they have no control over what happens. They may find it hard to accept the decline of the special person for whom they are giving care. Such feelings will depend in part on their prior relationship with client, the extent of responsibilities as a helper, and daily activities in life (professional, social, and leisure pursuits). These conflicting emotions may cause guilt and stress. This is both social need and a challenge; need for a better relationship with clients and challenge of showing love and affection to the clients.

According to Health Net (2013) national alliance for caregiving study, 68 percent of caregivers for veterans had high emotional stress. Again 40 percent had high physical strain, 7 percent of caregivers stopped working or they took an early retirement, and 50 percent experienced high financial hardships.

In the general household survey in 1995, it was estimated that there are 5.7 million caregivers in Britain, of whom 1.7 million provide over 20 hours of care per week (Office of National Statistics, 1997). Of the 5.7 million, 60% report providing care for an individual with physical disability, 18% for someone affected by ageing, 15% for someone with both mental and physical health problems and 7% for a person with a mental health problem alone.

Social needs and challenges experienced by caregivers in Britain, Australia and other parts of the world were reviewed by the researcher. This formed justification of the study in that, researcher wanted to find out whether these finding also reflects the situation of caregivers in Eldoret or not.

2.3.1 Implication of psychosocial challenges on caregivers

Gender is the aspect of being a male or a female. Women have higher rates of depression than men in the care-giving role according to McGrath (1992). Schulz (1991) study revealed that 39% of female caregivers, compared to 16% of male caregivers, qualified as being at-risk for clinical depression on the center for epidemiologic studies-depression scale (CES-D). In a randomized controlled trial, Gitlin, et al (1999) found that women were more likely than men to comply with a home environmental modification intervention, implement recommended strategies, and derive greater benefits. Male caregiver tends to have more of a 'managerial' style that allows them to distance themselves from the stressful situation to some degree by delegating tasks (Draper, 2004).

Age is the other factor whereby age-associated impairments in physical competence make the provision of care more difficult for older caregivers according to the study done by Lawton,et al,(1992). There is a positive association of age and caregiver burden in whites, but a negative association for African-Americans suggesting that older African-Americans are less likely to experience care-giving as physically burdensome.

Caregiver's health is another factor. Health according to the World Health Organization (WHO) is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. Caregiver health has also been identified as a significant predictor of caregiver depression by Lawton, et al, and Baumgarten, et al, (1992). Longitudinal studies demonstrated that caregivers are at a greater risk, than non-care-giving age-matched controls, for developing mild

hypertension and have an increased tendency to develop a serious illness (Shaw,et al, 1997) as well as increased risk for all-cause mortality (Schulz,et al 1995).

Ethnicity has an impact on the care-giving experience. According to Connel, et al (2001) study found a comprehensive differences in the stress process, psychological outcomes, and service utilization among caregivers of different racial and ethnic backgrounds .Studies consistently show important differences in perceived burden and depression among African-American, White, and Hispanic family caregivers (Calderon, 1998). Caucasian caregivers tend to report greater depression and appraise care-giving as more stressful than African-American caregivers according to the study done by Farran,et al,(1997). Hispanic caregivers report greater depression and behavioural burden than Caucasians and African-Americans (Harwood, et al 1998).

It was critical for researcher to compare and contrast psychosocial needs and challenges of caregivers in Eldoret town in regard to age, health, ethnicity and gender. This helped in drawing conclusions on effect of these factors and other demographic factors on caregivers in caregiving profession.

2.4 The Coping Strategies for Psychosocial Needs and Challenges of Caregivers

To cope means to be able to live with a certain situation. It is a response to a certain situation one finds himself in. Respite care program is considered to provide care while the caregiver is at work or when other obligations need to be met and to provide interaction and social opportunities for the clients according to Cleveland Clinic Health System (2005).

Respite care programs include adult day center which provides daily, structured programs in a community setting with activities, health-related services and rehabilitation to older adults who need a protective environment due to physical or

mental limitations (Cleveland Clinic Health System, 2005). Secondly, there is an in-home care services which are a service that provides professional workers who come directly to the caregiver's home to provide care. Often the temporary care provider stays on the premises. This service may not be available in all areas and may be expensive. It provides for the caregiver an opportunity for travel when care receiver cannot live independently and ability to transfer caregiving responsibilities to a trained care professional (Seniormag.com, 2007). Thirdly we have assisted living respite care which is a service where care is provided by assisted living centers when space is available. The clients move into the assisted living facility to receive temporary housing and care. It provides for the caregiver with the ability to leave the clients for an extended period of time; peace of mind knowing that client is receiving professional care; ability to test out an assisted living facility without the move being permanent. Caution should be taken since it may cause anxiety and fear in the clients if they do not believe that the move is temporary

Chan and Sigafoos (2001), Damaini, Rosenbaum, Swinton and Russell (2004), argued that Respite care has been acknowledged as reducing caregiver burnout and stress. It also provides support, improves caregiver self-esteem, and enhances family cohesion and adaptation.

There is increasing interest in examining the factors that help caregivers successfully manage their role, while minimizing the effect on their mood and general well-being (Quayhagen, 1998). Much of this research has been done within the general framework of stress and coping theory, examining coping styles of caregivers and the relationship between types of coping styles and reported symptoms of depression as

Lazarus (1984) found out. So the researcher wanted to find out how caregivers in Eldoret manage their role of caregiving.

Anecdotal literature by Haley (1987), suggests that caregivers who use more active coping strategies, such as problem solving, experience fewer symptoms of depression than do those who rely on more passive methods. Significant associations have been reported between positive strategies for managing disturbed behavior, active strategies for managing the meaning of the illness and reduced levels of caregiver depression. An important role for health-care professionals is in helping caregivers enhance their coping skills, supporting existing skills, and facilitating the development of new ones (Saad,1995). Aschbacher (2005) study highlighted the following active strategies; mindfulness-based stress reduction, writing therapy, coping effectiveness training, stress management and relaxation training. Passive coping styles have been associated with greater burden i.e persons who use an escape-avoidance type of coping are known to have more depression and interpersonal conflicts (Gruetzner, 2001).

Caregivers need to have the opportunity to learn more effective ways of coping with stress. If they can learn new ways to cope, they can reduce their anxiety and reliance on treatments (Gruetzner, 2001). Bourgeois et al (1997) report that caregiver's behavioural skills and effective self-management training programmes result in a lower frequency of patient behavioural problems and helps to improve the caregiver's mood. Burgio and Stevens (2000) designed a caregiver intervention that teaches caregivers behavioural management skills to address problem behaviours exhibited by individuals with dementia, as well as problem-solving strategies to increase pleasant activities for the caregiver. Researcher wanted to find out uniqueness of caregivers on the coping strategy. How is one caregiver in Eldoret town different from the other in

coping with psychosocial needs and challenges they find themselves in their course of duty?

Spiritual support can also be considered a coping resource and has been studied in older African-Americans and older Mexican-Americans (Levin,et.al 1995). Previous work examining the role of spiritual support observed that African-American caregivers report higher spiritual rewards for caregiving, and reliance on prayer and church support (Picot, 1997). Spirituality is a common phenomenon Africans use in their day to day lives. Whenever they are faced by bigger challenge than their capacity to handle, people tend to look on Supreme Being for answers. So how did this help caregivers in Eldoret town to cope with psychosocial needs and challenges?

Andree (2013) came up with the following measure as stress management skills: expanding the support system for the caregiver, finding help in various sources for caregiver tasks, educating caregivers and paying caregivers salaries competitive with those paid to professional healthcare providers doing similar tasks. This will allow them to retire from salaried jobs for companies where management is willfully ignorant of or unsympathetic to their workers' family caregiving burdens. Again, encouraging the growth of telecommuting jobs that enable caregivers to work at home while caring for their patients, and providing full medical benefits for caregivers and their patients. In addition, providing nursing and medical advice when needed not forgetting home visits. Providing respite services on demand, providing psychological counseling or psychiatric intervention for stress management, and collecting data documenting savings for the national healthcare system made possible by home caregivers. So researcher wanted to find out how caregivers in Eldoret town cope with stress.

Nolan et al (1996) in their study found the self-care strategies to be very helpful to over 50% of caregivers. These are realizing that the person you care for is not to blame for his or her position, taking life 'one day at a time', finding out as much as you can about the problem and keeping a little free time for yourself. Again, realizing that there is always someone worse off than you and that no one is to blame for things as well as keeping one step ahead of things by planning in advance. Also, getting as much help as you can from professionals and service providers as well as talking over your problems with someone you can trust.

Juliana (2014) found that self-awareness is a very critical coping strategy and entails the capacity for introspection and the ability to recognize oneself as an individual separate from the environment and other individuals. It entails being 'in touch with oneself.' It is getting to understand ones emotions, strengths, weaknesses, and limitations.

Donald (2013) found decision making techniques to be a good coping strategy. They involve reviewing pros and cons which involve listing the advantages and disadvantages of each option and contrast the costs and benefits of all alternatives. Simple prioritization is a method whereby choosing the alternative with the highest probability- weighted utility for each alternative is done. Satisfying entails examining alternatives only until an acceptable one is found and elimination by aspects involves comparing all available alternatives by aspects.

Personal therapy is another strategy whereby it is concerned with a deep internal searching and working through unresolved conflicts aiming at personality changes. Psychoanalysts call it (training analysis). Wosket (1999) parallels the depth of the "work with oneself" with gardening: you can choose gardening that eradicates every

tiny weed or gardening that pulls out only the large weed. The impact is seen of caregiver's characteristics which are believed to contribute to clients' constructive change, such as are for example, empathy, authenticity, and warmth (Macran and Shapiro, 1998). It offers the opportunity for the caregiver to explore and shield their personal issues which, if not identified and not been dealt with in the past, may come to the surface and impede their work in the future. Practically, this means that they will need to be resilient in order to be able to confront the suffering and to tolerate anger, criticism, contempt, and even rejection by some of their clients (Orlinsky, et al., 2005).

Finally Andree (2013) came up with time management skills. It is important to be aware that sometimes one will be spent time on activities beyond ones control and therefore it is important for one to make a daily "to do" list, do the most important/difficult things first; save up errands to do at once; take along a small task if you go somewhere you know you will have to wait and do an appraisal of the things you must do. Also one should learn to delegate what you can and forget what is unnecessary.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter highlights the research design, target population, sampling methods, sample size, data collection instruments and their procedures, validity and reliability of the instruments, data analysis methods and ethical issues. The study was done in Eldoret Hospice in Eldoret town. Hospice care is a type and philosophy of care that focuses on the palliation of a terminally ill or seriously ill patient's pain and symptoms, and attending to their emotional and spiritual needs. The modern concept of hospice includes palliative care for the incurably ill given in such institutions as hospitals or nursing homes, but also care provided to those who would rather spend their last months and days of life in their own homes. Hospice has faced resistance springing from various factors, including professional or cultural taboos against open communication about death among physicians or the wider population, discomfort with unfamiliar medical techniques, and professional callousness towards the terminally ill. Nevertheless, the movement has, with national differences in focus and application, spread throughout the world (Bernat & James 2008). Eldoret hospice is an institution that helps patients suffering from cancer for whom curative treatment is no longer appropriate and to give information, counseling and support to their families and close associates before and after death of the patient. It is structured in such a way that clients are cared for in the institution (out patients), have network with hospitals around Eldoret town with interest with cancer patients and visits clients (discharged from hospital and out patients) in their home setting as a follow up at a radius of 50-70 kilometers from Eldoret town. In this study the hospital studied was Moi Teaching and Referral Hospital (MTRH).

3.1 Research Design

The study was a mixed research design where some quantitative part was embedded in qualitative research. Qualitative research is development of concepts which enables us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences and views of the participants (Pope and Mays 1995). The study cut across the three dimensions of qualitative methods: understanding context, understanding people and understanding interactions of caregivers.

3.2 Target Population

Target population was caregivers; institutional caregivers, home setting caregivers, MTRH caregivers and primary caregivers.

3.3 Sampling and Sample Size

Table 3.1: Description of caregivers

Eldoret Hospice caregivers	MTRH caregivers (primary and/or family)	Home setting caregivers (primary and/or family)
6	6	6

Source: Eldoret Hospice (2015)

The sample size was 18 respondents as described above. Eldoret hospice caregivers (six) were institutional caregivers characterized by nurses, social workers and counseling psychologist. MTRH caregivers (six) were primary caregivers who lived with clients in hospital setting. Home setting caregivers (six) were primary caregivers who took care of clients in home setting.

All caregivers were identified by purposive sampling where a caregiver was a counselor, nurse, a social worker or a family member who had direct contact with cancer client in MTRH and/or home setting.

Saturation method guided the process which is also known as redundancy which is a stage where additional interview or observation is not believed to add new information- enough is enough Creswell (1998). It is a point where a researcher doesn't get new information or data with addition of respondents.

The following studies were carried out using small sample size which was guided by saturation method. Morse (1994) and Creswell (1998) suggested that from all of the phenomenological studies identified had at least six participants. Guest et al. (2006) carried out a systematic analysis of their own data from a study of sixty women, involving reproductive health care in Africa. They examined the codes developed from their sixty interviews, in an attempt to assess at which point their data were returning no new codes, and were therefore saturated. Their findings suggested that data saturation had occurred at a very early stage. Of the thirty six codes developed for their study, thirty four were developed from their first six interviews, and thirty five were developed after twelve. Their conclusion was that for studies with a high level of homogeneity among the population "a sample of six interviews may [be] sufficient to enable development of meaningful themes and useful interpretations" (p.78).

3.4 Study Methods and Instruments

3.4.1 Data collection methods and instruments

Table 3.2 Data collection methods and instruments

Method	Instrument
In-depth Interview	In-depth Interview guide
Focused group discussion	Focused group discussion guide
Life histories/unique cases	Key Informant Interview guide
Psychological assessment	Caregiver's self-rating scale (Judy Bradley, 1993).
	Self-Analysis Questionnaire (Dr. Charles Spielberger, 2001)

Source: Eldoret Hospice (2015)

In-depth interviews enabled the researcher to collect more information by getting both verbal and non-verbal communication where in-depth interview guide was used (appendix i).

Focused group discussion helped to collect information that cannot be directly observed or difficult to put down in writing. It also helped the researcher to get feedback in a group setting where Focused group discussion guide was used (appendix iii).

Life histories helped to get unique cases from the caregiver where Key Informant Interview guide was used (appendix ii).

Finally psychological assessment was done using self- analysis questionnaire where caregiver' self rating scale by Bradley (appendix ix) and self- analysis questionnaire by Spielberger (appendix v) were used.

3.5 Validity of the Study

Validity, in qualitative research, refers to whether the findings of a study are true and certain; "true" in the sense that research findings accurately reflect the situation, and "certain" in the sense that research findings are supported by the evidence. This was ensured through the following:

Piloting of the research instruments where pretesting was done. Pre-test is administration of instruments to the respondents of similar characteristics as respondents of the research itself to see how instruments measures what the researcher purpose to measure. So the researcher administered instruments to caregivers in Eten Hospital in the ward where cancer patients and their caregivers were.

Triangulation - it is a method used by qualitative researchers to check and establish validity in their studies by analyzing a research question from multiple perspectives. In this study, various method were used which are investigator, theory and methodological triangulation methods.

Investigator triangulation involves using several different supervisors in the analysis process. Typically, this manifests as an evaluation team consisting of colleagues within a field of study wherein each investigator examines the program with the same qualitative method (interview, observation, case study, or focus groups). The findings from each supervisor would then be compared to develop a broader and deeper understanding of how the different supervisors view the issue. If the findings from the different supervisors arrive at the same conclusion, then our confidence in the findings would be heightened. Supervisors were experts in psychology and sociology.

Theory triangulation involves the use of multiple perspectives to interpret a single set of data. Unlike investigator triangulation, this method typically entails using professionals outside of a particular field of study. One popular approach is to bring together people from different disciplines; however, individuals within disciplines may be used as long as they are in different status positions. In theory, it is believed that individuals from different disciplines or positions bring different perspectives. Therefore if each evaluator from the different disciplines interprets the information in the same way, then validity is established. Researcher ensured this with different people reviewing the work from different disciplines i.e psychology, sociology, anthropology, and technologist practitioner.

Methodological triangulation involves the use of multiple qualitative and/or quantitative methods to study the program. For example, results from surveys, focus groups, and interviews could be compared to see if similar results are drawn. If the conclusions from each of the methods are the same, then validity is established. In this study different methods were used and findings from each compared to the other.

Peer consultation – was done which helped to detect problems of overemphasized points, underemphasized points, vague descriptions, general errors in the data, biases or assumptions that the researcher could have made. These were Dr.abuya (Sociologist), Dr. Kitainge (Technologist) and Dr. Sorre (Anthropologist).

Consultation with supervisors- helped in offering proper guidance and objectivity of the study. Supervisors were Prof. Kimani Chege and Prof.Jamin R.M Masinde.

3.6 Reliability of the Instruments

Reliability was ensured through test re test technique of research instruments.

3.7 Data Collection Procedures

The researcher collected data by herself, no assistance. Data collection procedures were embedded from the instruments used in the study which were in-depth interview guide, key informant interview guide, focused group discussion guide, interview guide, caregiver's self-rating scale (Judy Bradley, 1993) and self-analysis questionnaire (Dr. Charles Spielberger, 2001).

Psychosocial needs and challenges was a very sensitive matter to caregivers and some were re-experiencing traumatic, grievous incidences as they give data. Therefore, the researcher worked hand in hand with a standby counselor who ensured psychological wellbeing during data collection process was taken care of.

In-depth interview guide had two sections, part A and B. Part A contained bio data of caregivers and part B was where caregivers could give detailed information concerning their experiences in caregiving work. This was used to any caregiver who could read and write. This gave demographic data of respondent (part A) and part B gave caregivers' understanding on caregiving as a concept.

Key informant interview guide was used on key informants at Eldoret hospice who were two in number. These were two caregivers (nurses) who happened to have stayed long enough at Eldoret hospice. This helped to get to know what goes on in Eldoret hospice plus their personal experiences as caregivers in the institution.

Focused group discussion guide was used in group setting where caregivers were handled as a group. This was used on MTRH caregivers, Primary caregivers and Home setting caregivers. Data was collected during ward rounds (MTRH) and home visits. Family members to cancer clients were interviewed as he questions set by the

researcher. At MTRH, there were two cancer clients and caregivers interviewed. The first client (stomach cancer) had four caregivers who stayed with her; one farmer (cousin), two daughters (pupils) and one accountant (husband). The second client (brain tumor) had two caregivers watching over him; a teacher (wife) and a farmer (cousin).

In home setting, there were three cancer clients and their caregivers interviewed. The first client (throat cancer) had three caregivers; a teacher (wife) and two daughters (pupils). The second client (stomach cancer) had two caregivers; one nurse (daughter in law) and a daughter (farmer). The third client (cancer of the leg) had one amputated leg due to metastasis of cancer and had two caregivers; a farmer (wife) and an accountant (brother).

In addition psychological assessment was done which was made possible by the use of two tools; caregiver's self-rating scale (Judy Bradley, 1993) and self-analysis questionnaire (Dr. Charles Spielberger, 2001). These tools were administered to Eldoret hospice caregivers. Caregiver's self rating scale was a tool where respondents were to express their feeling on ten questions asked and put a number 1-10. Number 1 was no feeling, numbers between express no feeling and nmber10 strongest feeling. This is well elaborated in appendix IV. Scoring was done and rated as follows. The low numbers (1, 2, and 3) give little or no value (honor) to the needs of the client. The high numbers (8, 9, and 10) give little or no value to your own needs as an individual and as a caregiver. The numbers in the middle (4, 5, 6, and 7) are where you find a balance between undercare and overcare. Neither of the two extremes is healthy; they represent positions where the caregiver is not helping the client.

Self-analysis questionnaire was specifically testing anxiety. So respondents were posed with ten questions and were to mark the appropriate number to indicate how they generally feel about the statements. The scoring was rated by the following which helped in making conclusions on where caregiver was as far as severity of anxiety is concerned.

10- 11 means lowest 10% of anxiety

13- 14 means lowest quarter

16-17 means anxiety level is above average

19-20 means anxiety level is around the 75th percentile

22-24 means when is a male anxiety level is around the 90th percentile

24-26 means when is a female anxiety level is around the 90th percentile

25 means when is a male anxiety level is at the 95th percentile

27 means when is a female anxiety level is at the 95th percentile

3.8 Data analysis methods

Qualitative Data Analysis (QDA) is the range of processes and procedures whereby we move from the qualitative data that have been collected into some form of explanation, understanding or interpretation of the people and situations we are investigating. QDA is usually based on an interpretative philosophy. The idea is to examine the meaningful and symbolic content of qualitative data. (http://onlineqda.hud.ac.uk/Intro).

Data from psychological assessment tools (Self- Analysis questionnaire and caregiver's self-rating scale) was analyzed through interpretive technique where coding was done. Again part A of interview guide was coded to get demographic characteristics of respondents.

Other data from Key informant interview guide, Focused group discussion guide and In-depth interview guide (part B) couldn't be coded and therefore recursive abstraction technique was used. This is a technique whereby datasets are summarized; those summaries are then further summarized and so on. The end result is a more compact summary that would have been difficult to accurately discern without the preceding steps of distillation. This helped in analyzing the concept of need and challenge whereby the researcher found that some needs emerged to be challenges and some challenges emerging to be needs.

The researcher also used descriptions, narrations and was presented by quotes and citations. Reasoning behind each summary step, examples from the data was documented which helped to draw out patterns from concepts and insights.

3.9 Ethical Considerations

Ethics in research means how a researcher ought to conduct himself and treat his respondents during research process. These are ethical considerations observed by researcher during the study. First and foremost researcher did seek research permit from NACOSTI and Eldoret Hospice as indicated in appendix vii and appendix viii respectively. Again researcher did seek voluntary and informed consent of client before conducting the research. So clients responded willingly. Also, researcher did adhere to protection of privacy of the clients and therefore confidentiality of information given by the clients in the field was held. In addition, reporting the

information as anonymous when analysis and presenting data was observed by the researcher during the study. Protecting psychological harm of the respondents was observed since counseling exposes emotions of the clients to the surface. So researcher had to process feelings with clients and various techniques helped in this like the core conditions of counseling; genuiness, empathy and unconditional positive regard.

CHAPTER FOUR

DATA ANALYSIS, PRESENTATION AND INTERPRETATION

4.0 Introduction

This chapter is structured in terms of demographic characteristics of the study population, psychological needs and challenges, social needs and challenges as well as coping strategies adopted by caregivers in Eldoret town. This was guided by the objectives of the study.

4.1 Demographic characteristics of the study population

Demographic characteristics of caregivers were collected in terms of gender, age, occupation, education and marital status. Gender is a state of being male or female.

Table 4.1: Demographic characteristics of the study population

Demographic characteristics	Caregivers in Eldoret hospice	Caregivers in MTRH	Caregivers in home setting
Gender	4 F	4 F	5 F
F-Female	2M	2 M	1 M
M-male			
Age in years	4 F- above 25	4F (two below 18 &	5F (two below 18&
	1M-above 25	two above 25)	three above25)
		2M -above 25	1M- above 25
Occupation	4F (2 nurses, 1 counselor & 1 social worker)	4F (2 pupils, 2 farmers)	5F (2 pupils, teacher, nurse & farmer)
	2M –nurse & social worker	2M (teacher &accountant)	1M- accountant
Education	4F (1 master, 1 bachelors and 2 diploma)	4F - primary school	5F (3 primary school &2 diplomas)
	2M- diplomas	2M- diplomas	1M- diploma

Marital status	4F- married	4F (2 singles & 2 married)	5 F (2 singles & 3 married)
	2M- married		
		2M- married	1M- married

Source: Field Data (2015)

The following are the interpretation of data given in the table above

- All caregivers had more female than male taking care of cancer clients

- Eldoret hospice caregivers were all adults. Both MTRH and home setting caregivers comprised of adults and children

- All caregivers were professionals in various fields.   Eldoret Hospice caregivers were trained in caregiving.   Both MTRH and home setting caregivers had majority with no training in caregiving.

- All caregivers were literate.   All Eldoret hospice caregivers reached tertially level of education. Both MTRH and home setting caregivers had reached primary school and tertially levels.

- All Eldoret hospice caregivers were married. Both caregivers in MTRH and home setting caregivers comprised of singles and the married.

4.2 Psychological Needs and Challenges Faced by Caregivers

The findings revealed that all caregivers faced psychological challenges in their course of duty and had various psychological needs.

4.2.1 Psychological challenges faced by caregivers

All caregivers experienced challenges. Clients' perception on the caregiver emerged as a challenge to caregivers. Clients perceived caregivers as their source of hope of living where they derived the meaning of life from as they tried to cope with cancer. This posed a big responsibility on caregivers to really be there for the client and give moral support, issuing drugs to manage pain, acceptance to take drugs, empowering

them. This was evident during Day care at Eldoret Hospice. Day care comprises of cancer patients and the caregivers. They usually meet the last Wednesday of the month at Eldoret hospice. They share their life experiences, challenges as well as good moments. The following are the issues raised by client in one of Day care gathering:

> *"How can I have hope of living yet I suffer from a chronic illness that has no cure? Why would God allow poor people like me to suffer from cancer which is very expensive to manage? What did this young child do to deserve leukemia? Where and who should we listen for advices; doctors, peers, friends, traditional doctors? How should I care for the cancer patient?"*

Again, there was a challenge of clients' behavior which cut across dependency syndrome of the clients towards caregiver, pessimism as well as depression as manifested by some clients. During the study, one client was totally over dependent on a caregiver and will not allow anyone else to take care of her. This made that caregiver to experience burnout, caregiver stress and abandon her own family (husband and children) in order to take care of this particular client. She lost friends because rarely would she find time out and even neglected her own health; forgot to take a bath, no exercising and eating food that is not balanced.

> *"………she hardly allow anyone else to take care of her, not even her husband…I am a cousin to her and she has grown to be over dependent on me in everything….feeding, bathing as well as taking her to toilet….this happens all night long!....if I fell asleep and she happens to wake up, she shouts my name, she expects me never to leave her side even when she falls asleep…..failure to which she becomes violent, starts speaking that she will die……."*

Again all caregivers reported to experience caregiver syndrome, burnout, compassion fatigue and disorders (mood, sleep, eating).

Table 4.2 psychological challenges faced by caregivers

Psychological challenge	No of caregivers affected			Percentages	
	Hospice	**MTRH**	**Home**		
Caregiver syndrome	6	6	6	100%	(18/18*100)
Burnout	5	3	6	77.78%	(14/18*100)
Compassion fatigue	6	6	6	100%	(18/18*100)

Source: Field Data (2015)

From the table above:

➤ All caregivers (Eldoret Hospice, MTRH and home setting) experienced caregiver stress and compassion fatigue.

➤ Eleven out of eighteen caregivers experienced burn out in their course of duty

Burn out was a challenge to caregivers. Some caregivers made the following statements:

"......I feel mentally worked up and I can't perform well at work..."
".....i get drained when I don't achieve my goals..."
"......sometimes I feel like quitting my job because I really get tired....."

Eldoret Hospice caregivers' burnout was as a result of lack of debriefing as they reported that, *"......we work many hours a week and rarely have forum for debriefing....."* Those in MTRH burnout was less compared to the rest they had many friends and people visiting hospital who could often speak to them; encourage, pray and even laugh with. Again adolescents in MTRH were not always with clients; at least they could find time out with friends and play which helped the in coping with the situation.

Compassion fatigue is a condition whereby the caregiver feels helpless to relieve the client (s) from suffering they find client(s) in as the effects of chronic illness as well as feeling sympathetic for the client(s). All the caregivers experienced this at one point in their caregiving. Female and male, singles and married, learned and unlearned adolescents and adults, all faced compassion fatigue. This was by the human nature that they were all human and it is very human to be sympathetic with a person whom you observe suffering for a long period of time and can't help to relieve that person from that condition. Some lamented in their speech:

> *".....i get directly affected that I start feeling for the client…."*
> *".....i feel I am not moving the client anymore…"*
> *"....it makes me feel helpless….i wish I could find another mother for these children after they lost their mother but I can't, I feel terrible…"*
> *"……I feel discouraged, I can't do much…can't offer the best…."*

All caregivers experienced different kind of disorders as they gave in their life histories as well as during group discussions. All caregivers experienced sleep and eating disorders. Eldoret Hospice caregivers, all the six (female and male) caregivers went through depression at one point of their caregiving work.

All caregivers experienced high level of anxiety as they handled cancer clients where the severity was measured using a Self- Analysis questionnaire by Spielberger (2001). The scores represented the severity of anxiety among caregivers.

Table 4.3: Severity of anxiety among caregivers

Gender	No. of caregivers in Eldoret hospice &scores	No. of caregivers in MTRH & scores	No. of caregivers in home setting & scores
Male	2 (25&25)	2 (22&24)	1-25
male	4 (21, 25, 26,27)	N/A	2 (25&26)

Source :(Field Data, 2015)

4.2.2 Psychological needs of caregivers

All caregivers reported that they needed more information pertaining different areas. Eldoret hospice caregivers said that they needed information, debriefing, supervision and training in order to handle cancer clients more effectively.

Both MTRH and home setting caregivers needed information about cancer as a chronic illness, causes, treatment, myths, prevention and management. One of caregivers made the following remarks:

> *"The client I am taking care of is my mother in law and she asks me so many questions which sometimes I lack answers but just attend to her. She asks…where did this so called cancer come from? Is it a curse from my ancestors? Does it have cure?"*

4.3 Social Needs and Challenges Faced by Caregivers

The findings revealed that all caregivers faced social challenges in their course of duty and had various social needs.

4.3.1 Social Challenges Faced by Caregivers

Eldoret Hospice caregivers said caregiving affected their personal relationships and social life as they find themselves 'carrying their work home.' The following were some of remarks they made

> "......my work doesn't end at hospice...I find myself thinking of my clients when am supposed to concentrate on my personal affairs...."
>
> ".......i feel socially isolated.....alone when in a crowd ..."

Again, they faced the challenge of balancing their needs and those of the clients. Caregiver's Self- rating scale by Judy Bradley, 1993, was administered to them. The test comprised of ten question, scores were derived by dividing additions from ten questions by ten.

Table 4.4: Caregivers' and clients' needs balance

	Caregiver's needs	scores
Client's needs	Caregiver A	2.7
Client's needs	Caregiver B	5.7
Client's needs	Caregiver C	4.8
Client's needs	Caregiver D	6.4
Client's needs	Caregiver E	5.0
Client's needs	Caregiver F	6.6

Source :(Field Data, 2015)

From the scores one caregiver showed under care for the client(s) and five caregivers maintained a balance of moderate care to caregiver's own needs/ moderate care to the client's needs.

On the other hand both **MRTH and home setting caregivers** faced a number of challenges in caregiving. Attitudes, prejudices and their beliefs on modern visa vie herbal medicine was really a matter of concern in regard to cancer. Clients seem to believe more on their herbalists than modern medicine where morphine drug is used in pain management. Both literate and illiterate were victims of this. Cultural aspect of clients also affected caregivers which later influenced cooperation of client in caregiving process. The Study showed that cultural beliefs play a part in influencing family emotions and concerns in the cancer experience. This was majorly caused by societal perception, myths on modern vis a vis indigenous medicine and traditional vis s vis modern counseling. The following were remarks made by a nurse caregiver in home setting.

> *".......herbalists have an upper hand and the family at large in decision making process than us...I feel I am not moving the client in convincing him/her to adapt the modern medicine since after I leave his/her premise the family takes over and corrupts their minds with herbal medicine....the last incidence I had with a nurse...so it's not about illiteracy!..."*

Both MTRH and home setting caregivers faced the challenge of loss and grief which manifested on emotional, psychological and social dimensions. During the study, three clients died and it was not easy for the caregivers to cope with it because of attachment that had developed towards these clients and the humanness in them. Loss and grief was really a challenge as the family members and community at large expects so much from these caregivers forgetting that caregivers equally were in the same predicament as they. This is where the need for psychological debriefing as well as bereavement counseling to the caregivers was critical. On loss and grief one of the caregivers said,

> *"......I became fond of this client...at one point he said to us caregivers, 'if I happen to die today, my God bless you a lot because*

you truly made me experience my last days on earth with joy….'
After two days, the client died! It was really hard for me to cope with
this as I wept a lot! However, the family members expected me to be
very strong for them, forgetting that we were equally going through
the same thing..."

Again, MTRH and home setting caregivers faced the challenge lack of adequate information on various issues. This cut across cancer concept, palliative care, basic counseling skills and handling depression which was a common disorder that caregivers encounter in the field of caring for clients and families with chronic illnesses like cancer. This resulted to feelings of frustrations, inadequacy and anxiety as the caregivers lamented:

"…. I faced this challenge whereby I had said all that I knew of
saying and the client was at the advanced level of severe pain.
Morphine drug, painkiller, couldn't help to ease the pain any
longer…I felt inadequate since I didn't know what to do when
observing the agony of the client…."

Another caregiver reported the following as her challenges during research:

"Judy (not her real name) was 40 years when diagnosed with
malignant tumor, cancer, in her stomach. The time of diagnosis she
was at stage 3 of the cancer and had to be admitted in MTRH
hospital for about six months which was on and off. During her
illness, she was totally dependent on me (cousin) and never wanted
to be attended to by any other person but Nelly even been taken to
toilet. Judy could say anytime she was asleep and after waking up,
"Where is Nelly (not her real name)? I don't want any other person
to take care of me but Nelly. She is the only person who understands
me well than anybody else, not even my husband……" I forgot my
family and lived with Judy in MTRH hospital and/or home where she
could go after discharge. At one time I told Eldoret Hospice
caregiver, "I don't know when I took shower…I don't sleep, Judy
keeps calling my name all night long and even during the day….I
don't know what is happening to my husband, I really pity him….my
children, I don't know the last time we had quality time together as
mother and her children should……" Judy died after 6 months of
struggling with cancer.

4.3.2 Social Needs of Caregivers

Social needs of the caregivers were influenced by the challenges they faced in their line of duty. All caregiver posed the need for sharing their experiences in caregiving which differed in nature. Eldoret Hospice caregivers said sharing will help avoid carrying work home and give them room to enjoy life with their families, friends and society at large. This should be done on regular bases at least weekly. MTRH and home setting caregivers wished to share their experiences for relief to anyone who cared enough to listen. One of the caregivers said, *"When I talk it out, I feel some of my burden is lifted from my heart and shoulders....."*

4.4 Coping Strategies for Psychosocial Needs and Challenges

Coping strategies varied with personality in reference to their value system, belief system, traits, information available and socialization process. The following were way through which caregivers reported as coping strategies.

4.4.1 Differentiation of self

Only one caregiver (Eldoret hospice) was able to differentiate himself while the rest found themselves attached with client's condition. This caregiver made this remarks in the course of explaining how he managed to attain this: *"......I cope by being myself first then the clients to follow..."*

4.4.2 Basic Counseling Skills

Eldoret hospice caregivers reported to have adopted basic counseling skills as a coping strategy. The major skills reported were attending and supportive skills. Family caregivers had no knowledge on basic counseling skills. These were one of caregiver's remarks:

> *"There are many times clients ask questions that even me I don't have answers, so I just listen and attend to them. Other times I might find a depressed client who does not want to talk; I apply silence as a skill and am there for the client…"*

4.4.3 Self Awareness

All caregivers were aware that they react to the same situations differently. Some said they cope with stress by singing it out, dancing, walking around, being silent, being busybodies and engaging in hobbies like swimming, playing football, reading motivational book (s).etc. These were some of caregiver's remarks:

> *"When I am very stressed najipa shughuli (walk around). As I walk along I calm myself done and I am able to move on with life."*

4.4.4 Spirituality

This is ability to ascribe to a supreme being. Man is a spirit that has a soul and lives in the body. This was seen to have helped caregivers in dealing with cancer by helping them derive meaning of life out of a hopeless situations that they found their clients being exposed to which affected them directly or indirectly. It also helped in providing an existential perspective on hope and suffering as well elaborated in logo therapy. Some even spend time to pray for their clients and their lives as well and this gives them strength to move on. Hope in the midst of suffering was seen to be instilled by posing existential questions about the meaning of life and this was some of questions posed by the researcher and the responses of the caregivers. Some of them were as follows;

> Researcher: *"…..how do you cope with this whole issue of watching clients dying every day and you say that you really enjoy your work, right?"*

> Caregiver: *"…. I told God to allow me serve other people wholeheartedly but never to allow any person of my family go through this horror. So I hope I care for these clients and never to care for any of my family member……"*

4.4.5 Clinical Supervision

Only Eldoret hospice caregivers endeavored to seek supervision which was still rarely done. MTRH and home setting caregivers were not even aware of its existence. This helped in coping with clients. Some said *"Every time I feel overwhelmed with client issues, I seek supervision especially after going several ward rounds and home visits."*

4.4.6 Sharing and Debriefing

All caregivers spend time sharing on individual and/or group counseling. Eldoret hospice caregivers would present a case after a ward round and home visits where they would share. Here they select a difficult case and share relinquishing the emotion associated with the experience. MTRH and home setting caregivers would share with whoever cared enough to listen. This talk therapy brought a lot of benefit. Caregivers described memorable experiences in their line of duty and one narrated a very touching one and her experience in debriefing session as follows:

> *"…….I broke down when narrating this experience in a debriefing session and I didn't know that it had affected me this much but I felt relief afterwards. One day we visited this client in our usual home visits and he told us, 'when you don't find me, know that I have appreciated so much.'……"*

Again finding motivated clients who are ready to continue living despite the condition was also part of sharing which they would stir one another to continue with caregiving. This really instilled hope and acted as a source of strength to the caregivers to continue caring for the clients. They reported that despite the challenges, meeting just one client who was ready to fight with cancer and continue

living positively with the condition really was a source of encouragement as their

remarks could speak:

> *"……..I found this client who told me, 'next time call me that I speak to those who are suffering like me and have given up in life and I will tell them….umekufa mara nyingi, anza kuishi, (u have been dying many times, start living now)….."*

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

This chapter contains summary of findings, conclusion, recommendations and research gap identified by researcher after carrying out the study.

5.1 The Concept of Cancer

From the story of Judy and Nelly in page 50 it is clear on how severity of cancer affects caregiver especially primary caregiver on her personal life, relationships and parenting as well. It was a challenge to caregivers from Eldoret Hospice convincing Nelly that she should take breaks and talk with Judy to allow other people to as well take care of her. This was equally seen as a need for caregiver to get information on self-care as well elaborated in caregivers' Bill of Rights:

Caregiver's Bill of Rights

1. Caregivers have the right to receive sufficient training in caregiving skills along with accurate understandable information about the condition and needs of the clients.

2. Caregivers have the right to appreciation and emotional support for their decision to accept the challenge of providing care.

3. Caregivers have the right to protect their assets and financial future without severing their relationship with the clients.

4. Caregivers have the right to respite care during emergencies and in order to care for their own health, spirit, and relationships.

5. Caregivers have the right to expect all family members, both men and women, to participate in the caregiving.

6. Caregivers have the right to provide care at home as long as physically, financially and emotionally feasible; however, when it is no longer feasible caregivers have the obligation to explore other alternatives, such as a residential care facility.

7. Caregivers have the right to temporarily alter their premises as necessary to provide safe and livable housing for clients.

8. Caregivers have to right to accessible and culturally appropriate services to aid in caring for clients.

9. Caregivers have the right to expect professionals, within their area of specialization, to recognize the importance of palliative (ease without curing) care and to be knowledgeable about concerns and options related clients and caregivers.

10. Caregivers have the right to a sensitive, supportive response by employers in dealing with the unexpected or severe care needs.

(Source: The Caregiver Education and Support Services, et.al 1993)

5.2 Psychological Needs and Challenges of Caregivers

All caregivers faced various challenges and had various needs to be attended to.

5.2.1 Psychological Needs of Caregivers

Information on various issues in caregiving was seen to be a need just like Grbich, 2001, and Kirk, 2004, findings revealed. All caregivers needed training on areas that they found themselves inadequate. Eldoret Hospice caregivers needed training on

different cultures whom they could meet once they go for ward rounds and home visits. This has to do with ritual, language, taboo of various communities. MTRH and home setting caregivers needed training on modern medicine to help their client adapt modern pain management technique where morphine drug is used.

5.2.2 Psychological Challenges Faced by Caregivers

Christine, 2009, and Sheehy, 2010 studies identified **caregiver stress** as a challenge to caregivers just like this study revealed. Caregiver syndrome is the stress that caregivers experience as they care for the client(s). All caregivers reported they experience caregiver syndrome where signs and symptoms of depression, anxiety, and anger were evident. Stress across all caregivers was brought by a numbers of factors. Eldoret hospice caregivers were stressed with big work load and few caregivers to give the services. This was evident with weekly schedule where they had to work 45 hours; 8am-5pm everyday from Monday to Friday. Again sometimes they would go to work on Saturdays especially with Day care, world cancer day, which could take the whole day. Day care is a day where family and/or primary caregivers meet in Eldoret hospice with cancer clients where they get hospice care and interact one with another.

MTRH caregivers were stressed by fact that they had a lot of hope that been in hospital nurses, doctors in MTRH would help them in caregiving but this didn't reduce work load either. Nurses and doctors could see clients for at most 10 minutes at a go and the rest of the day caregivers would be with clients to take them to toilet, bathing, give medicine which could happen day and night. There was one instance where Eldoret Hospice caregiver had to force one MTRH caregiver to go out, have a walk around and refresh, because the caregiver had not moved from the ward for

about 3 days. Home setting caregivers were stressed because of work load since caregiving take time and energy. Those working and had clients to take care of lamented of work load that it was very tedious to work and take care of cancer clients at home. This explained why all home setting caregivers at home had a lot of burn out compared to MTRH caregivers.

Burnout was the other challenge faced by caregivers. It is a psychological term that refers to long-term exhaustion and diminished interest in work. It is not a recognized disorder in the DSM although it is recognized in the ICD-10 and specified as a "State of vital exhaustion" (Z73.0) under "Problems related to life-management difficulty" (Z73), but not considered a "disorder" (WHO, 1994).

Eldoret Hospice caregivers' burnout was as a result of lack of debriefing. MTRH caregivers hardly experienced burnout because they had many friends and people visiting hospital who could often speak to them; encourage, pray and even laugh with. Again adolescents in MTRH were not always with clients; at least they could find time out with friends and play which helped the in coping with the situation.

 According to the study done by Travis, et al, 2004, revealed that caregivers experience disorders just as this study revealed. **Disorders** were also other psychological challenges caregiver experienced. These were mood, sleep and eating disorders. Mood disorders were evident with caregivers where depression and anxiety disorders stood out. More females than male had depression with both literate and illiterate, young and old. Depression is mood disorder that range in degree from mild –severe characterized by emotional, cognitive and behavior change. It is a prolonged feeling of hopelessness and inadequacy. It is ranked as number one disease in developed countries.   It can also be said to be a temporary emotional state that

normal individual experience or a persistent state that may be considered a psychological disorder (Karen, 2001). 10% - 25% patients suffer from depression and 30% - 50% go unnoticed. It is common about 40 years of age and it is more frequent in women than in men. Major depression affected all caregivers at one point in caregiving. The patient have to undergo at least five (5) or more signs and symptoms of major depression under unipolar depression for at least two weeks. These are lack of sleep, fatigue and lack of energy, loss of appetite, sadness, reduced social interactions and lack of interest in most activities (anhedonia) (Karen, 2001).

Anxiety was the other challenge faced by caregivers. All Eldoret Hospice caregivers had high anxiety levels. Both men and women reported high anxiety in their line of duty. Anxiety is like a mental tongue. It default mode is to search for what may be about to go wrong. It continually, and without your conscious consent, scans your life- even when asleep, in dreams and nightmares. It reviews your work, love, play- until it finds an imperfection. When it finds one, it won't let go. Two techniques can help to lower everyday anxiety levels. Both techniques are cumulative, rather than one-shot fixes. They require 20 to 40 minutes a day, (Martin, 1994). Anxiety is a feeling of dread and gnawing apprehension about vague or unrealized threats and hardship that exist sometimes in future but are not a clear, immediate danger to wellbeing, 'low throttle.' Anxiety disorder is characterized by manifest anxiety or self-defeating behaviour patterns armed at warding off anxiety. It can be seen as a fairy long lasting disruption of a person's ability to deal with stress, often accompanied by feelings of fear and apprehension. Anxiety illnesses are among the most common disorders, affecting more than 23 million Americans (about 1 in 9). Majority of sufferers do not seek help because they may not recognize their symptoms as a psychiatrist problem or may fear being stigmatized with a "mental illness"

(Harvard Health Letter, 1998). There is an evidence that anxiety condition is genetic as findings suggests that a genetic predisposition to anxiety, when triggered by certain life experiences, like early losses or trauma, may alter a person's brain chemistry, causing an illness to surface (Harvard Health Letter, 1998). Anxiety disorders were generalized anxiety disorder (GAD) and post-traumatic stress disorder- vicarious traumatization.

Generalized anxiety disorder (GAD) is a syndrome as excessive and uncontrollable worry over a period of time at least six months, about several life circumstances. It is characterized by chronic state of diffuse anxiety, misery, restlessness, snappy, irritability, and difficulty in concentrating; tire easily, chronic muscle tension and insomnia (Thayer, et al.1996). GAD is believed to affect about 10 million Americans. It affects people of both sexes and all ages but is diagnosed more often in adult women, possibly because of hormonal differences or because women seek mental health treatment more frequently than men, whose rate of anxiety may be underestimated. Some Health experts believe that men manifest anxiety differently from women: they drink more alcohol, smoke more, and more prone to aggressive behavior (Harvard Health Letter, 1998). From the study GAD was majorly caused by caregivers' unconscious imagination that their clients could as well be their children, partners as well as relatives as they care for these clients. These brought uncontrollable worry like one said, *".....I imagine these were my children suffering like this having lost their mother of cancer….this makes me worry a lot and I usually react by spending more time with my children….."* GAD frequently coexists with depression. A March 1998 symposium in Boston, cosponsored by the National Institute of Mental Health and the Anxiety Disorder Association of America, was among the first to look at the interplay between fear and anxiety and the workings of

the brain. Some scientists are focusing on a brain structure amygdala, which regulates fear, memory, and emotions. When a person is exposed to a fearful event, the amygdala coordinates the brain's physical responses, such as increased heart rate and blood pressure. Preliminary Research suggests that the release of stress hormone norepinephrine and cortisol may act in a way that greatly increases memory of the fearful or traumatic event, allowing it to remain vivid for years (Harvard Health Letter, 1998).

All caregivers faced the challenge of **loss and grief**. During the research, three clients died and caregivers who were taking care of these clients were really grieved. One died in hospital while two died at home. One caregiver from Eldoret hospice lamented, *'....I was really attached to her and I never thought she would die that soon. I feel very sad.'* Eldoret hospice caregivers manifested normal grief .MTRH & home setting caregivers had incidences of anticipatory grief. This lead to search for meaning in life feeling, hopeleness, confusion and helplessness. Anticipatory grief is an intrusive and frequent worry about a loved one whose death is neither imminent nor likely. Anticipatory mourning also occurs when a loved one has a terminal illness like cancer (Rando &Therese 2000). Grief is normal, natural, time limited; can continue anywhere from two weeks to almost two years, and is usually different for each relationship or event. It is however, normal to be able to experience joy, contentment, and humor even amidst the worst loss. People manifests and recover from grief differently. Some factors contributing to recovery from grief include strong social support, optimism, and physical exercise. Most people recover from grief and can continue with their usual activities, while still feeling moments of sadness, within six months.

Again all caregivers faced **compassion fatigue** at one point in caregiving. Meador et al, 2008, study revealed caregivers' experiencing compassion fatigue during caregiving. According to this study, caregivers reported that compassion fatigue was because of human nature that they were all human and it is very human to be sympathetic with a person whom you observe suffering for a long period of time and can't help to relieve that person from that condition. Majority said, *"Cancer is a chronic illness and you cannot compare us with any other caregiver. Watching someone suffering for long with nothing you can do to relieve the client from it is one horrific experience."*

5.3 Social Needs and Challenges Faced by Caregivers

All caregivers faced various challenges and had various needs to be attended to.

5.3.1 Social challenges faced by caregivers

The findings from Briggs, 2000, were also found during this study. This is Eldoret hospice caregivers said caregiving to have affected their personal relationships and social life as they find themselves 'carrying their work home'. Again in striking a balance between their needs and that of clients, it was found that one caregiver showed under care for the client(s) and five maintained a balance of moderate care to caregiver's own needs/ moderate care to the client's needs.

MRTH & home setting caregivers faced a number of challenges in caregiving. Attitudes, prejudices and their beliefs on modern vis a vis herbal medicine was really a matter of concern in regard to cancer. Clients seem to believe more on their herbalists than on the caregivers who come along with modern treatment like use of morphine drug to manage pain. Both literate and illiterate were victims of this. This

was a unique finding in that home setting caregiver (nurse) continued to give herbal medicine to her client (mother in law) despite her knowledge on modern medicine. This can be explained in Dorothea Orem's Self care Deficit Nursing theory that when an individual is unable to meet their own self-care requisites, a "self-care deficit" occurs. It is the job of the client to determine these deficits, and define a support modality. So it is not the work of caregivers to determine the care but client for caregiving is client- centered.

According to the study done by Grunfeld et al, 2004 and Health Net, 2013, caregivers who are employed and have clients to take care at home did quit their job because of caregiving demand. However, during this study, this home setting caregiver (nurse) and others employed in various fields continued working despite the work load.

5.4 Coping Strategies for Psychosocial Needs and Challenges of Caregivers

The researcher found that there has been a range of factors that help caregivers successfully manage their role, while minimizing the effect on their mood and general well-being in their course of duty. Caregivers reported to handle challenges and needs they experience at work as follows. Coping strategies varied with personality in reference to caregivers' value system, belief system, traits, information available and socialization process. Personality is the ability to understand uniqueness of human beings, describing behavior of clients, making predictions based on set traits of human nature and explaining behavior of clients (Gruetzner 2001).

There was challenge of clients' behavior which cut across dependency syndrome of the clients towards caregiver, pessimism as well as depression as manifested by some clients. However, Eldoret Caregivers overcame this by empowering clients. Through

occupational therapy; three clients were able to be self dependent and bring income to their families. They adopted skills in shoe making, bead work and motivational speaking.

Differentiation of self was another way Eldoret caregiver coped with caregivers. Differentiation of self was proposed by Bowen (1990) and defined it as one's ability to separate one's own intellectual and emotional functioning from that of family. He spoke of people functioning on a single continuum or scale. Individuals with "low differentiation" are more likely to become fused with predominant family emotions. It is that ability of one being able to separate himself/herself from the issues of the client (s) s/he is handling. From the study it meant the ability of caregivers being able to separate their lives with that of cancer clients; the condition of cancer not to influence their lives in regard to how they view life in general. Making sure that client issues remains client issues and caregiver's issues remains caregiver's.

In addition Self awareness was another coping strategy used by caregivers just like Juliana, 2014, study revealed. It entails being 'in touch with yourself.' Get to understand your emotions, strengths, weaknesses and limitations. This was greatly enhanced by caregivers understanding their personality, how it affected their lives and other people as well. This also entailed caregivers having knowledge on how to manage their weaknesses, emotions and limits (Juliana, 2014). Type theory explains type A (extroverts) and type B (introverts) personalities. Extroverts are sanguines and cholerics while introverts are melancholics and phlegmantics. Sanguines personality are out going, fun loving, spontaneous, talkative but gives up very easily, disorganized, speak before they think and have a shot memory span. Cholerics are goal oriented, believes in people, focused but domineering, angry and proud people.

Melanchorics are very sensitive, intelligent, perfectionate, loyal but controlling, reserved, keep grudges and don't forgive easily. Phlegmantic are peace keeper, accommodating, but indifferent, not assertive (Juliana, 2014).

Spirituality was another coping strategy. It was seen to be captured by all caregivers where God, Supreme Being, played a major role in the coping process just like Levin et al, 1995, study revealed. A few studies have shown patients and caregivers to have parallel spiritual tasks when dealing with cancer, such as finding meaning and hope in the disease process while also posing existential questions about the meaning of life (Taylor, 2003).Spirituality can fortify caregivers against hopelessness, help caregivers derive meaning from the cancer experience, and provide an existential perspective on hope and suffering (Ward, et.al. 1996).

Finally, Clinical Supervision was another coping strategy. It is an activity that brings two or more professionals where one is skilled in area of supervision and practice. The functions of supervision are formative which entails learning, restorative where emotional support is ensured and normative where accountability is followed (Wosket, 1999).Supervision is essential to ensure high standards of professional practice. Ongoing supervision helps practitioners to monitor and review the quality of their work as well as their client's progress. Supervision, moreover, is a form of professional self-regulation. It is essential for the right to autonomous practice in the helping professions. It helps in self-awareness to the caregiver (Wosket, 1999). Supervision can also help the caregiver to develop in-depth understanding of the client and facilitate appropriate goal setting. Caregiver may also acquire new skills and knowledge to improve their functioning through goal directed work. Cormier &

Hackney (1999) contend that formulation of goals have motivational, educational and evaluative advantages.

5.5 Demographic Characteristic of Caregivers and their Implications

According McGrath 1992, depression was found to be more on women than men. However, according to this study, both men and women caregivers experienced depression.

Lawton, et al, 1992, found impairment and aging to go hand in hand. According to this study, however, no single caregiver experienced any impairment.

5.6 Conclusion

From the study it was evident that caregiving is a rewarding process but demanding on the side of the caregiver. Much have been done on the clients but caregivers have been a forgotten lot in that the public as well as caregivers themselves put little effort, if any, on psycho-social needs and challenges of the caregivers. The public think that caregivers are well equipped with head knowledge on care and therefore need no care from outside at all.

On the other hand, the caregivers themselves know that 'they need care' but fail to substantiate this concept. This care is primarily upon them to take the initiate to 'look for care' and not wait for the 'care to come.' The questions come, 'where is this care? Who gives the care? Who cares for the caregivers?' Ironically this care is just within the caregiver as a person and need to examine himself /herself. The researcher found that caregivers are well equipped with the care they need as the coping strategies shown. This cuts across the differentiation of self, spirituality as well as intrinsic

motivation ones they get a motivated client who has the will to continue living despite the situation at hand. This was well explained by one caregiver when responded, "……*I cope by being myself first then the clients to follow…*" Again, when the caregivers find themselves in challenges like caregiver syndrome, burnout and compassion fatigue, it is upon them to 'look for care' in areas like debriefing sessions, education programs, team building activities, regular meeting and group counseling as they recommended in the study and not sit back and wait for 'care to come.' So it is the caregivers themselves who forgot themselves.

However, the study tends to create awareness to the institutions and the public to establish these programs of caring for psychosocial needs and challenges of caregivers. So the care is both within and without the caregivers.

Again all caregivers faced psychological & social challenges as they handle cancer clients. This cuts across literate and illiterate, learned and unlearnt, singles and married, male and female, young and old. Therefore, psychosocial challenges faced by caregivers are universal; anyone is at risk.

In addition Psychosocial needs vary with personality, context, location, knowledge, gender, age, occupation, status. Caregivers in Kenya express unique needs than those in western world. For example they needed to know culture of clients which influenced indigenous and modern medicine as far as cancer is concern whereas this is not a case in western world.

5.7 Recommendations

The following were the major recommendation made by the Eldoret Hospice Caregivers:

1. Debriefing sessions- the caregivers reported that this needs to be a routine like after every home visit and/or ward round which is usually done on weekly basis.

2. Education programs- seminars and workshops should be held as often as possible since the last to be organized was fifteen years ago as reported by the caregivers.

3. Team building activities- this should be done to enhance human growth and development as seen in self-awareness. Again this will foster bonding among the caregivers as they get to know one another better.

4. Positive Reinforcement- appreciations and incentives should be given to the caregiver as a way of encouragement in their course of duty. Work pay should also be increased as well as regular time off with and/or without burnout.

5. Regular Meetings at work should be the order of the day in order to exchange notes about the progress at work. This should be done at least on weekly basis.

6. Group counseling- Daycare and Rounds should be done weekly. Daycare is a where the caregivers and the cancer clients get to meet in a group setting and exchange notes about their progress, challenges as well as encouraging them to face cancer with courage and positivity. A round in this case is where caregivers meet in a group setting and share issues one at a time on personal and work matters.

From this study these were the recommendations:

1. Differentiation of self is a life-long issue and caregivers need to learn this in order to cope well with cancer clients. This is well achieved by caregivers learning to empathize and not sympathize with client(s). Empathy is the ability of the counselor to enter into the client's phenomenological world. It is intellectual and feeling with the client. Sympathy on the other hand is feeling what the client is feeling, if client is crying you cry with her/him.

2. Primary and home setting caregivers need some training on basic counseling skills to help them cope effectively with cancer clients

3. Caregivers should adopt the following measure to cope with psychosocial needs and challenges as highlighted in the caregiver's handbook (1993). Joining a caregiver support group is one of the strategies. Such groups provide a unique forum for caregivers to come together and share their feelings in a supportive environment. The group will help caregivers feel less isolated and can create strong bonds of mutual help and friendship. Participating in a support group can help manage stress, exchange experiences, and improve skills as a caregiver. Sharing coping strategies in a group setting lets caregivers help one another as well as to realize that some problems have no solutions and that accepting the situation is reality. Caregiving is probably one of the many conflicting demands on caregivers' time. It is important to set realistic goals. Recognize what one can and cannot do, define priorities, and act accordingly. Turn to other people for help – caregivers' family, friends, and neighbors. Caregivers should have a list of tasks for anyone who may offer assistance which may include: running an errand; preparing a meal; taking client for a ride; and taking our children after school one day. When a

caregiver need a break from providing care to the client, it's important to look at respite care. For example, a companion can stay with a client for a few hours at a time on a regular basis to give the caregiver time off. Or have client participate in an adult day care program, or any other program, where he or she can socialize with peers in a supervised setting; this gives the client a necessary break from staying home all the time.

4. Training programs adapted for Eldoret Caregivers should capture the aspect of culture from which the clients comes from so that caregivers can have a better understanding on societal perceptions, myths, prejudices, ritual and taboos clients follow

5. All caregivers should be interdependent, work together as a team, for better care delivery to cancer clients.

5.8 Research Gaps

1. Because basic research has uncovered chemical and hormonal differences in how males and females respond to fear and anxiety, investigators are studying the role of estrogen and cyclical hormonal changes may play in women with anxiety disorders

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APPENDICES

Appendix I: In-Depth Interview Guide

INSTRUCTIONS

Do not write your name anywhere.

Tick where appropriate.

Any information given will be held with a lot of confidentiality.

PART A BIO DATA

1. A. male   ( ) B. Female (   )   C. Others ( )

2. Age   A. below 18 years

    B. between 18-25 years

    C. above 25 years

3. Marital status

A. single (   )   B. married (   )   C. Divorced/ separated (   )   D. Never married ( )

E. Others (   )

    4. What is your profession?

    A Counselor ( )   B. social worker   ( )   C. Nurse   ( )   D. others   ( )

PART B

1. What do you understand by the following terms:

   A. Caregiver…………………………………………………………………

   …………………………………………………………………………

   B. Psycho-social

   Care………………………………………………………………….

   …………………………………………………………………………

   C. Psychosocial

   needs……………………………………………………………….

   ………………………………………………………….............................

2. What are the psychosocial challenges that you have gone through in caring for

   the clients?

   ....……………………

   …………………………………………………………….................................

   ....…………………………………

   …………………………………………………………………………………

   …………………………………………………………………………………

   …………………………………………………..

3. How do you cope with psychosocial challenges you experience as you carry

   out your duties?

   ....

   ....

   ....

   ....

   ....

4. What influence has your employer had in your job performance?

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

…………………………………………………………………

5. i. what are your psychosocial needs that need to be addressed for you to perform well in your line of duty?...

....

....

....

....

ii. From your profession, what are some of the measures your institution(s) has taken to take care of your pscho-social needs?...

....

....

....

....

6. What are some recommendations you would recommend towards psycho-social care for caregivers in the institution?

....

....

....

....

....

....

7. How has caring for others affected you as a person?

....

....

....

....

8. Describe one memorable experience as a caregiver

………………………………………………………………………………..

....

Appendix II: Key Informant Interview Guide

Topics of discussion

- Personal experiences as a caregiver; the worst and the best experience as a caregiver.

- Psychosocial needs and challenges experienced by the caregiver.

- Psychosocial care that a caregiver has received from the institution.

- Attitude, opinions, feelings and perceptions towards psycho-social care for the caregivers.

- The influence of the employer on the caregiver

- Coping strategies

Appendix III: Focused Group Discussion Guide

Topics of discussion

- ➢ Introduction by the members.

- ➢ Understanding of the following terms: psycho-social care, psychosocial needs and caregiver.

- ➢ Personal experiences as a caregiver; the worst and the best experience as a caregiver.

- ➢ Psycho-social that a caregiver has received from the institution the caregiver works for.

- ➢ Attitude, opinions, feelings and perceptions towards psycho-social care for the caregivers.

- ➢ Influence of employer on the caregiver

Appendix IV: Caregiver's Self-Rating Scale

Instructions

Put a number from 1 to 10 to best describe your feelings. Number 1 is no feeling, numbers between express stronger feelings with 10 being strongest feeling.

1. Abandonment to withdraw protection or support or to actively abuse your client.

2. Neglect to allow life-threatening situations to persist or to display consistent coldness or anger.

3. Detachment/Aloofness to maintain an air of detachment or being aloof, perfunctory in your care, no genuine concern, only obligation. Concerned only with physical well-being of your client.

4. General support given freely, with a guarded degree of warmth and respect, occasional feelings of manipulation. Concerned with both emotional and physical well-being of client.

5. Expressed empathy the ability to feel what your client feels. A quality relationship where feelings can be freely expressed and caringly received with non-judgmental positive regard.

6. Sympathy feeling sorry for client, giving sympathy, focusing on the losses experienced by client.

7. Occasional over-involvement care characterized by periodic attempts to do for rather than be with.

8. Consistent Over-involvement where client is regarded as object of series of tasks which must be performed.

9. Heroic Over-involvement care characterized by sometimes frantic and desperate attempts to provide for every possible need your client has; increased dependence, client not allowed independence.

10. Fusion of personalities between caregiver and client. The caregiver's needs no longer have any value or meaning; the caregiver has abandoned him/herself to needs of the client.

Appendix V: Self-Analysis Questionnaire

Is your life dominated by anxiety? Read each statement and then mark the appropriate number to indicate how you generally feel. There are no right or wrong answers.

1. I am a steady person.

Almost never	sometimes	Often	Almost always
4	3	2	1

2. I am satisfied with myself.

Almost never	sometimes	Often	Almost always
4	3	2	1

3. I feel nervous and restless.

Almost never	sometimes	Often	Almost always
4	3	2	1

4. I wish I could be as happy as others seem to be.

Almost never	sometimes	Often	Almost always
4	3	2	1

5. I feel like a failure.

Almost never	sometimes	Often	Almost always
4	3	2	1

6. I get in a state of tension and turmoil as I think over my recent concerns and interests.

Almost never	sometimes	Often	Almost always
4	3	2	1

7. I feel secure.

Almost never	sometimes	Often	Almost always
4	3	2	1

8. I have self-confidence.

Almost never	sometimes	Often	Almost always
4	3	2	1

9. I feel inadequate.

Almost never	sometimes	Often	Almost always
4	3	2	1

10. I worry too much over something that does not matter

Almost never	sometimes	Often	Almost always
4	3	2	1

Appendix VI: Letter from NACOSTI

NATIONAL COMMISSION FOR SCIENCE,
TECHNOLOGY AND INNOVATION

Telephone: +254-20-2213471,
2241349, 310571, 2219420
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9ᵗʰ Floor, Utalii House
Uhuru Highway
P.O. Box 30623-00100
NAIROBI-KENYA

Ref: No.

Date:

22ⁿᵈ September, 2015

NACOSTI/P/15/6806/6626

Juliana Njeri Mugure
Moi University
P.O. Box 3900-30100
ELDORET.

RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on *"Psychosocial attributes of caregivers at Eldoret Hospice in Eldoret Town,"* I am pleased to inform you that you have been authorized to undertake research in **Uasin-Gishu County** for a period ending **22ⁿᵈ September, 2016.**

You are advised to report to **the County Commissioner and the County Director of Education, Uasin-Gishu County** before embarking on the research project.

On completion of the research, you are expected to submit **two hard copies and one soft copy in pdf** of the research report/thesis to our office.

SAID HUSSEIN
FOR: DIRECTOR-GENERAL/CEO

Copy to:

The County Commissioner
Uasin-Gishu County.

The County Director of Education
Uasin-Gishu County.

National Commission for Science, Technology and Innovation is ISO 9001: 2008 Certified

Appendix VII: Research Permit

THIS IS TO CERTIFY THAT:
MISS. JULIANA NJERI MUGURE
of MOI UNIVERSITY, 0-30100
ELDORET,has been permitted to conduct
research in *Uasin-Gishu   County*

on the topic: *PSYCHOSOCIAL*
ATTRIBUTES OF CAREGIVERS AT
ELDORET HOSPICE IN ELDORET TOWN

for the period ending:
22nd September,2016

Permit No : NACOSTI/P/15/6806/6626
Date Of Issue : 22nd September,2015
Fee Recieved :Ksh 1000

Applicant's
Signature

Director General
National Commission for Science,
Technology & Innovation